National Institute for Health and Care Excellence

Draft for consultation

Supporting Adult Carers

RQH - Evidence review for support needs of adult carers who are caring for people at the end of life

NICE guideline tbc

Evidence reviews

August 2019

Draft for Consultation

These evidence reviews were developed by the National Guideline Alliance part of the Royal College of Obstetricians and Gynaecologists

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Support needs of adult carers who are caring for people at the end of life

Review question

What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Introduction

Caring for a family member or friend at the end of life can be very challenging and carers can experience considerable practical and emotional challenges. Advance planning is widely regarded as vital in ensuring that health and social care practitioners can actively engage and support carers both in discussions about where and how end of life should take place and in managing the additional care needs of their relatives. However, evidence from the Hospice Movement and a number of condition specific voluntary organisations indicates that carers may need multiple opportunities to discuss and to understand the diagnosis and changing prognosis of the person they care for. They may need active encouragement to discuss their feelings, raise issues about medication management or other practical caring issues and to accept support from friends and family. Accepting practical help in the family home may seem initially invasive to some carers and cultural issues around end of life care in some minority groups may impact on carers' choice of support. Continuity of care and the opportunity to develop positive relationships with professional staff and with any homecare or similar workers are highly valued.

Many people will die in a hospice or in hospital and there are ongoing issues about acknowledging the importance of privacy and dignity for both the carer and the person approaching the end of life, with accurate information and advice about the logistical and legal issues that need to be addressed. The need for active support does not necessarily end with the death of the person being cared for and many carers may need ongoing support in addressing the emotional impact of bereavement.

Summary of protocol

Please see Table 1 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs and who are at the end of life (≤1 year to live), or such carers who have provided such care. • Relevant social-/health- care and other practitioners involved in providing end of life care.
Intervention	• as outlined in protocols for key areas D, E, F and G
Comparison	• as outlined in protocols for key areas D, E, F and G
Outcomes	Quantitative outcomes: • as outlined in protocols for key areas D, E, F and G Qualitative outcomes: • Expected themes might include: ○ Return to work/education after death of person receiving careNeed to be prepared for caring role and end of caring role ○ Need to be recognised as expert or involvement of carer in decisions regarding treatment/palliative care of person receiving care ○ Need for emotional or bereavement support/grief counselling ○ Need for practical support/advice to prepare for end of life and for a life after death of person receiving care (e.g. support writing advanced statements or making advanced decisions to refuse treatment) ○ Need for comprehensive information about support available (e.g. carer support groups) ○ Involvement of carer and person receiving care in treatment decisions relating to end of life and place of care or end of life/death ○ Continuity of support ○ Return to work/education after death of person receiving care.

For full details see the review protocol in appendix A

Evidence

Included studies

This is a mixed-methods review so qualitative and quantitative studies were eligible for inclusion. The objective of this review is to determine what the most important support needs of adult carers are at the end of life, and after the death, of the person receiving care.

For the quantitiative part of the review, we looked for systematic reviews and randomised control trials (RCTs). For the qualitative part of the review, we looked for studies that collected and analysed data using qualitative methods (including focus groups, interviews, thematic analysis, framework analysis and content analysis). Surveys restricted to reporting descriptive data that were analysed quantitatively were excluded.

Evidence is summarised in a GRADE table for the quantitative studies and GRADE-CERQual tables for qualitative studies. These are provided in appendix F.

Quantitative component of the review

Five RCTs discussed in 6 papers were included, these studies are summarised in Table 2.

Two studies were from Australia (Hudson 2005, Hudson 2013 & 2015) and the other 3 were from the United Kingdom (Walsh 2007), Germany (Kogler 2015) and Canada (Holtslander 2016). Most of the studies included in the review were 2-arm RCTs and aimed to compare the effectiveness of an intervention to a control, with the exception of a 3-arm RCT (Hudson 2013 & 2015).

Overall the included RCTs provided data on 828 adult carers. The smallest sample size was 23 (Holtslander 2016) and the largest was 298 carers of people with advanced cancer (Hudson 2013 & 2015). The included RCTs focused on carers of people with advanced cancer receiving palliative care. One study (Kogler 2015) did not specify the terminal illnesses and included carers of people who were receiving palliative care with a life expectancy of less than 6 months.

There were no studies that examined interventions to support adult carers to enter, remain in or return to work or provide respite or practical support. Three RCTs (Hudson 2005, Hudson 2013 & 2015, Walsh 2007) compared psycho-educational intervention(s) to a control, and 2 RCTs (Holtslander 2016, Kogler 2015), psychological/emotional interventions to a control group.

The following outcomes were reported for these interventions:

- Psycho-educational intervention: Carer knowledge/confidence or efficacy, impact of caring on carer and caring-related morbidity
- Psycho-emotional intervention: Impact of caring on carer, caring-related morbidity and carer quality of life.

There was were no data about the impact on carer skills, caring-related accidents or incidents or resource and service use for the psycho-educational interventions; and no data about the impact on social capital and carer choice/control/efficacy for the psychological/ emotional interventions.

No quantitative evidence was identified related to interventions on meeting the support needs of carers after the person being cared for dies.

Two studies (Hudson 2013 & 2015, Kogler 2015) reported results in a format that was impossible to input into RevMan for Forest plots or assess using GRADE and so these have been reported as a narrative (See Appendix D).

Common study limitations included: unclear blinding and allocation concealment, with some studies showing attrition bias, selective outcome reporting and inadequate sample size power.

Qualitative component of the review

Fifteen qualitative studies were included (Ashton 2016, Briggs 2010, Caswell 2015, Dosser 2014, Dosser 2012, Epiphaniou 2012, Forbat 2012, Jack 2015, Nelson 2017, Newbury 2011, O'Brien 2015, Payne 2015, Percival 2014, PHE 2016, and Seamark 2014).

Table 3 provides a summary of the 15 included qualitative studies. They were published between 2010 (Briggs 2010) and 2017 (Nelson 2017). Three focused on carers of people dying with specific conditions (Cancer, Motor Neuron Disease and Dementia), while the rest focused on dying people but did not specify their condition.

All studies were conducted in the UK. Six papers were about care and support needs in the home setting. Five papers focused on care and support needs in a hospital/hospice/care unit setting. Four papers looked at the needs and experiences of carers across a mix of both home and hospital/care unit settings. Three papers focused specifically on older people (aged 60 and over) who were dying. Five papers included dying people across a range of ages although still mostly 60 years and over. The remaining 7 studies were not clear about the age ranges of the dying people.

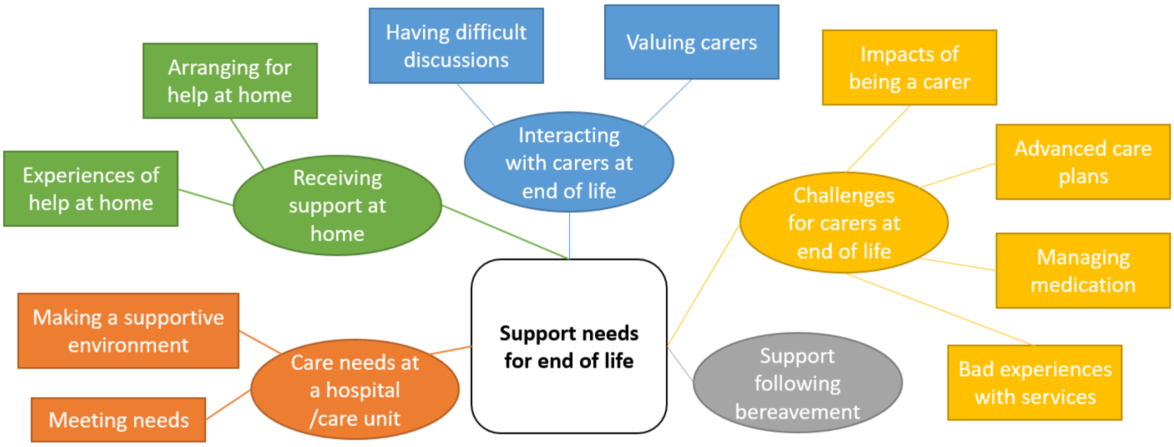
Five papers included findings about the needs and experiences of both carers and professional care providers. Nine papers reported exclusively on carers. One paper focused exclusively on the experiences of professional care providers.

The majority of included studies collected data via semi-structured or unstructured interviews. Thematic analysis was the most commonly mentioned data analysis method, followed by content analysis. One paper (Dosser 2014) described itself as ‘participatory action research’ and included field notes and a diary from the researcher and actions from meetings, as well as interviews. Only 1 included study collected qualitative data as part of a mixed methods study (Percival 2014) while the rest could all be described as purely qualitative research papers.

The Critical Appraisal Skills Programme (CASP) Checklist was used to assess the risk of bias of qualitative studies.

A number of central themes were explored (as shown in Figure 1).

Figure 1: Thematic map



Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of studies included in the evidence review

A summary of the quantitative and qualitative studies that were included in this review are presented in Table 2 and Table 3.

Quantitative component of the review

Table 2: Summary of included quantitative studies

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
Holtslander 2016	**Setting** Canada **Study type**	N=23 **Carer Characteristics**	• I = Psychosocial writing	• Psychological/emotion

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
	2 group feasibility RCT **Aim of the study** This RCT aimed to compare the effectiveness of 2 interventions, a psychosocial writing intervention (Finding Balance Intervention) versus waiting list control, to provide adult carers of people with advanced cancer with psychological and emotional support **Study dates** 2011-2012 **Follow-up** 2 weeks from baseline	• Age: 60-69 years/ 70-79 years/80+ years(N): ○ I = 5/5/3 ○ C = 4/5/1 • Gender (M/F - N): ○ I = 3/10 ○ C = 5/5 **Care recipient characteristics:** • Condition = Advanced cancer	intervention (Finding Balance) • C = Wait list Control	al support intervention
Hudson 2005	**Setting** Australia **Study type** 2 group RCT **Aim of the study** This RCT was aimed to compare the effectiveness of 2 interventions, a psycho-educational intervention versus standard care (standard home-based palliative care services), in adult carers of people with advanced cancer receiving home-based palliative care. **Study dates** N/R **Follow-up** 5 weeks from baseline, and 8 weeks from patient death	N=106 **Carer Characteristics** • Age, Mean - years (SD): 60.8 (14.0) • Gender (M/F - N): 36/70 **Care recipient characteristics:** • Condition = Advanced cancer receiving home based palliative care	• I = Psycho-education + standard care • C = Treatment as Usual	• Psycho-educational support intervention
Hudson 2013	See Hudson 2015 **Follow-up** 1 week post intervention (5 weeks post recruitment)	See Hudson 2015	See Hudson 2015	• Psycho-educational support intervention
Hudson 2015	**Setting** Australia **Study type** 3 group RCT	N=298 **Carer Characteristics** • Age, Mean - years (SD): 60.8 (13.9)	• I1 = Psycho-education + standard care (1 Face-to-face	• Psycho-educational support intervention

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
	Aim of the study This RCT was aimed to compare the effectiveness of 2 interventions, a psycho-educational intervention (deliverd either face-to-face or by telephone) versus standard care, in adult carers of people with advanced cancer receiving home-based palliative care. **Study dates** 2009-2011 **Follow-up** 8 weeks following patient's death	- Gender (M/F - N): 85/211 (2 carers N/R) **Care recipient characteristics:** - Condition = Advanced cancer receiving home based palliative care	visit + 3 telephone calls) - I2= Psycho-education + standard care (2 Face-to-face visits + 2 telephone calls) - C = No intervention Home visits were done for first contact, and the second as the final contact.	

Kogler 2015	**Setting**
	Germany
	Study type
	2 group RCT
	Aim of the study
	This RCT was aimed to compare the effectiveness of 2 interventions, a cognitive behavioural intervention (existential behavioural therapy) versus standard care, in adult carers of people with advanced cancer and neurological disorders -with a life expectancy <6 months.
	Study dates
	2008-2010
	Follow-up
	3, 12 months from baseline
		N=130
		Carer Characteristics
		- Age, Mean - years (SD):
		  ○ I = 54.5 (13.6)
		  ○ C = 54.0 (13.2)
		- Gender (M/F - N):
		  ○ I = 20/53
		  ○ C = 18/39
		Care recipient characteristics:
		- Condition = Palliative care patients with life expectancy <6 months
			- I = Existential Behavioural Therapy
			- C = Treatment as usual
				- Psychological/emotional support intervention

Walsh 2007	**Setting**
	UK
	Study type
	2 groups mixed methods
	Aim of the study
	This mixed-methods RCT was aimed to compare the effectiveness of 2 interventions, a psycho-
		N=271
		Carer Characteristics
		- Age, Mean - years (SD):
		  ○ I = 56.4 (14.6)
		  ○ C = 56.1 (13.2)
		- Gender: (M/F - N):
		  ○ I = 27/107
		  ○ C = 29/108
			- I = Carer advisor intervention
			- C = Treatment as usual
				- Psycho-educational support intervention

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
	educational intervention (a carer advisor intervention) versus standard care (standard specialistic palliative care services), in adult carers of people with advanced cancer receiving palliative care. **Study dates** 2001-2003 **Follow-up** 4, 9, 12 weeks from baseline	**Care recipient characteristics:** • Advanced cancer receiving palliative care		

C: control group; F: Female; I: intervention group; M: Male; N: Number; N/R: not reported; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial

Qualitative component of the review

Table 3: Summary of included qualitative studies

Study and aim of the study	Participants	Methods	Themes
Ashton 2016 **Aim of the study** To explore the experiences of advance care planning amongst family caregivers of people living with advanced dementia	• N=12 adult carers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: 35 - 82 • **Care recipient** ○ Condition= Dementia	• **Methods** Data was collected through (face-to-face) semi-structured interviews and analysed by content analysis • **Recruitment:** Purposive sample of family caregivers within a specialist dementia unit	• Having difficult discussions with carers • Advanced care plans (ACPs) at end of life
Briggs 2010 **Aim of the study** To gain an understanding of the experiences and expectations of carers of patients diagnosed with lifelimiting diseases during the last year of life	• N= 20 adult carers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: 17-84 • **Care recipient** ○ Condition= Dying people	• **Methods** Data was collected through ethnographic methods (open-ended qualitative interviews and observations). Interviews were transcribed verbatim for inductive analysis and categorised thematically, with the key areas of investigation providing the overall framework for coding • **Recruitment:** Approached through service professionals and asked if they	• Valuing the carer and their knowledge • Bad experiences with professional services • Arranging for help at home at end of life

Study and aim of the study	Participants	Methods	Themes
		would consent to participate	
Caswell 2016 **Aim of the study** To understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers	• N = 13 adult carers • N = 32 care providers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** Field notes from observations were written up and narratives were constructed from the case notes accessed. Research interviews were, with the permission of the participant, recorded and then transcribed. Analytic procedures were based in the constant comparative method • **Recruitment:** The family carers of the 39 patient cases who had relatives were invited to take part in an interview	• Having difficult discussions with carers • Valuing the carer and their knowledge • Making a supportive environment for carers at end of life • Meeting needs
Dosser 2012 **Aim of the study** To investigate the current support offered to carers near the end of life in an acute hospital setting	• N = 13 adult carers • N = 26 care providers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** Carers underwent individual semi-structured interviews, as did 3 palliative care specialists. 23 nursing staff participated in focus groups. Thematic analysis was used to analyse the data • **Recruitment:** Convenience sampling was used. 3 volunteers were approached by hospital staff. All remaining eligible carers were sent a letter explaining the study and inviting them to participate	• Having difficult discussions with carers • Making a supportive environment for carers at end of life
Dosser 2014 **Aim of the study** To improve communication between staff and carers. To improve the care environment for carers experiencing the death of the person they care for	• N = 24 care providers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** Participatory action research. Data came from a number of sources, including snapshot interviews and audio recordings in practice, the reflective diary of the researcher, field notes, action meetings and poster notes.	• Having difficult discussions with carers • Making a supportive environment for carers at end of life

Study and aim of the study	Participants	Methods	Themes
		Emerging data were presented to the action team where the findings were discussed and refined in an ongoing and reflexive process. The analysis aimed to describe what was done, explain why, and demonstrate the implications • **Recruitment:** The entire registered nurse workforce on the ward was recruited	
Epiphaniou 2012 **Aim of the study** To identify existing coping and support mechanisms among informal cancer caregivers in order to inform intervention development	• N = 20 adult carers • **Carer** ○ Gender-M/F (N)= 9/11 ○ Age range: 25-79 **Care recipient** ○ Condition= Cancer	• **Methods** Flexible, open-ended, semi-structured interviews, and a thematic analysis • **Recruitment:** Recruited from the community palliative care team	• Having difficult discussions with carers • The burden of being a carer • Experiences of receiving support at home at end of life
Forbat 2012 **Aim of the study** What are the support needs of caregivers when someone is receiving palliative care	• N = 17 adult carers • **Carer** ○ Gender-M/F (N)= 4/13 ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** Semi-structured interview using open-ended questions, analysed inductively and thematically • **Recruitment:** A systematic sampling technique was used, where every fifth person was taken from the caseload of community specialists	• Valuing the carer and their knowledge • The burden of being a carer • Experiences of receiving support at home
Jack 2015 **Aim of the study** To explore family carers' experiences with a hospice at home service	• N = 20 adult carers • **Carer** ○ Gender-M/F (N)= 5/15 ○ Age range: 18 of 20 were aged 50 or over • **Care recipient** ○ Condition= Dying people	• **Methods** Semi-structured interview, and thematic analysis • **Recruitment:** Purposive sample - open invitation through ads seeking past service users	• Experiences of receiving support at home at end of life
Nelson 2017 **Aim of the study** Explore the experiences of carers	• N = 10 adult carers • **Carer** ○ Gender-M/F (N)= 2/8	• **Methods** Interviews, analysed thematically • **Recruitment:**	• Valuing the carer and their knowledge • Arranging for help at home at end of life

Study and aim of the study	Participants	Methods	Themes
of patients dying in their own homes	○ Age range: N/R • **Care recipient** ○ Condition= Dying people	20 invitations sent out, from a range of demographics, to those who'd reported especially good or bad experiences - from pool of 400 users	
Newbury 2011 **Aim of the study** Describe the experiences of carers in receipt of the bespoke support package	• N = 15 adult carers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: 27-87 • **Care recipient** ○ Condition= Dying people	• **Methods** Qualitative approach, interviewed before and after death, using grounded theory methodology • **Recruitment:** Not reported	• Having difficult discussions with carers • The burden of being a carer • Arranging for help at home at end of life • Experiences of receiving support at home at end of life
O'Brien 2015 **Aim of the study** Explore the experiences of hospitalisation that occurred after a diagnosis of MND was made	• N = 21 adult carers • **Carer** ○ Gender-M/F (N)= 10/11 ○ Age range: N/R • **Care recipient** ○ Condition= Motor Neuron Disease	• **Methods** Secondary analysis 2 sets of narrative-style interviews, and a consensus based thematic analysis • **Recruitment:** Purposive sampling of family carers of people with MND resident in Northwest England	• Bad experiences with professional services • Meeting needs
Payne 2015 **Aim of the study** To explore how family members manage delivering end of life medications	• N = 59 adult carers • **Carer** ○ Gender-M/F (N)= 18/41 ○ Age range: 44-90 • **Care recipient** ○ Condition= Dying people	• **Methods** Single face-to-face interviews conducted, and for analysis a constant comparative approach was utilised until saturation of themes was achieved • **Recruitment:** Recruited through GP practices - staff identified carers who met criteria, and posted information packs	• Managing medication at end of life
Percival 2014 **Aim of the study** Examine the aspects of domiciliary care perceived to be of most value	• N = 42 adult carers • N = 6 care providers • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** In-depth face-to-face interviews and observations of practice, analysed by thematic and content analysis • **Recruitment:** Not reported	• Experiences of receiving support at home at end of life • Experiences of receiving support at home at end of life

Study and aim of the study	Participants	Methods	Themes
PHE 2016 **Aim of the study** To understand the following: the awareness and knowledge of community end of life care across a number of key audiences; their perceptions of community end of life care; their experiences of end of life care and any community initiatives; any improvements that could be made to community end of life care	69 adult carers and their dying relatives • **Carer** ○ Gender-M/F (N)= N/R ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** Interviewed some in groups, dyads or individually. The qualitative analysis comprised a variety of approaches, primarily in the form of theme-discussion and development • **Recruitment:** Recruited by professional market research recruiters	• Experiences of receiving support at home at end of life • Carers support needs following bereavement
Seamark 2014 **Aim of the study** To elicit family carers' views about the community support that made death at home possible	• N = 59 adult carers • **Carer** ○ Gender-M/F (N)= 18/41 ○ Age range: N/R • **Care recipient** ○ Condition= Dying people	• **Methods** In-depth semi-structured interviews conducted, an inductive approach to analysis was informed by the principles of grounded-theory methods • **Recruitment:** Recruited through GP practices - staff identified carers who met criteria, and posted information packs	• Having difficult discussions with carers • Bad experiences with professional services • Arranging for help at home at end of life • Experiences of receiving support at home at end of life

F: Female; M: Male; N: Number; N/R: not reported; PHE: Public Health England.

See the full evidence tables in appendix D.

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

One study was identified with respect to the cost-effectiveness of interventions used to support carers at the end of life of the cared-for person (Pham 2014). This Canadian study assessed 3 interventions to support adult carers of people with a terminal illness. Table 4 provides a brief summary of the included study.

See also the economic evidence study selection chart in appendix G.

Table 4: Summary of included studies (economic evidence)

Study	Population	Intervention/Comparison	Perspective and cost year	Comments
Pham 2014 Cost utility analysis Canada	Carers of people at the end of life	Family conference between intensive care unit team and caregivers Multicomponent psychological educational training provided by advanced practice nurses Multifaceted supportive interventions Usual care	Health payer 2013	The authors noted that improvement in health related quality of life/QALYs may not have been the primary focus of the intervention

QALYs: Quality adjusted life years

See the economic evidence tables in appendix H and economic evidence profiles in appendix I.

Excluded studies

Studies not included in this review with reasons for their exclusion are provided in appendix K – Excluded studies.

Summary of studies included in the economic evidence review

A Canadian cost-utility analysis (Pham 2014) compared 3 interventions for supporting carers at the end of life of their care recipient to usual care:

a. Patient care planning discussions through an end of life family conference between the intensive care unit (ICU) team and the caregivers, with the intention to lessen the impact of bereavement on carers
b. Educational interventions for carers and the person they care for, where multicomponent psycho-educational training is provided by advanced practice nurses in order to promote activation, self-management and empowerment
c. Supportive interventions for carers, such as breaks from care giving, providing programs that aim to increase coping skills and enhancing well-being through the use of counselling or psychotherapy for example

End of life care and related healthcare resource use were simulated using a Markov model for a population cohort of Ontarian decendents in their last year of life and their principle informal carers. The analysis adopted the perspective of the health payer (the Ontario Ministry of Health and Long Term Care). Costs were presented in Canadian dollars for a

2013 price year and included included hospital costs, community care costs, outpatient costs and long term care costs. Costs were not discounted as the analysts defined a 1 year time horizon based on the cohort's final year of life. Data on resource use and effectiveness was obtained from a variety of sources including systematic reviews, linked health administration databases, survey data, planning documents, expert opinion and other published material. Quality adjusted life years (QALYs) were estimated using effect estimates made for disease specific measures of health related quality of life (HRQoL) and making a strong assumption of constant relative responsiveness between diseases specific HRQoL measures and generic scales such as EuroQOL 5 dimensions (EQ-5D).

The analysis showed that when compared to usual care:

i. Family conferences were found to be effective in reducing depressive symptoms among carers in a 3 month period of bereavement for carers of people dying in ICU. Despite increasing mean healthcare costs, the intervention appeared cost-effective with probabilistic sensitivity analysis indicating there was a 52% probability of improving family conferences being cost-effective using a cost-effectiveness threshold of 50,000 CAD (Canadian Dollars) per QALY. However, sensitivity analysis indicated that the results might change with additional data or different assumptions.
ii. Multicomponent psycho-educational training was not cost-effective, being dominated by usual care. Although this increased health related quality of life (HRQoL) for carers, it increased the mean healthcare cost and reduced the overall effectiveness of end of life care for the people being cared for. The intervention was found to have a 26% chance of being cost-effective at a cost-effectiveness threshold of 50,000 CAD per QALY
iii. Multifaceted supportive interventions may be cost-effective with this strategy leading to a very small, but not statistically significant, improvement in carers' HRQoL and an increase in the mean healthcare costs. Sensitivity analysis suggested that the conclusions were subject to considerable uncertainty and could change with additional data or different assumptions. Probabilistic sensitivity analysis indicated that there was only a 28% probability of this intervention being cost-effective at a cost-effectiveness threshold of 50,000 CAD per QALY.

Therefore, the authors noted that strong conclusions about the cost-effectiveness of interventions targeted on carers of people at the end of life were not possible and that future studies would require further data on the impact on the HRQoL of patients and carers and resource utilisation. However, they also noted as a limitation that their analysis has measured benefit using QALYs, which they acknowledged might not be the primary focus of the interventions evaluated.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

Evidence statements

Each evidence statement has an identifying code to ensure ease of reference to the data during presentation and committee discussions. The code is derived from the title of the review and in this case is 'EoL' and then a number. EoL stands for (support needs of adult carers who are caring for people) at the end of life.

Quantitative and qualitative components of the review

Evidence statements from the included studies are organised by intervention category and then by outcome within each category, starting with quantitative data and then relevant themes from the qualitative studies.

Work, education and training

- **EoL1.** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Training to provide practical support

Caring-related morbidity

- **EoL2.** Very low quality evidence from 1 RCT conducted in Australia (n=298), could not differentiate levels of carers anxiety (The Hospital Anxiety and Depression Scale) for carers of patients with advanced cancer receiving a psychoeducational or control intervention at 5 weeks and 8 weeks from patient death
- **EoL3.** Moderate to low quality evidence from 2 RCTs conducted in the UK and Australia could not differentiate levels of psychological distress (General Health Questionnaire) for carers of patients with advanced cancer receiving a psycho-educational or control intervention at 1 week post intervention (uncertain quality evidence) and 4, 9 and 12 weeks (low quality evidence) follow-up from baseline. In a follow-up study, 8 weeks after the care recipient's death, there was some evidence that 2 psychoeducational intervention groups when combined may have lower psychological distress compared to carers in the control group. This was not demonstrated in individual intervention groups compared to each other or the control arm.

Impact of intervention on caring-related accidents/incidents

- **EoL4.** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **EoL5.** Moderate to very low quality evidence from 2 RCTs conducted in Australia, could not differentiate levels of competency (Caregiver Competence Scale) on adult carers of patients with advanced cancer receiving a psychoeducational intervention versus a control condition irrespective of different frequency of modes of delivery (face-to-face, telephone) and follow-up time (range 1 week post intervention to 8 weeks from patient death).
- **EoL6.** Moderate to very low quality evidence from 2 RCTs conducted in Australia demonstrated conflicting evidence about the effectiveness of psychoeducational interventions on perceived levels of preparedness in adult carers of people with advanced cancer.
- **EoL7.** Low quality evidence from 1 RCT from Australia including carers of patients with advanced cancer found improved levels of self-efficacy (Instrument developed by Zeiss) in terms of problem solving skills at 5 weeks follow-up from baseline. There was very low quality evidence showing no difference in respite and rewarding interaction self efficacy domains between the psychoeducational intervention and control arms
- **EoL8.** Moderate to very low quality evidence from 2 RCTs (range n=45 to 298) based in Australia, could not differentiate levels of Rewards (Rewards of Caregiving Scale) on adult carers of patients with advanced cancer receiving a psychoeducational intervention

versus a control condition irrespective of different frequency and modes of delivery (face-to-face, telephone) and follow-up time (range 1 week post intervention to 8 weeks from patient death).

Impact of caring on carer

- **EoL9.** Low quality evidence from 1 RCT conducted in the UK, could not differentiate levels of carer strain (Carer Strain Index) on adult carers of patients with advanced cancer receiving a psychoedcuational intervention versus a control condition at 4 (n=185), 9 (n=136), and 12 weeks (n=123) follow-up from baseline.
- **EoL10.** Low quality evidence from 1 RCT conducted in the UK, could not differentiate levels of carer quality of life (Caregiver Quality of Life Index) on adult carers of patients with advanced cancer receiving a psychoedcuational intervention versus a control condition at 4 (n=175), 9 (n=130), and 12 weeks (n=116) follow-up from baseline
- **EoL11.** Moderate quality evidence from 1 RCT based in Australia, could not differentiate levels of 75 carers' family need (Family inventory of need, Part Scale B) for carers of patients with advanced cancers receiving psychoeducational or control interventions at 5 weeks follow-up from baseline.

Resource and service use (health or social care)

- **EoL12.** No data reporting on this outcome

Practical support

- **EoL13.** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Psychological and emotional support

Impact of caring on carer

- **EoL14.** Very low quality evidence from 1 RCT conducted in Canada (n=19) could not differentiate the carer's subjective experience of caring (Inventory of Daily Widowed Life) and levels of hope (Herth Hope Index) between the psychological/emotional support intervention and control groups
- **EoL15.** Low quality evidence from 1 RCT conducted in Germany looked at whether mindfulness was a predictor of carer adjustment in carers of patients (n=30) with a life expectancy of less than 6 months. No differentiation could be found for carer satisfaction with life (SWLS) at 6 weeks from basline measurement, 3 and 12 months from the end of the intervention. The meaning of life evaluation (SMiLE) was found to be higher if mindfulness at baseline was 1 point higher, at 3 and 12 months from the end of the intervention.

Caring-related morbidity

- **EoL16.** Low quality evidence from 1 RCT conducted in Germany (n=30) found mindfulness to predict lower psychological distress in carers of patients with a life expectancy of less than 6 months, at 6 weeks from baseline and 3 months from the end of the intervention. However, this was not found at 12 months from the end of the intervention.
- **EoL17.** Low quality evidence from 1 RCT conducted in Germany (n=30) found no evidence to suggest that the psychological emotional intervention affected the levels of somatisation (BSI subscale) at 12 months. There was some evidence to suggest a change in mindfulness affected somatisation, but not a combination of the two (intervention effect and change in mindfulness)
- **EoL18.** Low quality evidence from 1 RCT conducted in Germany (n=30) found some evidence to suggest that the individual intervention effect and change in mindfulness (from baseline to 12 months) reduced depression (BSI subscale) but not a combination of the two (intervention effect + change in mindfulness)

- **EoL19.** Low quality evidence from 1 RCT conducted in Germany (n=30) found no evidence to suggest that the psychological emotional intervention affected the levels of anxiety (BSI subscale) at 12 months. There was some evidence to suggest a change in mindfulness affected somatisation, but not a combination of the two (intervention effect and change in mindfulness)

Social capital

- **EoL20.** No data reporting on this outcome.

Carer quality of life

- **EoL21.** Low quality evidence from 1 RCT conducted in Germany (n=30) found conflicting results for the measurement of quality of life for carers. Mindfulness was not found to predict higher quality of life (QoL-NRS, WHOQOL-Bref) in carers of patients with a life expectancy of less than 6 months at 6 weeks from baseline, 3 (WHOQOL-Bref only) and 12 months from the end of intervention. At 3 months from the end of the intervention, quality of life (QoL-NRS) was higher if mindfulness at baseline was 1 point higher. The long term effect of the intervention on Qol-NRS had some evidence of mindfulness mediation

Carer choice/control/efficacy

- **EoL22.** No data reporting on this outcome.

Qualitative themes

- **EoL23. Interacting with carers at the end of life, having difficult discussions with carers:**
    - There is moderate quality evidence from 3 studies that carers can find it difficult to comprehend and accept the seriousness of the patient’s condition. Understanding that the person they care for is dying and taking in details may be difficult. It will often require more than one conversation. Some reach a state of denial and feel reluctant to ‘give up'.
    - There is low quality evidence from 1 study that carers need to be told things sensitively and given time to process, however it is also important to use clear language and avoid being vague or euphemistic. This can prevent misunderstandings later on.
    - There is moderate quality evidence from 2 studies that carers value receiving further information about the patient’s condition and the end of life process directly from professional care staff. Frequent face-to-face updates with professionals when at care or treatment units, or by phone with GPs when at home, has a big impact.
    - Very low quality evidence from 1 study also found that at the end of life carers do not engage well with further information from books, leaflets or websites.
    - There is low quality evidence from 1 study that unlike specialist hospice or acute care staff, ward nurses may be hesitant to talk with families and carers about the end of life. They do not see it as their role, and felt families may appreciate conversations with more senior or specialist staff, even though families often come to them. Many also felt underconfident in their skills and ability to have difficult conversations.
    - There is low quality evidence from 1 study that after communication training ward nurses felt confident in their ability to offer help and have difficult conversations. Families greatly appreciated having this extra support available.
- **EoL24. Interacting with carers at the end of life, valuing carers:**
    - There is low quality evidence from 3 studies that carers often feel that support services don’t pay them consideration and ignore their significant role, knowledge and experience. This is an oversight given the levels of care they provide as well as the personal and condition-specific knowledge they have.
    - There is very low quality evidence from 1 study that some carers feel wary that they should not push or assert themselves too much in their demands with care staff. They

  fear they may be labled as 'difficult' and this will damage their relationship with professionals. They beleive this will be detrimental to the support that they and the person they care for receive.
  - There is low quaity evidence from 1 study that carers who feel included in decisions and processes subsequently feel better towards the service they received and happier with the end of life process overall.
- **EoL25. Challenges for carers at end of life, impacts of being a carer:**
  - There is low quality evidence from 1 study that carers feel highly responsible for the person they care for. Providing care impacts them and takes a toll on their lifestyle – however this toll is somewhat mediated by their own life-stage (job status, health etc).
  - There is very low quality evidence from 1 study that carers feel determined they have to be 'strong' and maintain the appearance that everything is 'fine'.
  - There is low quality evidence from 1 study that being a carer for a dying person puts a strain upon that relationship. Carers may become snappy or irritated towards them due to the pressure of burden. Patients may act demandingly, complacently or entitled towards their carer. Carers feel unhappy that their relationship can become soured by this towards the end of the person's life.
  - There is moderate quality evidence from 3 studies that close family networks usually rally around patients and carers towards the end of life and offer support.
  - Low quality evidence from 1 study also found that carers sometimes feel pressured to look after their family members as well as the dying person - including to act like everything is fine in front of them, consoling them, and taking on extra responsibilities in order that other family members don't also feel strained.
- **EoL26. Challenges for carers at end of life, advanced care plans (ACPs) at end of life:**
  - There is low quality evidence from 1 study that carers of people who may lack capacity now or in future (in this case, people living with dementia) agreed ACPs are appropritate. ACPs allow them to confront important and inevitable decisions at a calmer, less stressful time.
  - There is low quality evidence from 1 study that advanced care planning is an uncomfortable experience. Open and honest but sensitive discussions were appreciated. It is important to remember that they are a person with a life history, and not only a dying patient.
- **EoL27. Challenges for carers at end of life, managing medication at end of life:**
  - There was low quality evidence from 1 study that carers come up with their own strategies for how to manage medication. These need to be understood and worked with.
  - There is low quality evidence from 1 study that the responsibility of managing medication gives carers concerns. They are especially worried about making mistakes such as giving too much, not enough, or forgetting to give it at all.
  - Low quality evidence from 1 study also found that carers are anxious about challenging medical practitioners about their instructions if they disagreed with them.
  - Low quality evidence from 1 study found that some drugs (especially morphine) are important for pain relief but can also make the patient lose their composure and dignity. When a patient is on the edge of dying, some carers recalled fondly how they brought the patient off their drugs in the final hours and were able to make final precious memories as they regained lucidity.
- **EoL28. Challenges for carers at end of life, bad experiences with professional services:**
  - There is low quality evidence from 2 studies that in homecare or hospital settings carers sometimes had to deal with professionals that don't have specialist knowledge or training about the condition. Carers had to fill in these knowledge gaps, often

  - repeatedly to different staff. This was especially true with rare conditions or special cases and can lead to frustration and occasionally conflict.
  - Very low quality evidence from 1 study also found that professionals sometimes failed to understand when a patient had communication difficulties – and this was undignifying to the patient and made them less autonomous.
  - There is low quality evidence from 2 studies that bad experiences can do irreversible damage to carers' perceptions and relationships with professionals. Bad experiences may be detrimental to the final memories the carer has with the person they care for. It may also stop them from feeling willing to seek help in future when it's necessary.
- **EoL29. Receiving support at home at end of life, arranging for help at home at end of life:**
  - There is low quality evidence from 2 studies that carers feel overwhelmed and vulnerable at this time, and find organizing care at home highly taxing. Carers report being given a long list of phone numbers but still feeling unsure who to call. Arranging for out-of-hours help was especially distressing.
  - There is low quality evidence from 2 studies that filling out forms and striving to see what help they qualify for added further stress to carers, when they wanted to make the most of the time they had with the person they care for.
  - Very low quality evidence from 1 study found that carers want to have some input but ideally the arrangements for homecare would mostly be arranged and directed by professionals.
  - There is very low quality evidence from 1 study that carers in rural settings that want to remain in their own homes acknowledge that it's harder to get support to them. Receiving help, assistance and reassurance over the phone was acceptable but it needed to be regular. Also it helped if they got to meet the professionals face-to-face at least once.
  - There is low quality evidence from 2 studies that there is often a lack of strategic communication between agencies. Carers commonly report negative experiences. In 1 example a patient died and the care agency – not having been informed of this - continued to send carers. Carers were pleasantly surprised on the occasions when communication did work.
- **EoL30. Receiving support at home at end of life, experiences of receiving support at home at end of life:**
  - There is high quality evidence from 3 studies that support at home could be a very valued presence. Competent professional staff made carers feel comforted and supported, and better able to enjoy their final time with the person they care for.
  - There is moderate quality evidence from 2 studies that home care staff help out domestically as well as with care tasks. This gave carers a chance for some respite, and often enabled them to keep their jobs and own livlihoods. Above all it improved the quality of the time and interaction they had with dying person.
  - There is moderate quality evidence from 2 studies that that carers value the praise and encouragement they get from professional home care staff. Where they doubt themselves or the actions they are taking as carers, professionals could guide them or reassure them that the care they are giving is adequate and appropriate.
  - There is high quality evidence from 4 studies that carers find the decision to accept help at home very difficult. Carers often give up work or social lives to avoid or reduce the need for outside help.
  - There is low quality evidence from 2 studies that carers find it hard to adjust to outsiders coming into the home, often several times per day and often varying people. Accepting help in the home can feel very invasive. The same applied to medical equipment brought in to the home. Introducing new workers and equipment to the home must be done sensitively.

  - There is moderate quality evidence from 2 studies that having continuity with the staff who visit their house is very important to carers. Being introduced to new staff and having to repeat information and preferences is distressing for both the carer and the patient.
  - There is low quality evidence from 1 study that receiving help at home was most beneficial when it was flexible and when visitng care staff weren't rushed. Being able to adapt as the situation changes, and give more or less time as necessary, was greatly appreciated.
- **EoL31. Carers needs at a hospital/care unit setting, making a supportive environment for carers at end of life:**
  - There is high quality evidence from 3 studies that having calm side-bedrooms for patients who are dying was greatly appreciated compared to being on a ward. This allowed family to have intimate moments in peace, as well as avoid being distressed or selfconscious that they were disturbing neighbours. Similarly, having quiet side rooms with seating, kettles, microwaves etc where families could take time out or have difficult conversations with staff was helpful.
  - There is low quality evidence from 1 study that carers who are keeping vigil with a dying relative appreciate being occasionally checked up on by staff, even though they are going through a sensitive personal time.
- **EoL32. Carers needs at a hospital/care unit setting, meeting needs:**
  - There is very low quality evidence from 1 study that carers find it highly distressing when dying patients, especially those with severe disabilities such as MND, are left without having their personal basic care and hygene needs met.
  - There is low quality evidence from 1 study that carers at hospital units sometimes find it difficult to find any member of staff to ask questions to.
- **EoL33. Support following bereavement, carers support needs following bereavement:**
  - There is very low quality evidence from 1 study that carers feel the need for support navigating legal and logistical tasks (funerals and death certification) after the person they care for has passed away.
  - There is low quality evidence from 1 study that carers feel a need to talk and grieve with others once the person they care for has passed. This may become especially apparent when coming to terms with the gap in their life that had previously been filled by caring. For some this may involve opening up to informal support networks, but for others seeing a counsellor was considered very helpful.

Economic statements

- **EoL34** One partially applicable cost utility analysis from Canada with minor limitations compared family conference between the intensive care unit team and caregivers with usual care for carers of people at the end of life. The intervention was found to be cost-effective with an incremental cost-effectiveness ratio (ICER) of 41,690 CAD per QALY using a cost-effectiveness threshold of 50,000 CAD per QALY.
- **EoL35** One partially applicable cost utility analysis from Canada with minor limitations compared multicomponent psychological education with usual care. The intervention was found to be not cost-effective with an ICER of 479,509 CAD per QALY using a cost-effectiveness threshold of 50,000 CAD per QALY.
- **EoL36** One partially applicable cost utility analysis from Canada with minor limitations compared supportive interventions for carers with usual care. The intervention was found to be not cost-effective with an ICER of 87,205 CAD per QALY using a cost-effectiveness threshold of 50,000 CAD per QALY.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review searched for evidence on carers of people at the end of life across all of the domains covered in reviews D, E, F, and G. The most important outcomes for this review matched the critical and important outcomes relevant to those reviews.

Quantitative evidence was identified relating to psychoeducation and psycho-emotional support interventions. For psychoeducational interventions the critical outcomes were caring-related morbidity, and the impact of intervention on caring-related accidents/incidents, although evidence was only found for caring-related morbidity. The important outcomes were impact of caring on carer, carer skills and knowledge/confidence, and resource/service use, although evidence was only found for the first 2 of these. For psycho-emotional support interventions the critical outcomes were caring-related morbidity, and the impact of caring on carer, with evidence identified for both. The important outcomes were social capital, carer quality of life, and carer choice/control/efficacy, although evidence was only found for carer quality of life.

Qualitative evidence was identified relating to training for carers – with a theme emerging about carers' need for training or support for handling medication. Qualitative evidence was also identified relating to psychological support for carers, with 1 theme emerging about carers need for emotional support and counselling after bereavement, and another about helping carers utilise and maintain family relationships.

Most of the qualitative evidence related to practical support for carers at the end of life and/or after the cared-for person dies. The emerging themes identified what types of support and services carers had experienced as well as the acceptability, barriers and facilitators to successful service delivery at this time. The interventions and settings covered by the qualitative data included support in the home at the end of life, support at a hospital/hospice/other unit at the end of life, and advanced care plans. One of the most important themes throughout was how carers preferred to be talked to and interacted with by staff and professionals during this time.

The quality of the evidence

The quantitative evidence statements were assessed using GRADE methodology and were classified as ranging from very-low to moderate quality. No RCT evidence was identified favouring any of the interventions tested. As a result the committee made very little use of the quantitative findings when drafting recommendations. There was no evidence that any service type or approach to end of life care (homecare, hospice) should be encouraged over another. Instead the committee took account of the qualitative evidence which identified the features of services that carers find enhance or diminish their experience.

The qualitative evidence was assessed using GRADE-CERQual methodology and was found to range from very-low to high quality. It suggested changes that carers would improve the acceptability of services for them across the end of life process. This included help to remain in their occupations, help to foster their skills as carers, and support for any practical or emotional/psychological difficulties. The participants in the studies were carers of people at the end of life, from across the UK with a range of conditions. The people being supported were mostly over 60 years of age. Although this contributed to the findings being considered generally applicable the committee noted a lack of data about the needs of someone caring for a younger adult at the end of life.

For most of the qualitative statements the rating of quality was downgraded due to adequacy of the data, as many themes only had 1 or at most 2 studies studies supporting them. Many of the qualitative statements were also automatically downgraded for imprecision, as the papers did not report the Mean or SD statistics needed for imprecision to be calculated.The committee mostly focused on drafting recommendations in areas that had at least moderate quality evidence. Still, areas with low quality evidence statements were sometimes still considered as a basis for recommendations especially if the individual studies were judged to be at least moderate quality and could be strengthened by the committee's experience.

Synthesis of quantitative and qualitative data

During their discussion of the evidence, the committee synthesised the quantitative and qualitative data, making judgements about the extent to which the combined findings coud be used as a basis for recommendations.

Five RCTs provided quantitative evidence about the effectiveness of interventions for carers when the person they care for is at the end of life. Three provided moderate to very low quality data about psycho-educational interventions and the other 2 provided very low to low quality data about psycho-emotional support interventions. Given the relatively low overall quality of the statements and lack of any demonstrated effectiveness the committee made no use of the quantitative evidence. Instead the recommendations were drafted focussing entirely on the strength of the qualitative component.

Benefits and harms

Quantitative evidence did not show discernable benefits of any interventions over their control conditions and so the committee did not draft any recommendations to suggest that particular services or interventions should be introduced (or ceased) based on effectiveness data. Instead the committee drafted recommendations based on the qualitative findings about needs and difficulties that carers identified as a result of their own experiences. By drafting recommendations based on this evidence, it is intended that carers' experience will be improved. This will also make them better placed to support the person they care for at the end of life.

Information and support

Qualitative evidence from the review found that carers may misunderstand or forget important information. Staff can also sometimes be reserved or overly euphemistic with information. Misunderstandings may be detrimental to the carers' final time with the dying person. Carers and staff think it's important that staff take time to reinforce important messages across the end of life journey, are tactful but also willing to repeat information. The committee agreed that taking time to communicate in these ways would improve the carer's experiences at this time and save time correcting confusions later on. On this basis the committee agreed to draft recommendations about offering frequent opportunities for discussion and avoiding the use of jargon.

The evience also showed that carers wanted to be able to discuss things with the staff around them regardless of who they are, but some junior staff such as nurses or domiciliary care workers reported they do not feel comfortable talking about these topics - or felt it was not their place. The committee therefore agreed to recommend that health and social practitioners involved in end of life care should be competent to have conversations about death and dying because it will allow carers a better chance to process their situation and feel attended to. The committee agreed that being competent with this would also make staff feel more comfortable and capable of providing help.

Qualitative evidence found that first impressions were important to carers - reducing their levels of distress and building trust for them to share information and seek help more readily. Failing to make carers feel respected or valued may cause them to hold back asking important questions that will improve the care they give or put them off sharing information that may be important for practitioners to know. This evidence led the committee to recommend extra care during early contact with carers when the person they care for is at the end of life.

Evidence from this review also found that carers have difficulty adjusting to having care professionals and equipment brought in to their home. Carers also reported that a high turnover of staff visting their home was distressing, as they could not build a bond and instead had to repeat information and preferences to new people each time. The committee felt strongly about the importance of being sensitive to carers when they start accepting help into their home, and being mindful that the influx of new or regularly changing people and equipment may be invasive. They drafted 2 recommendations which aimed to address this.

Qualitative evidence from this review suggested that the support of wider family networks is often helpful and appreciated by families at this time because they can provide additional help and support. However in some cases family can also make things more complicated through having emotional needs of their own or creating additional emotional and practical work for carers. From their experience the committee agreed that carers frequently take on too much by themselves. They noted that the strongest quality evidence suggested that family support was a positive influence and so used this evidence used to draft a recommendation about encouraging carers to think about ways they can get support from family, friends and wider networks.

Advance care planning

Qualitative evidence found that advanced care plans can be a process intervention for carers of people at the end of life. Existing guidelines were identified by the committee on this topic, and so they agreed it would be relevant to refer to them within their recommendations. [NG108, 4.1-4.2].

Providing care at the end of life

Qualitative evidence found that carers often have worries and coping strategies relating to medication at the end of life. The evidence suggested that family members and carers, as well as the dying person, often have their own views or preferences about taking certain medications at the end of life – such as opiate painkillers which may make a person unable to communicate coherently during their final time. The committee agreed that these views, concerns and preferences were important and agreed that family members, carers, and the people they care for do often have questions about medication at the end of life. As a result the committee recommended that family members, carers and the people they care for should be involved in discussions and planning about pharmacological interventions and agreed to do so by referring to section 1.5 in the existing NICE guideline, NG31. The committee also proposed that structured medication reviews may be relevant at this time because of the concerns that family and carers may have, and so the committee also drafted a recomendation referring to the existing NICE guideline NG5 outlining how to do this.

A range of moderate-to-high quality qualitative evidence was identified suggesting that help and support at home could be very positive and was greatly appreciated by carers supporting someone at the end of life. In the committee's experience the provision of professional homecare and support varies across regions. They elected to draft a recommendation to encourage the full range of support be offered where it is available.

When staying and keep vigil at hospitals, hospices or other care units at the very end of life qualitative evidence found that carers value having privacy, comfort and refreshments available. Having opportunities to rest means they reduce the risk of missing valuable final moments with the dying person, and also means they could be present for any final care decisions. On this basis the committee drafted a recommendation on this topic and discussed a several other useful facilitations, based on their own experience, such as free parking and flexible visiting hours. They were aware that some units might not be able to offer privacy through a seperate sideroom, but could be still encouraged to offer a screenedoff area. This would reduce carers' about disturbing others at a sensitive time, and equally others on the unit will not be affected.

Some qualitative evidence was identified suggesting that carers value having information signposting them to practical and emotional support at the end of life. The committee agreed that this extended beyond counselling services to include things like funeral services – and better signposting would lead to better utilisation of services, as well as a less stressful experience having to search at a difficult time.

No other evidence was identified about carers needs after the end of life, however during discussions of the evidence the committee agreed that carers may have information and support needs before and after the person dies, needing to plan for their own future, for example financially or occupationally. The therefore committee reached a concensus to recommend that professionals should consider carers' changing support and information needs regarding their own future at this time.

Using end of life evidence to draft recommendations about other topics within the guideline

Evidence from this review alongside the review about changes in the caring role (RQI) suggested that carers appreciate being recognised for the work they do in order to improve the life of the cared-for person. The wealth of knowledge that carers have about the person they care for, their needs and their preferences helps services provide better, more personalised support. In light of this evidence the committee agreed that carers should be recongised and valued both for their own sake and because of its significance to the person they care for. They therefore drafted a recommendation about recognising the benefits of identifying carers, which is in the section of the guideline on identifying carers.

Cost-effectiveness and resource use

Whilst some cost-effectiveness evidence was found the results were equivocal and difficult to generalise for all carers. Therefore, it was still necessary for the committee to make additional qualitative assessments of cost-effectiveness given the breadth of recommendations drafted on the support needs of adult carers who are caring for people at the end of life and after the person receiving care dies.

The committee considered that there was considerable variability in the provision of home-care, hospital and hospice services. As a result they recognised that implementation of the recommendations might largely represent current practice in some areas but require a much greater change in practice in other areas. The majority of recommendations were based on qualitative evidence about the preferences of carers, rather than quantitative evidence about effectiveness. Therefore the recommendations are largely concerned with the types of things service-providers and commissioners should keep in mind in the development of their existing services rather than strong recommendations for forming new practice.

The committee acknowledged that there are resource implications in providing help and support at home to carers providing end of life care. Given the lack of evidence on effectiveness and cost-effectiveness, the committee only drafted a weak recommendation with respect to help and support at home. Nevertheless, the committee considered that their recommendations were consistent with government legislation (Care Act 2014) especially in regard of the duty of the local authority to promote the "well-being" of carers. The committee noted that there is geographical variation in home-care provision and the extent to which it is self-funded or funded through alternative sources such as health trusts or the local authority. The recommendations do not mandate new services but give suggestions for providing help and support at home in the context of the current practice framework. The recommendations promote the considerations of features ogf help and support that would improve it according to evidence of carer's experiences.

The committee noted that it is good practice in the NHS to provide dignity to dying patients and provide support to their carers. Ideally the committee agreed that a side room would usually best facilitate this in a hospital setting. However, the committee recognised that such facilities were often not available in the NHS and that it would be very expensive to rectify this in the short term. Therefore, in addition to recommending the use of side rooms where available the committee also recommended alternatives that would promote privacy and dignity to patients dying in hospital and their carers. The committee noted that these alternatives would not represent a significant resource impact.

Several recommendations relate to modes of communicating that have the potential to greatly enhance the experience of the carer without having a significant resource impact. Being available to talk, giving information well, and giving praise and recognition, whether at home or on a unit, may take a small amount of extra time but will reduce the need for further time, clarification or reassurance at a later date. Additional training may sometimes be required to enhance communication skills but the committee expected this to become embedded within general professional training and continuing professional development over time, without the need for additional resources specific to these recommendations.

The committee's recommendations regarding bereavement support can mostly be achieved by better signposting, information and promotion of existing services rather than the need to develop new ones.

The committee noted that there was some published economic evidence suggesting that patient planning care discussions through an end of life family conference could be cost-effective, albeit only partially applicable to social care in England. Therefore alongside more qualitative considerations of cost-effectiveness, they considered that a recommendation to encourage the broader concept of family network support was supported on economic grounds. The committee did not think that the recommendation as worded would require a significant uplift in resources as family network support can be encouraged in many forms.

Other factors the committee took into account

Advanced care planning benefits carers by allowing them to process and prepare for difficult topics and consider important issues at a time of less stress. Practitioners should approach this topic tactfully, and the committee felt it best to refer to existing guidelines that outline best practice in this area. Managing medication was another area where the committee wanted to refer to existing guidelines. Carers said they would benefit from support as it is often a central part of their role.

The committee were also interested in enquiring about the rights of working carers at the end of life period, and promoting the right to flexibility/ time off to attend appointments.

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Appendices

Appendix A – Review protocols

Review protocol for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Table 5: Review protocol

Field (based on PRISMA-P)	Content
Review question	What are the support needs of adult carers who are caring for people at the end of life, and after the person receiving care dies?
Type of review question	Systematic mixed studies review
Objective of the review	To determine what the most important support needs of adult carers are at the end of life, and after the death, of the person receiving care.
Eligibility criteria – population/disease/condition/issue/domain	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Relevant social-/health-care and other practitioners involved in providing care.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	• As outlined in protocols for key areas 4, 5, 6 and 7.
Eligibility criteria – comparator(s)/control or reference (gold) standard	• As outlined in protocols for key areas 4, 5, 6 and 7.
Themes	Support needs of adult carers will be identified from the literature. However, expected themes are • Need to be prepared for caring role and end of caring role • Need to be recognised as expert or involvement of carer in decisions regarding treatment/palliative care of person receiving care • Need for emotional or bereavement support/grief counselling

Field (based on PRISMA-P)	Content
	• Need for practical support/advice to prepare for end of life and for a life after death of person receiving care (e.g. support writing advanced statements or making advanced decisions to refuse treatment) • Need for comprehensive information about support available (e.g. carer support groups) • Involvement of carer and person receiving care in treatment decisions relating to end of life and place of care or end of life/death • Continuity of support • Return to work/education after death of person receiving care
Eligibility criteria – study design	• See the corresponding section in the protocols for review questions 4, 5, 6 and 7. Generally there will be no restrictions on the types of studies that will be considered for inclusion.
Other inclusion exclusion criteria	Additional inclusion criteria • Setting of intervention can be people's own homes and any other health and social care setting (including neighbourhood and community) in which adult carers provide care and support • Only studies from the following geographical areas/countries will be included: UK, Australia, Canada, Europe, Japan, New Zealand, South Africa, and USA. Studies from other countries will not be included due to substantial differences in their carer populations and/or social-/health-care systems. • Full-text English-language articles published in or after 2003 • Full-text reports of complex/multi-component interventions will be assessed for relevance to this review question Exclusion criteria • Views/experiences regarding the organisation of services for supportive and palliative care will be excluded as these are likely to be addressed in the upcoming NICE guideline End of life care for adults in the last year of life: service delivery (GID-CGWAVE0799) • Conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study. • Non-English language articles A step-wise approach to the included evidence will be used if required: although only studies published in or after 2003 will be initially included, subsequent modifications to the inclusion criteria may be warranted, subject to ratification by the GC, if the volume of studies to examine is very high. For example, studies may be restricted to those conducted in the UK or a more recent date of publication may be used. If changes to the initial inclusion criteria are deemed necessary, reasons for these will be explicitly noted in the methods section of the guideline.

Field (based on PRISMA-P)	Content
Proposed sensitivity/sub-group analysis, or meta-regression	• Not applicable
Selection process – duplicate screening/selection/analysis	Duplicate screening will be performed using STAR - minimum sample size is 10% of the total for <1000 titles and abstracts, and 5% of the total for ≥1000 titles and abstracts. All discrepancies are discussed and resolved between 2 reviewers. Any disputes will be resolved in discussion with the Senior Systematic Reviewer. Data extraction will be supervised by a senior reviewer. Draft excluded studies and evidence tables will be discussed with the Topic Advisor, prior to circulation to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair.
Data management (software)	NGA STAR software will be used for generating bibliographies and citations, study sifting, data extraction and recording quality assessment of studies. A GRADE-CERQual Microsoft Excel template will be used to record and organise the overall quality of findings from the qualitative evidence; a Microsoft Excel template will also be used to record the findings of questionnaire surveys.
Information sources – databases and dates	As outlined in protocols for key areas 4, 5, 6 and 7.
Identify if an update	This review question is not an update.
Author contacts	Developer: The National Guideline Alliance
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
Search strategy – for one database	The literature included in this review will be identified during the course of the reviews for questions 4, 5, 6 and 7. A separate search for this question will not be conducted.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix G (clinical evidence tables) or H (economic evidence tables) of the full guideline.
Data items – define all variables to be collected	For details please see evidence tables in appendix G (clinical evidence tables) or H (economic evidence tables) of the full guideline.
Methods for assessing bias at outcome/study level	See the corresponding sections in the protocols for review questions 4, 5, 6 and 7.
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual.

Field (based on PRISMA-P)	Content
Methods for analysis – combining studies and exploring (in)consistency	For details please see the methods chapter of the full guideline.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. If sufficient relevant RCT evidence is available, publication bias will be explored using RevMan5 software to examine funnel plots.
Assessment of confidence in cumulative evidence	See the corresponding sections in the protocols for review questions 4, 5, 6 and 7.
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by the National Guideline Alliance and chaired by Mr. Phil Taverner in line with section 3 of Developing NICE guidelines: the manual. Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Roles of sponsor	NICE funds the National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England.
PROSPERO registration number	Not registered.

AMSTAR: Assessing the Methodological Quality of Systematic Reviews; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimal important difference; NICE: National Institute for Health and Care Excellence; RCT: Randomised Controlled Trial; RoB: Risk of Bias; SD: Standard Deviation.

Appendix B – Literature search strategies

Literature search strategies for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

The search for this topic was last run on 7th November 2017.

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem or caregivers/ use psyh or caregiver burden/ use psyh
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	exp *cognitive therapy/ or (counseling.hw. and exp *counseling/) or *friend/ or *friendship/ or *group dynamics/ or *group process/ or *group therapy/ or *hotline/ or *mindfulness/ or *peer group/ or *problem solving/ or *psychotherapy/ or *reality therapy/ or *relaxation training/ or *self-help/ or *social adaption/ or *social network/ or *social support/ or exp *support group/
5	*advance care planning/ or *bereavement/ or *case management/ or *crisis intervention/ or *friends/ or *group process/ or *group therapy/ or *human relation/ or exp *peer group/ or *social network/ or *support group/ or *terminal care/
6	4 or 5
7	6 use emez
8	exp counseling/ or cognitive behavioral therapy/ or mindfulness/ or patient centered care/ or problem solving/ or psychotherapy*.sh. or exp psychotherapy, group/ or reality therapy/ or relaxation therapy/ or social support/
9	bereavement/ or case management/ or crisis intervention/ or education, nonprofessional/ or friends/ or group processes/ or hotlines/ or interpersonal relations/ or palliative care/ or exp peer group/ or professional family relations/ or exp psychotherapy, group/ or self-help groups/ or exp social networking/ or terminal care/
10	8 or 9
11	10 use mesz, prem
12	case management/ or client centered therapy/ or exp cognitive behavior therapy/ or exp counselling/ or exp group psychotherapy/ or mindfulness/ or exp problem solving/ or psychotherapy/ or reality therapy/ or exp relaxation therapy/ or social support/
13	advocacy/ or bereavement/ or crisis intervention services/ or crisis intervention/ or “death and dying”/ or friendship/ or group dynamics/ or group counseling/ or hot line services/ or interpersonal relationships/ or outreach programs/ or palliative care/ or peer counseling/ or peer evaluation/ or peer relations/ or peers/ or exp peer relations/ or exp social networks/ or self help techniques/ or social networks/ or social group work/ or support groups/ or terminally ill patients/
14	12 or 13

#	**Searches**
15	14 use psyh
16	*internet/ or *computer/ or *computer network/ or *internet/ or *online system/ or exp *computer assisted therapy/ or *social media/ or *social network/ or exp *telecommunication/
17	16 use emez
18	computers/ or computer assisted instruction/ or computer communication networks/ or exp internet/ or online systems/ or o social media/ or exp social networking/ or therapy, computer assisted/ or telecommunications/ or telemedicine/
19	18 use mesz, prem
20	computer assisted instruction/ or computer assisted therapy/ or computers/ or exp computer mediated communication/ or exp online therapy/ or exp internet/ or exp social media/ or exp social networks/ or telecommunications media/ or telemedicine/
21	20 use psyh
22	or/17,19,21
23	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
24	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
25	counsel*.ti,ab.
26	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
27	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
28	((communit* or social) adj2 support*).ti,ab.
29	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
30	or/7,11,15,22-29
31	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
32	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
33	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
34	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab.
35	((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab. or (peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
36	((bereav* or death or dying or end of life or grief* or ((palliative or terminal) adj care))

#	Searches
	adj3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or anticipatory grief).ti,ab.
37	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
38	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
39	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
40	(psychoeducat* or psycho educat*).ti,ab.
41	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
42	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
43	((emotion* or one to one or transition*) adj support*).ti,ab.
44	(lay adj (led or run)).ti,ab.
45	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
46	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
47	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
48	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
49	(carer* network* or support group*).ti,ab.
50	or/31-49
51	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
52	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
53	(information adj (needs or provision or support)).ti,ab.
54	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
55	or/51-54
56	*education/ or *health education/ or *education program/ or *first aid/
57	56 use emez
58	caregiver/ed or education/ or first aid/ or exp health education/
59	58 use mesz, prem
60	client education/ or education/ or educational programs/ or health education/
61	60 use psyh
62	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or

#	**Searches**
	taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
63	(psychoeducat* or psycho educat*).ti,ab,hw.
64	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
65	or/57,59,61-64
66	exercise*.hw. or exp *physical activity/ or *"physical education"/ or exp *sports/
67	66 use emez
68	exp exercise/ or physical exertion/ or exp "physical education and training"/ or exp sports/
69	68 use mesz, prem
70	exercise/ or exp physical activity/ or "physical education"/ or exp sports/
71	70 use psyh
72	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
73	or/67,69,71-72
74	exp *employment/ or exp *return to work/ or *supported employment/ or *vocational education/ or *vocational rehabilitation/ or *work/ or *work resumption/ or (employment and rehabilitation).hw.
75	74 use emez
76	employment/ or employment, supported/ or rehabilitation, vocational/ or return to work/ or unemployment/ or vocational education/ or work/ or workplace/ or (employment/ and rh.fs.)
77	76 use mesz, prem
78	employment status/ or exp vocational rehabilitation/ or reemployment/ or (employment and rehabilitation).hw. or vocational education/ or work adjustment training/
79	78 use psyh
80	*child welfare/ or *financial management/ or *social care/ or *social security/ or *social welfare/ or “social work/
81	80 use emez
82	“aid to families with dependent children”/ or child welfare/ or financing, government/ or government programs/ or public assistance/ or social security/ or social welfare/ or social work/
83	82 use mesz
84	government programs/ or social security/ or child welfare/ or "welfare services (government)"/ or community welfare services/ or exp social case services/ or social services/ or social security/
85	84 use psyh
86	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or

#	Searches
	therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
87	((individual placement adj2 support) or ips model).ti,ab.
88	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
89	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
90	rehabilitation counsel*.ti,ab.
91	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
92	(volunteering or (work adj2 placement*)).ti,ab.
93	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
94	(return adj to* adj (education or study or training or work*)).ti,ab.
95	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
96	(signpost* or sign post*).ti,ab.
97	or/75,77,79,81,83,85-96
98	*day care/ or *respite care/
99	98 use emez
100	day care, medical/ or respite care/
101	100 use mesz, prem
102	adult day care/ use psyh or day care centers/ use psyh or respite care/ use psyh
103	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
104	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
105	or/99,101-104
106	*assistive technology/ or *occupational therapy/ or *telehealth/ or *telemedicine/ or *telemetry/ or *telemonitoring/
107	106 use emez
108	assistive technology/ or occupational therapy/ or self-help devices/ or telemedicine/ or telemetry/ or telemonitoring/
109	108 use mesz, prem
110	assistive technology/ or occupational therapy/ or telemedicine/ or telemetry/
111	110 use psyh
112	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
113	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
114	(gps track* or location technology).ti,ab.

#	Searches
115	occupational therap*.ti,ab.
116	or/107,109,111-115
117	exp acupuncture/ use emez or exp alternative medicine/ use emez or biofeedback/ or massage/ use emez or meditation/ use emez or acupressure/ use mesz, prem or massage/ use mesz, prem or acupuncture/ use mesz, prem or exp complementary therapies/ use mesz, prem or exp mind body therapies/ use mesz, prem or exp alternative medicine/ use psyh or biofeedback/ use psyh or massage/ use psyh or mind body therapy/ use psyh
118	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
119	meditation.sh. or meditat*.ti,ab.
120	(acceptance adj2 commitment therap*).ti,ab.
121	dyadic intervention*.ti,ab.
122	(reminiscence adj (group* or therap*)).ti,ab.
123	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
124	art/ or art therapy/ or music/ or music therapy/ or singing/ or painting/ use emez or singing/ use emez, mesz, prem or paintings/ use mesz, prem
125	124 use emez,mesz
126	art/ or art education/ or art therapy/ or "painting (art)"/ or music/ or music education/ or music therapy/ or singing/
127	126 use psyh
128	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
129	or/117-123,125,127-128
130	30,50,55,65,73,97,105,116,129
131	3 and 130
132	interviews as topic/ or qualitative research/
133	132 use emez
134	interviews as topic/ or anthropology, cultural/ or focus groups/ or exp tape recording/ or personal narrative/ or narration/ or nursing methodology research/ or observation/ or qualitative research/ or sampling studies/ or cluster analysis/ or videodisc recording/
135	134 use mesz, prem
136	cluster analysis/ or "culture (anthropological)" or interviews/ or narratives/ or observation methods/ or qualitative research/ or tape recorders/
137	136 use psyh
138	(interview* or action research or audiorecord* or ((audio or tape or video*) adj5 record*) or colaizzi* or (constant adj (comparative or comparison)) or content analy* or critical social* or (data adj1 saturat*) or discourse analys?s or emic or ethical enquiry or ethno* or etic or experiences or fieldnote* or (field adj (note* or record* or stud* or research)) or (focus adj4 (group* or sampl*)) or giorgi* or glaser or (grounded adj (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or human science or husserl* or ((life or lived) adj experience*) or maximum variation or merleau or narrat* or ((participant* or nonparticipant*) adj3 observ*) or ((philosophical or social) adj research*) or (pilot

#	Searches
	testing and survey) or purpos* sampl* or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or tape record* or taperecord* or testimon* or (thematic* adj3 analys*) or themes or theoretical sampl* or unstructured categor* or van kaam* or van manen or videorecord* or video record* or videotap* or video tap*).ti,ab.
139	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)).ti,ab,hw,pt.
140	or/133,135,137-139
141	"*attitude to health"/ or *consumer/ or *consumer attitude/ or *health care quality/ or *patient attitude/ or *patient compliance/ or *patient preference/ or *patient satisfaction/
142	141 use emez
143	*attitude to health/ or comprehensive health care/ or exp consumer participation/ or exp consumer satisfaction/ or "patient acceptance of health care"/ or patient care management/ or patient centered care/ or exp patient compliance/ or patient satisfaction/ or "quality of health care"/
144	143 use mesz, prem
145	exp client attitudes/ or client satisfaction/ or consumer attitudes/ or exp health attitudes/ or exp consumer attitudes/ or patient satisfaction/ or treatment compliance/
146	145 use psyh
147	((carer* or caregiv* or care giv* or famil* or friend* or mother* or father* or son or daughter*) adj3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or buy in* or choice* or co?operat* or co operat* or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not speech perception) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry)).ti,ab.
148	((consumer or patient) adj2 (focus* or centered or centred)).ti,ab.
149	or/142,144,146-148
150	or/140,149
151	clinical trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
152	151 use mesz, prem
153	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
154	153 use mesz, prem
155	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
156	155 use emez
157	(assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab. use psyh
158	or/152,154,156-157
159	meta-analysis/

#	**Searches**
160	meta-analysis as topic/ or systematic reviews as topic/
161	“systematic review”/
162	meta-analysis/
163	(meta analy* or metanaly* or metaanaly*).ti,ab.
164	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
165	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
166	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
167	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
168	(search* adj4 literature).ab.
169	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
170	cochrane.jw.
171	((pool* or combined) adj2 (data or trials or studies or results)).ab.
172	or/159-160,163,165-171 use mesz, prem
173	(or/161-164,166-171) use emez
174	meta analysis/ use psyh or or/163-171 use psyh
175	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review* or qualitativ*)).ti,ab,hw,pt.
176	or/172-175
177	or/158,176
178	exp case control study/ or cohort analysis/ or cross-sectional study/ or follow up/ or longitudinal study/ or observational study/ or prospective study/ or retrospective study/
179	178 use emez
180	exp case control studies/ or exp cohort studies/ or cross-sectional studies/ or epidemiologic studies/
181	180 use mesz, prem
182	(cohort analysis or followup studies or longitudinal studies or prospective studies or retrospective studies).sh,id. or (followup study or longitudinal study or prospective study or retrospective study).md.
183	182 use psyh
184	((epidemiologic* or observational) adj (study or studies)).ti,ab.
185	(cohort*1 or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*).ti,ab.
186	(case adj2 (control or series or stud*)).ti,ab.
187	(nonequivalent control group or posttesting or pretesting or pretest posttest design or pretest posttest control group design or quasi experimental methods or quasi experimental study or time series or time series analysis).sh.

#	Searches
188	(((nonequivalent or non equivalent) adj3 control*) or posttest* or post test* or pre test* or pretest* or quasi experiment* or quasiexperiment* or timeseries or time series).tw.
189	or/179,181,183-188
190	177 or 189
191	190
192	united kingdom/
193	(national health service* or nhs*).ti,ab,in,ad.
194	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
195	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in,ad.
196	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
197	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
198	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
199	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
200	or/192-199 use emez
201	exp united kingdom/
202	(national health service* or nhs*).ti,ab,in.

#	Searches
203	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
204	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
205	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
206	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
207	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
208	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
209	or/201-208
210	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
211	209 not 210
212	211 use mesz, prem
213	(national health service* or nhs*).ti,ab,in,cq.
214	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
215	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.

#	Searches
216	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
217	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
218	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
219	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
220	or/213-219 use psyh
221	or/200,212,220
222	150 and 221
223	131 and or/177,222

Database: Social Policy and Practice, Health Management Information Consortium - OVID

#	Searches
1	(carer* or caregiv* or care giv*).ti,ab.
2	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
3	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
4	counsel*.ti,ab.

#	**Searches**
5	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
6	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
7	((communit* or social) adj2 support*).ti,ab.
8	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
9	or/2-8
10	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
11	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
12	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
13	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab. or ((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab.
14	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief").ti,ab.
15	(peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
16	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
17	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
18	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
19	(psychoeducat* or psycho educat*).ti,ab.
20	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
21	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
22	((emotion* or one to one or transition*) adj support*).ti,ab.
23	(lay adj (led or run)).ti,ab.
24	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
25	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
26	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap*

#	Searches
	or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
27	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
28	(carer* network* or support group*).ti,ab.
29	or/10-28
30	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
31	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
32	(information adj (needs or provision or support)).ti,ab.
33	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
34	or/30-33
35	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
36	(psychoeducat* or psycho educat*).ti,ab,hw.
37	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
38	or/35-37
39	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
40	39
41	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
42	((individual placement adj2 support) or ips model).ti,ab.
43	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
44	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
45	rehabilitation counsel*.ti,ab.
46	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
47	(volunteering or (work adj2 placement*)).ti,ab.

#	Searches
48	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
49	(return adj to* adj (education or study or training or work*)).ti,ab.
50	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
51	(signpost* or sign post*).ti,ab.
52	or/41-51
53	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
54	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
55	or/53-54
56	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
57	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
58	(gps track* or location technology).ti,ab.
59	occupational therap*.ti,ab.
60	or/56-59
61	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
62	meditation.sh. or meditat*.ti,ab.
63	(acceptance adj2 commitment therap*).ti,ab.
64	dyadic intervention*.ti,ab.
65	(reminiscence adj (group* or therap*)).ti,ab.
66	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
67	or/61-66
68	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
69	68
70	or/9, 29, 34, 38, 40, 52, 55, 60, 67, 69
71	1 and 70

Database: Social Services Abstracts, Sociological Abstracts, International Bibliography for Social Sciences (IBSS), Applied Social Sciences Index and Abstracts (ASSIA) - Proquest

#	Searches
S1	noft (carer* or caregiv* or “care giv*”)

#	**Searches**
S2	noft (psychotherap*)
S3	noft (((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
S4	noft (((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
S5	noft (“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*)))
S6	noft (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
S7	noft ((“person centred” or replacement) near/1 (care or therap*))
S8	noft ((communit* or social) near/2 support*)
S9	noft ((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*))
S10	S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9
S11	noft (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*)))
S12	noft ((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
S13	noft ((peer* or support* or voluntary or volunteer*) near/2 group*)
S14	noft ((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*))
S15	noft (((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
S16	noft ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
S17	noft (((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
S18	noft (((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”)
S19	noft (((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*)))
S20	noft (psychoeducat* or “psycho educat*”)
S21	noft ((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*)))
S22	noft ((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*))
S23	noft ((emotion* or “one to one” or transition*) near/1 support*)

#	Searches
S24	noft (lay near/1 (led or run))
S25	noft ((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
S26	noft ((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
S27	noft (advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system))))
S28	noft ((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*))
S29	noft (carer* network* or “support group*”)
S30	S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29
S31	noft (helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*)))
S32	noft (helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
S33	noft (information near/1 (needs or provision or support))
S34	noft (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
S35	S31 or S32 or S33 or S34
S36	noft (((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train)))
S37	noft (psychoeducat* or “psycho educat*”) ti,ab,hw.
S38	noft (((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement)))
S39	S36 or S37 or S38
S40	noft (“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”)
S41	S40
S42	noft (((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*))
S43	noft ((“individual placement” near/2 support) or “ips model”)
S44	noft ((permitted or voluntary or rehab*) near/3 work*)
S45	noft ((psychosocial or “psycho social” or social) near/2 rehab*)

#	**Searches**
S46	noft (“rehabilitation counsel*”)
S47	noft ((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
S48	noft (volunteering or (work near/2 placement*))
S49	noft (((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
S50	noft (return near/1 to* near/1 (education or study or training or work*))
S51	noft (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
S52	noft (signpost* or “sign post*”)
S53	S42 or S43 or S44 or S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52
S54	noft (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*))
S55	noft (((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*)
S56	S54 or S55
S57	noft ((assistive near/2 (platform* or technolog*)) or “interactive health communication”)
S58	noft (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
S59	noft (“gps track*” or “location technology”)
S60	noft “occupational therap*”
S61	S57 or S58 or S59 or S60
S62	noft ((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
S63	noft (meditat*)
S64	noft (acceptance near/2 “commitment therap*”)
S65	noft (“dyadic intervention*”)
S66	noft (reminiscence near/1 (group* or therap*))
S67	noft ((emotional or self) near/1 disclosure)
S68	S62 or S63 or S64 or S65 or S66 or S67
S69	noft (art or cafe or cafes or gallery or music or sing or singing)
S70	S69
S71	s10 or s30 or s35 or s39 or s41 or s53 or s56 or s61 or s68 or s70
S72	S1 and S71

#	Searches
S73	noft (interview* or “action research” or audiorecord* or ((audio or tape or video*) near/5 record*) or colaizzi* or (constant near/1 (comparative or comparison)) or content analy* or “critical social*” or (data near/1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field near/1 (note* or record* or stud* or research)) or (focus near/4 (group* or sampl*)) or giorgi* or glaser or (grounded near/1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) near/1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) near/3 observ*) or ((philosophical or social) near/1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or “structured categor*” or “tape record*” or taperecord* or testimon* or (thematic* near/3 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
S74	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or “meta anal*” or synthes* or “systematic review*”))
S75	noft ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) near/3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
S76	noft ((consumer or patient) near/2 (focus* or centered or centred))
S77	S73 or S74 or S75 or S76
S78	noft (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) near/1 blind*) or factorial* or placebo* or random* or volunteer*)
S79	S78
S80	noft (“meta analy*” or metanaly* or metaanaly*)
S81	noft ((systematic or evidence) near/2 (review* or overview*))
S82	noft (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) near/1 synthes*) or metasynthes*)
S83	S80 or S81 or S82
S84	noft ((epidemiologic* or observational) near/1 (study or studies))
S85	noft (cohort* or “cross section*” or crosssection* or followup* or “follow up*” or followed or longitudinal* or prospective* or retrospective*)
S86	noft (case near/2 (control or series or stud*))
S87	noft (((nonequivalent or non equivalent) near/3 control*) or posttest* or “post test*” or “pre test*” or pretest* or “quasi experiment*” or quasiexperiment* or timeseries or “time series”)
S88	S84 or S85 or S86 or S87

#	Searches
S89	S77 or s79 or S83
S90	S72 and S89

Database: CINAHL – Ebsco

1 (mh "caregivers")
2 tx (carer* or caregiv* or “care giv*”)
3 #1 or #2
4 (mh "counseling+")
5 (mh "psychotherapy, group+")
6 (mh "cognitive therapy+")
7 (mh "mindfulness")
8 (mh "patient centered care")
9 (mh "problem solving")
10 (mh "reality therapy")
11 (mh "simple relaxation therapy (iowa nic)")
12 (mh "social support (iowa noc)") or (mh "support, psychosocial")
13 tx (psychotherap*)
14 (mh "case management")
15 (mh "crisis intervention")
16 (mh "crisis intervention (iowa nic)")
17 (mh "education, nonprofessional")
18 (mh "social networks")
19 (mh "group processes")
20 (mh "interpersonal relations")
21 (mh "professional-family relations")
22 (mh "support groups")
23 (mh "peer group")
24 (mh "psychotherapy, group")
25 (mh "social networking+")
26 (mh "computers and computerization")
27 (mh "computer assisted instruction")
28 (mh "computer communication networks")
29 (mh "online systems")
30 (mh "social media+")
31 (mh "therapy, computer assisted")
32 (mh "telecommunications")
33 (mh "telemedicine")
34 (mh "internet+")
35 (mh "social networking+")
36 tx (((psychological* or psychosocial or psychotherapeutic) n2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
37 tx (((behaviour* or behavior*) n2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) n3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
38 tx (“case manag*” or counsel* or ((“person centred” or replacement) n1 (care or therap*)))
39 (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web)

n1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) n1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
40 tx ((“person centred” or replacement) n1 (care or therap*))
41 tx ((communit* or social) n2 support*)
42 tx ((intervention* or therap* or program* or workshop*) n7 (caregiver* or “care giver*” or carer*) n7 (burden or distress* or stress*))
43 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #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
44 tx (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)))
45 tx ((peer* or voluntary or volunteer*) n3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
46 tx ((peer* or support* or voluntary or volunteer*) n2 group*)
47 tx ((peer* or support* or voluntary or volunteer*) n3 (intervention* or program* or rehab* or therap* or service* or skill*))
48 tx (((peer* n3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* n3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
49 tx ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) n1 care))
near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
50 tx (((communit* or family or social) n1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
51 tx (((carer* or caregiv* or “care giv*”) n2 (mentor* or support*)) or (unpaid n3 support*) or “mentoring scheme*”)
52 tx (((carer* or caregiv* or “care giv*”) n3 (communication or integrat* or relations or relationship*) n3 (practitioner* or professional* or worker*)) or (famil* n3(intervention* or program*)))
53 tx (psychoeducat* or “psycho educat*”)
54 tx ((emotion* n1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) n1 (adapt* or reintegrat* or support*)))
55 tx ((dyadic or loneliness or psychosocial* or “psycho social*”) n2 (assist* or intervention* or program* or support* or therap* or treat*))
56 tx ((emotion* or “one to one” or transition*) n1 support*)
57 tx (lay n1 (led or run))
58 tx ((crisis or crises or emergenc*) n3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
59 tx ((coping or resilien* or “well being” or wellbeing) n2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
60 tx (advocate or advocacy or ((support* n3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* n1 (service* or system))))
61 tx ((network* or peer*) n2 (discuss* or exchang* or interact* or meeting*))
62 tx (carer* network* or “support group*”)

63 #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64 tx (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*)))
65 tx (helpseek* or ((search* or seek*) n3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
66 tx (information n1 (needs or provision or support))
67 tx (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
68 #64 or #65 or #66 or #67
69 (mh "education")
70 (mh "health education")
71 (mh "first aid") or (mh "first aid (iowa nic)")
72 tx (((carer* or caregiv* or “care giv*”) n5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) n3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) n3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) n1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* n2 (build* or coach* or educat* or learn* or train)))
73 tx (psychoeducat* or “psycho educat*”) ti,ab,hw.
74 tx (((medication or pain) n2 manag*) or “pain control program*” or ((educat* or train*) n5 (handling or movement)))
75 #69 or #70 or #71 or #72 or #73 or #74
76 (mh "exertion")
77 (mh "exercise+")
78 (mh "physical education and training+")
79 (mh "sports+")
80 tx (“aerobic train*” or exercis* or gym* or jog* or (physical n1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure n2 (activit* or intervention* or program* or therap*)) or “leisure based”)
81 #76 or #77 or #78 or #79 or #80
82 (mh "employment")
83 (mh "employment, supported")
84 (mh "rehabilitation, vocational")
85 (mh "job re-entry")
86 (mh "unemployment")
87 (mh "vocational education")
88 (mh "work")
89 (mh "work environment")
90 (MH "Dependent Families")
91 (mh "child welfare")
92 (mh "financing, government")
93 (mh "government programs")
94 (mh "public assistance")
95 (mh "social welfare")
96 (MH "Economic and Social Security")
97 (mh "social work")
98 tx (((employ* or job* or reemploy* or vocation* or work*) n3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or

interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* n2 employ*) or (work n2 coach*))
99 tx ((“individual placement” n2 support) or “ips model”)
100 tx ((permitted or voluntary or rehab*) n3 work*)
101 tx ((psychosocial or “psycho social” or social) n2 rehab*)
102 tx “rehabilitation counsel*”
103 tx ((prevocat* or vocat*) n3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
104 tx (volunteering or (work n2 placement*))
105 tx (((carer* or “care giv*” or caregiv*) n3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
106 tx (return n1 to* n1 (education or study or training or work*))
107 tx (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) n3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) n7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) n7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
108 tx (signpost* or “sign post*”)
109 #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110 (mh "day care")
111 (mh "respite care") or (mh "respite care (iowa nic)")
112 tx (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) n3 support*))
113 tx (((crisis or volunteer) n1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) n2 break*) or signpost*)
114 #110 or #111 or #112 or #113
115 (mh "assistive technology")
116 (mh "occupational therapy")
117 (mh "assistive technology devices+")
118 (mh "telemedicine")
119 (mh "telemetry")
120 (mh "telenursing")
121 tx ((assistive n2 (platform* or technolog*)) or “interactive health communication”)
122 tx (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
123 tx (“gps track*” or “location technology”)
124 tx “occupational therap*”
125 #115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126 (mh "acupressure")
127 (mh "massage")
128 (mh "acupuncture")
129 (mh "alternative therapies+")

130 (mh "mind body techniques+")
131 (mh "medicine, chinese traditional")
132 (mh "moxibustion")
133 tx ((alternative or complementary) n2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching n2 lo) or cizhen or dianzhen or electroacupunctur* or (jing n2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
134 (mh "meditation") or (mh "meditation (iowa nic)") or tx (meditate*)
135 tx (acceptance n2 “commitment therap*”)
136 tx “dyadic intervention*”
137 tx (reminiscence n1 (group* or therap*))
138 tx ((emotional or self) n1 disclosure)
139 (mh "self disclosure")
140 (mh "art")
141 (mh "music")
142 (mh "singing")
143 (mh "paint")
144 (mh "art therapy")
145 (mh "singing")
146 tx (art or cafe or cafes or gallery or music or sing or singing)
147 #126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148 #3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)
149 (mh "cluster analysis") or (mh "qualitative studies") or (mh "observational methods") or (mh "narratives") or (mh "audiorecording") or (mh "videorecording") or (mh "focus groups") or (mh "anthropology, cultural") or (mh "structured interview") or (mh "unstructured interview") or (mh "semi-structured interview")
150 tx (interview* or “action research” or audiorecord* or ((audio or tape or video*) n5 record*) or colaizzi* or (constant n1 (comparative or comparison)) or “content analy*” or “critical social*” or (data n1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field n1 (note* or record* or stud* or research)) or (focus n4 (group* or sampl*)) or giorgi* or glaser or (grounded n1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) n1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) n1 observ*) or ((philosophical or social) n1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or ”tape record*” or taperecord* or testimon* or (thematic* n1 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
151 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
152 (mh "attitude to health") or (mh "consumer participation") or (mh "consumer satisfaction+") or (mh "patient centered care") or (mh "patient compliance") or (mh "quality o health care")

153 tx ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) n3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not “speech perception”) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
154 tx ((consumer or patient) n2 (focus* or centered or centred))
155 #149 or #150 or #151 or #152 or #153 or #154
156 (mh "clinical trials") or (mh "randomized controlled trials") or ab (placebo or randomised or randomized or randomly) or ti (trial)
157 (mh "meta analysis")
158 (mh "systematic review")
159 tx (“meta analy*” or metanaly* or metaanaly*)
160 tx ((systematic* or evidence*) n2 (review* or overview*))
161 tx (“reference list*” or bibliograph* or “hand search*” or “manual search*” or “relevant journals”)
162 tx (“search strategy” or “search criteria” or “systematic search” or “study selection” or “data extraction”)
163 (search* n4 literature)
164 tx (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)
165 so cochrane
166 tx ((pool* or combined) n2 (data or trials or studies or results))
167 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
168 #157 or #158 or #159 or #160 or #161 or #162 or #163 or #164 or #165 or #166 or #167
169 #155 or #156 or #168
170 #148 and #169

Database: Cochrane Library - Wiley

#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2
4	mesh descriptor: [counseling] explode all trees
5	mesh descriptor: [psychotherapy, group] explode all trees
6	mesh descriptor: [cognitive behavioral therapy] this term only
7	mesh descriptor: [mindfulness] this term only
8	mesh descriptor: [patient centered care] this term only
9	mesh descriptor: [problem solving] this term only
10	mesh descriptor: [reality therapy] this term only
11	mesh descriptor: [relaxation therapy] this term only
12	mesh descriptor: [social support] this term only
13	(psychotherap*):ti,ab,kw
14	(mesh descriptor: [case management] this term only
15	mesh descriptor: [crisis intervention] this term only
16	mesh descriptor: [education, nonprofessional] this term only
17	mesh descriptor: [friends] this term only
18	mesh descriptor: [group processes] this term only
19	mesh descriptor: [hotlines] this term only
20	mesh descriptor: [interpersonal relations] this term only
21	mesh descriptor: [professional family relations] this term only
22	mesh descriptor: [self-help groups] this term only
23	mesh descriptor: [peer group] explode all trees
24	mesh descriptor: [psychotherapy, group] explode all trees
25	mesh descriptor: [social networking] explode all trees
26	mesh descriptor: [computers] this term only
27	mesh descriptor: [computer assisted instruction] this term only
28	mesh descriptor: [computer communication networks] this term only
29	mesh descriptor: [online systems] this term only
30	mesh descriptor: [social media] this term only
31	mesh descriptor: [therapy, computer assisted] this term only
32	mesh descriptor: [telecommunications] this term only
33	mesh descriptor: [telemedicine] this term only
34	mesh descriptor: [internet] explode all trees
35	mesh descriptor: [social networking] explode all trees
36	(((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*):ti,ab,kw
37	(((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”):ti,ab,kw

38	(“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*))):ti,ab,kw
39	(((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”):ti,ab,kw
40	((“person centred” or replacement) near/1 (care or therap*)):ti,ab,kw
41	((communit* or social) near/2 support*):ti,ab,kw
42	((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*)):ti,ab,kw
43	#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #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
44	(befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*))):ti,ab,kw
45	((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)):ti,ab,kw
46	((peer* or support* or voluntary or volunteer*) near/2 group*):ti,ab,kw
47	((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*)):ti,ab,kw
48	(((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*))):ti,ab,kw
49	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief"):ti,ab,kw
50	(((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”):ti,ab,kw
51	(((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”):ti,ab,kw
52	(((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*))):ti,ab,kw
53	(psychoeducat* or “psycho educat*”):ti,ab,kw
54	((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*))):ti,ab,kw
55	((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*)) :ti,ab,kw
56	((emotion* or “one to one” or transition*) near/1 support*):ti,ab,kw
57	(lay near/1 (led or run)):ti,ab,kw

58	((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)):ti,ab,kw
59	((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*)):ti,ab,kw
60	(advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system)))):ti,ab,kw
61	((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*)):ti,ab,kw
62	(carer* network* or “support group*”):ti,ab,kw
63	#44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64	(helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*))):ti,ab,kw
65	(helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))):ti,ab,kw
66	(information near/1 (needs or provision or support)):ti,ab,kw
67	(selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport) :ti,ab,kw
68	#64 or #65 or #66 or #67
69	mesh descriptor: [education] this term only
70	mesh descriptor: [health education] explode all trees
71	mesh descriptor: [first aid] this term only
72	(((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train))):ti,ab,kw
73	(psychoeducat* or “psycho educat*”) ti,ab,hw.
74	(((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement))):ti,ab,kw
75	#69 or #70 or #71 or #72 or #73 or #74
76	mesh descriptor: [physical exertion] this term only
77	mesh descriptor: [exercise] explode all trees
78	mesh descriptor: [physical education and training] explode all trees
79	mesh descriptor: [sports] explode all trees
80	(“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”):ti,ab,kw
81	#76 or #77 or #78 or #79 or #80
82	mesh descriptor: [employment] this term only
83	mesh descriptor: [employment, supported] this term only

84	mesh descriptor: [rehabilitation, vocational] this term only
85	mesh descriptor: [return to work] this term only
86	mesh descriptor: [unemployment] this term only
87	mesh descriptor: [vocational education] this term only
88	mesh descriptor: [work] this term only
89	mesh descriptor: [workplace] this term only
90	mesh descriptor: [aid to families with dependent children] this term only
91	mesh descriptor: [child welfare] this term only
92	mesh descriptor: [financing, government] this term only
93	mesh descriptor: [government programs] this term only
94	mesh descriptor: [public assistance] this term only
95	mesh descriptor: [social security] this term only
96	mesh descriptor: [social welfare] this term only
97	mesh descriptor: [social work] this term only
98	(((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*)):ti,ab,kw
99	((“individual placement” near/2 support) or “ips model”) :ti,ab,kw
100	((permitted or voluntary or rehab*) near/3 work*):ti,ab,kw
101	((psychosocial or “psycho social” or social) near/2 rehab*):ti,ab,kw
102	“rehabilitation counsel*”:ti,ab,kw
103	((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)):ti,ab,kw
104	(volunteering or (work near/2 placement*)):ti,ab,kw
105	(((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”) :ti,ab,kw
106	(return near/1 to* near/1 (education or study or training or work*)):ti,ab,kw
107	(“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))):ti,ab,kw
108	(signpost* or “sign post*”):ti,ab,kw
109	#82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110	mesh descriptor: [day care, medical] this term only
111	mesh descriptor: [respite care] this term only

112	(“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*)):ti,ab,kw
113	(((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*):ti,ab,kw
114	#110 or #111 or #112 or #113
115	mesh descriptor: [assistive technology] this term only
116	mesh descriptor: [occupational therapy] this term only
117	mesh descriptor: [self-help devices] this term only
118	mesh descriptor: [telemedicine] this term only
119	mesh descriptor: [telemetry] this term only
120	mesh descriptor: [telemonitoring] this term only
121	((assistive near/2 (platform* or technolog*)) or “interactive health communication”):ti,ab,kw
122	(“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*):ti,ab,kw
123	(“gps track*” or “location technology”):ti,ab,kw
124	“occupational therap*”:ti,ab,kw
125	#115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126	mesh descriptor: [acupressure] this term only
127	mesh descriptor: [massage] this term only
128	mesh descriptor: [acupuncture] this term only
129	mesh descriptor: [complementary therapies] explode all trees
130	mesh descriptor: [mind body therapies] explode all trees
131	mesh descriptor: [medicine, chinese traditional] this term only
132	mesh descriptor: [moxibustion] this term only
133	((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci) :ti,ab,kw
134	meditation.sh. or meditat*:ti,ab,kw
135	(acceptance near/2 “commitment therap*”):ti,ab,kw
136	“dyadic intervention*”:ti,ab,kw
137	(reminiscence near/1 (group* or therap*)):ti,ab,kw
138	((emotional or self) near/1 disclosure):ti,ab,kw
139	mesh descriptor: [self disclosure] this term only
140	mesh descriptor: [art] this term only
141	mesh descriptor: [music] this term only
142	mesh descriptor: [singing] this term only
143	mesh descriptor: [painting] this term only
144	mesh descriptor: [art therapy] this term only
145	mesh descriptor: [singing therapy] this term only
146	(art or cafe or cafes or gallery or music or sing or singing):ti,ab,kw

147	#126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148	#3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)

Non-database searches

In addition to the above databases, searches were undertaken in a range of websites and other relevant sources:

1. Agency for Healthcare Research and Quality
2. Care Quality Commission
3. Carer Research and Knowledge Exchange Network
4. Carers Trust
5. Carers UK
6. Centre for Mental Health
7. Centre for International Research on Care, Labour and Equalities
8. Department of Health
9. Department for Work and Pensions
10. Directors of Adult Social Services
11. Equality and Human Rights Commission
12. Eurocarers
13. Google UK
14. Health and Social Care Information Centre
15. Health in Wales
16. Healthcare Improvement Scotland
17. Healthcare Quality Improvement Partnership
18. Institute for Public Policy Research
19. Joseph Rowntree Foundation
20. Kings Fund
21. National Audit Office
22. New Policy Institute
23. NHS England
24. NHS Improving Quality
25. Office for National Statistics
26. Research in Practice
27. Royal College of General Practitioners
28. Royal College of Nursing
29. Royal College of Physicians
30. Royal College of Psychiatrists
31. SIGN
32. Turning Point
33. Welsh Government

Economics

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	**Searches**
1	caregiver/ use emez or caregivers/ use mesz, prem
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	budget/ or exp economic evaluation/ or exp fee/ or funding/ or health economics/ or exp health care cost/
5	4 use emez
6	exp budgets/ or exp "costs and cost analysis"/ or economics, nursing/ or economics, pharmaceutical/ or economics/ or exp economics, hospital/ or exp economics, medical/ or exp "fees and charges"/ or value of life/
7	6 use mesz
8	budget*.ti,ab.
9	cost*.ti.
10	(economic* or pharmaco?economic*).ti.
11	(price* or pricing*).ti,ab.
12	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
13	(financ* or fee or fees).ti,ab.
14	(value adj2 (money or monetary)).ti,ab.
15	or/5,7-14
16	3 and 15

Database: Cochrane Library – Wiley

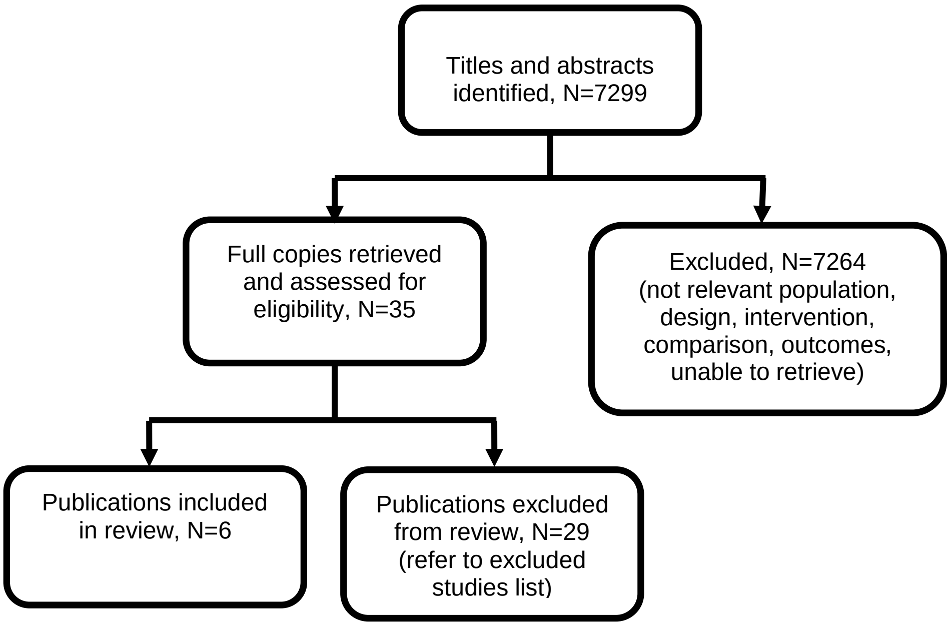
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

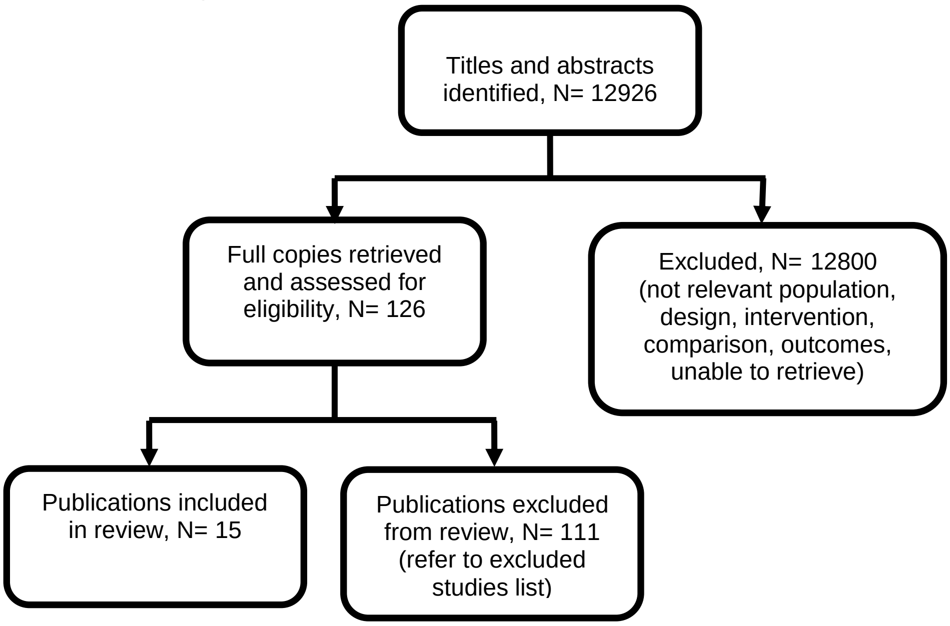
Quantitative component of the review

Figure 2: Flow diagram of quantitative article selection for support needs for end of life



Qualitative component of the review

Figure 3: Flow diagram of qualitative article selection for support needs for end of life



Appendix D – Evidence tables

Evidence tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Quantitative component of the review

Table 6: Evidence tables for the quantitative studies

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>**Full citation**

Holtslander, L., Duggleby, W., Teucher, U., Cooper, D., Bally, J. M., Solar, J., Steeves, M., Developing and pilot-testing a Finding Balance Intervention for older adult bereaved family caregivers: A randomised feasibility trial, European Journal of Oncology Nursing, 21, 66-74, 2016</td>
<td>**Sample size**
N = 23 adult carers
• Intervention: 13;
• Control: 10

Characteristics Carer
• Age, 60-69 years/ 70-79years/80+ years(n): Intervention= 5/5/3; C = 4/5/1
• Gender (M/F): intervention: 3/10; control: 5/5
• Relationship to care recipient: N/R
• Lives alone/ Lives with others:</td>
<td>**Intervention details:**
• Name of intervention in the paper: Psychosocial writing intervention (Finding Balance Intervention)
• Name of control in the paper: WLC
• Intervention (according to the protocol): Cognitive -/emotion-oriented/activity-based interventions
• Control (according to the protocol): WLC</td>
<td>**Details**
• Randomization methods: The assignment to each intervention group was randomised by the research coordinator who drew a label from an envelope containing an equal number of intervention and control labels. No details about the allocation concealment
• Blinding methods: No details on blinding of participant carers, personnel, or outcome assessors</td>
<td>**Results**
<table>
<tr><td rowspan="3">Outcomes</td><td colspan="6">2 weeks follow-up from baseline</td></tr>
<tr><td colspan="3">Intervention</td><td colspan="3">Control</td></tr>
<tr><td>Mean</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer - subjective experience of caring: Inventory of Daily Widowed Life (IDWL) – Oscillation Balance</td><td>6.11</td><td>6.99</td><td>9</td><td>0.700</td><td>9.64</td><td>10</td></tr>
</table>
</td>
<td>**Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomised trials)**
• Random sequence generation: low risk
• Allocation concealment - unclear risk: Not described in sufficient detail
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - unclear risk: Not</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ref Id
712162
Country/ies where the study was carried out
Canada
Study type
2 groups feasibility RCT
Aim of the study
This RCT aimed to compare the effectiveness of 2 interventions, a psychosocial writing intervention (Finding Balance Intervention) versus waiting list control, to provide adult carers of people with advanced cancer with psychological and emotional support
Study dates</td>
<td>Intervention= 10/3; C = 8/2
Carer recipient Condition:
- Advanced cancer
Inclusion criteria
a) women and men ages 60 or older; b) English speaking; c) had resided with and provided care for a spouse with advanced cancer who died within the last 18 months; and d) were freely consenting to be involved in the study
Exclusion criteria
N/R - see the inclusion criteria</td>
<td>Mode of delivery
- Face-to-face
- Individual
- N/R</td>
<td>- Follow-up: 2 weeks from baseline
- Sample size statistical power: Not achieved. This study was a pilot (feasibility) RCT</td>
<td><table><tr><td>Impact of caring on carer - Hope: Herth hope index (HHI)</td><td>39.9</td><td>4.11</td><td>9</td><td>39.2</td><td>7.33</td><td>10</td></tr></table>
- Oscillation Balance = Restoration orientated coping (RO) - loss oriented coping (LO)
- A score of zero indicates oscillation balance.
- Score >0 indicates more restoration orientated coping/ moving forward.</td>
<td>described in sufficient detail
- Incomplete outcome data - high risk: Attrition bias due to amount of incomplete outcome data in the intervention group (4 carers withdrew from the study, all who withdrew were assigned to the intervention group).
- Selective reporting - low risk
- Other risk of bias - high risk: Sample size statistical power has been not achieved (It was not staistically powered study, as this was a feasibility mixed-methods trial and the focus was more on the qualitative part)
Overall risk of bias: very serious
Other information</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Publication date: 2016 **Data collection**: 2011-2012 **Source of funding** N/R					Related to interventions in RQG
Full citation Hudson, PI, Aranda, S, Hayman-White, K, A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial, Journal of Pain and Symptom Management, 30, 329-341, 2005 **Ref Id**	**Sample size** N = 106 adult carers • Intervention: 54; • Control: 52 **Characteristics Carer** • Age (years): Mean (SD) - range: 60.8 (14.0) - 21 to 64 • Gender (M/F): 36/70 • Relationship to care recipient: parents/spouses = 71; daughters-sons =8;	**Intervention details:** • Name of intervention in the paper: Psyco-education + standard care • Name of control in the paper: TAU (standard home-based palliative care services) • Intervention (according to the protocol): Specific carers psychoeducation interventions	**Details** • Randomization methods: The assignment to each intervention group was randomised by an independent statistician using a a computer-generated software system. Allocation was concealed to the investigators • Blinding methods: No details on blinding of participant carers, personnel, or outcome assessors	**Results** Although validated scales were used to measure outcomes, some of them have been altered/ tailored to an End of Life Care Cancer population: • the Preparedness for Caregiving Scale: no adjustments • Caregiver Competence Scale: no adjustments • rewards of Caregiving Scale: 4 of the 15 items focused on caregivers of the aged and were excluded. Item 4 also removed as it related to nursing home resident care • the Hospital Anxiety and Depression Scale (HADS): No single universally accepted cut off score, authors suggested 7-8 for probable and 10-11 for possible cases of anxiety and depression. Cut off score of 11 was chosen as it was not expected that the majority of caregivers would be suffering from pre-exiting depression and/or anxiety	**Limitations (assessed using the Cochrane 'Risk of bias' tool for randomised trials)** • Random sequence generation: low risk • Allocation concealment - low risk • Blinding of participants and personnel - unclear risk: Not described in sufficient detail • Blinding of outcome assessment - unclear risk: Not

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>707277

Country/ies where the study was carried out

Australia

Study type
2 groups RCT

Aim of the study
This RCT aimed to compare the effectiveness of 2 interventions, a psycho-educational intervention versus standard care (a standard home-based palliative care services), in adult carers of people with advanced cancer receiving home-based palliative care.

Study dates</td>
<td>other/undisclosed = 26
• Living with care recipient (yes/no): N/R
Carer recipient Condition:
• Advanced cancer receiving home-based palliative care.

Inclusion criteria
a) primary family caregiver; b) residing with a person with advanced cancer; c) admitted to a community (home-based) palliative care service; d) over 18 years of age; e) English speaking; and g) did not have intellectual or psychiatric illness that would preclude completion of study requirements. Furthermore patient was required to have an Eastern Cooperative</td>
<td>• Control (according to the protocol): TAU
Mode of delivery
• Face-to-face, guidebook and audiotape
• Individual
• N/R</td>
<td>• Follow-up: 5 weeks from baseline, and 8 weeks following patient death
• Sample size statistical power: Not achieved.</td>
<td>• Self efficacy Scale (Zeiss 1999[1]): Item 7 was change to 'Get enough sleep <i>almost</i> every night'- deemed implausible to expect caregivers of dying patients to get at least 7hrs/night. Item 8: perceived capacity for caregivers to get out of the house were reduced to 2 hours (6 hours seen as too much to expect given the context of care)
• Mastery Scale: Only 6 items from the original 12 item scale were used because they were identified in 2 separate factor analyses in a respite care and institutional caregiver sample. Questionable reliability.

5 week from baseline follow-up
<table>
<tr><th rowspan="2">Outcome</th><th colspan="2">Intervention, n=40</th><th colspan="2">Control, n=35</th></tr>
<tr><th>Mean</th><th>SD</th><th>Mean</th><th>SD</th></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Preparedness (The Preparedness for Caregiving Scale)</td><td>2.76</td><td>0.81</td><td>2.67</td><td>0.81</td></tr>
<tr><td>Carer knowledge/confidence or efficacy: Self efficacy (Instrument developed by Zeiss 1999[1])
• Problem solving
• Respite</td><td>7.37
6.79
8.29</td><td>1.92
2.16
1.50</td><td>8.14
6.23
8.22</td><td>1.35
2.67
2.50</td></tr>
</table></td>
<td>described in sufficient detail
• Incomplete outcome data - high risk: Attrition bias due to amount of incomplete outcome data in both intervention groups (missing data at follow-up: 27 control, 34 intervention group). Available case analysis.
• Selective reporting - High risk No self efficacy data reported at Time 3. Other risk of bias - high risk:
• Sample size statistical power has been not achieved.
• Validated scales altered to reflect end of life care/ cancer population affecting reliability. Mastery outcome not reported due to low reliability.</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Publication date: 2005

Data collection
N/R

Source of funding
N/R</td>
<td>Oncology Group (ECOG) status of 0--3 (that is at least capable of minimal selfcare; up and about more than 50% of waking hours)

Exclusion criteria
N/R - see the inclusion criteria</td>
<td></td>
<td></td>
<td>
<table>
<tr><td>• Rewarding interaction</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Competence (Caregiver Competence Scale)</td><td>2.37</td><td>0.63</td><td>2.40</td><td>0.54</td></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Rewards (Rewards of Caregiving Scale)</td><td>3.09</td><td>0.82</td><td>2.82</td><td>0.99</td></tr>
<tr><td>Caring-related morbidity: Anxiety (The Hospital Anxiety and Depression Scale)</td><td>7.76</td><td>3.56</td><td>8.06</td><td>3.95</td></tr>
</table>
8 weeks following patient's death
<table>
<tr><td rowspan="2">Outcomes</td><td colspan="2">Intervention, n=25</td><td colspan="2">Control, n=25</td></tr>
<tr><td>Mean</td><td>SD</td><td>Mean</td><td>SD</td></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Preparedness (The Preparedness for Caregiving Scale)</td><td>2.83</td><td>0.79</td><td>2.59</td><td>0.88</td></tr>
</table>
</td>
<td>Overall risk of bias: very serious

Other information
Related to interventions in RQE</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Carer knowledge/confidence or efficacy: Self efficacy (Instrument developed by Zeiss 1999[1])
• Problem solving
• Respite
• Rewarding interaction</td><td>N/R</td><td>N/R</td><td>N/R</td><td>N/R</td></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Competence (Caregiver Competence Scale)</td><td>2.53</td><td>0.51</td><td>2.47</td><td>0.48</td></tr>
<tr><td>Carer knowledge/ confidence or efficacy: Rewards (Rewards of Caregiving Scale)</td><td>3.50</td><td>0.70</td><td>3.04</td><td>0.82</td></tr>
<tr><td>Caring-related morbidity: Anxiety (The Hospital Anxiety and Depression Scale)</td><td>6.96</td><td>4.02</td><td>6.76</td><td>3.72</td></tr>
</table>

Outcomes not reported: Mastery (both time points), Self-efficacy at 8 weeks following patient's death
Note: HADS was stated to be used in the methods, but not specifically for anxiety – that is unclear whether depression should have also been reported</td><td></td></tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Summers, M., Zordan, R., White, V., Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial, Psycho-Oncology, 22, 1987-93, 2013 **Ref Id** 379597 **Country/ies where the study was carried out** See Hudson 2015 **Study type** See Hudson. 2015	**Sample size** See Hudson 2015 **Characteristics** See Hudson 2015 **Inclusion criteria** See Hudson 2015 **Exclusion criteria** See Hudson 2015	**Interventions** See Hudson 2015	**Details** See Hudson 2015	**Results** Results reported at Time 2: 1 week post-intervention (5 weeks post recruitment) Mixed Model repeated measure analysis (ITT, accounting for missing data without resorting to casewise deletion) Note: General Health Questionnaire (GHQ) scores were found to have a significant departure from a normal distribution, $p<0.001$ by a joint test of skew and kurtosis. Square root transformation (no longer statistically significant, $p=0.23$), on this basis the square root of the GHQ scores were used in the analyses. **Caring-related morbidity: General Health (General Health Questionnaire):** • Mean scores at Time 1 (baseline): 14.7 one visit group, 14.5 two visit group, 15.0 control group • Model: Significant effects of age ($p<0.001$), gender ($p=0.04$), non significant effect of time, intervention and interaction of intervention with time ($p\geq0.15$) • Two intervention groups versus control, one visit group versus control, two visit group versus control, one visit versus two visit group: all non significant ($p\geq0.18$) • Effect sizes non statistically significant and small (<0.3) **Carer knowledge/confidence/ efficacy: Preparedness for caregiving (Preparedness for Caregiving Scale)** • Significant effect of age ($p=0.016$), gender non significant at Time 1. Age was retained in the model • Model: Significant effect for age ($p<0.023$) and time ($p=0.05$), non significant effects of intervention and intervention with time interaction	**Limitations (assessed using the Cochrane 'Risk of bias' tool for randomised trials)** See Hudson 2015 **Other information** Related to interventions in RQE (only for data collection; same of Hudson 2015)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study See Hudson 2015 **Study dates** See Hudson 2015 **Source of funding** See Hudson 2015				• Two intervention groups versus control (p=0.08), one visit versus control and one visit versus two visit (p≥0.39), two visit versus control p=0.035 • Effect sizes small (<0.3) (statistical significance not described) **Carer knowledge/ confidence/ efficacy: Rewards (Rewards of Caregiving Scale)** • Non significant effect of age and gender • Model: No significant effects of time, intervention and their interaction • All comparisons non significant • Effect sizes very small (≤0.10) **Impact of caring on carer: Competency (Caregiver Competence Scale)** • Non significant effect of age, women scored significantly higher than men (p=0.04) so gender was included in the model • Model: Non significant effect of gender (p=0.073), intervention (p=0.53) and time (p=0.10), interaction of intervention and time (p=0.081) • Two intervention groups versus control **(p=0.03),** two visit versus control **(p=0.04).** One visit versus control, one visit versus two visit - non significant (p≥0.15) • Effect sizes small (≤0.33) **Impact of caring on carer: Family inventory of need (Part Scale B)** • Significant effect of age (p<0.005); older reported their needs being met, non significant for gender	

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
				• Model: significant effect of time ($p=0.006$) and age ($p=0.009$), non significant effect of intervention and interaction of time with intervention ($p\geq0.19$) • All comparisons non significant ($p\geq0.07$) Effect sizes small (<0.3)	
Full citation Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Zordan, R., Summers, M., Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial, Psycho-Oncology, 24, 19-24, 2015 **Ref Id** 379599 **Country/ies where the study was carried out**	**Sample size** N = 298 adult carers • Intervention 1: 57 • Intervention 2: 93 • Control: 148 **Characteristics Carer** • Age (years), Mean (SD) - range: 60.8 (13.9) - 22 to 88 • Gender (M/F): 85/211 (2 carers N/R) • Relationship to care recipient: N/R • Living with care recipient (yes/no): N/R • **Carer recipient Condition:** • Advanced cancer receiving home-	**Intervention details:** • Name of intervention in the paper: 1) Psyco-education + standard care (2 face-to-face visits and 2 telephone calls): 2) Psyco-education + standard care (1 face-to-face visit and 3 telephone calls) • Name of control in the paper: No intervention • Intervention (according to the protocol): Specific carers psychoeducation interventions • Control (according to the protocol): No intervention	**Details** • Randomization methods: The assignment to each intervention group was randomised by 1 research assistant who sequentially linked a participant number to a computer generated random list. • Blinding methods: Outcome assessors were blinded to the allocated intervention. No details on blinding of participants and personnel • Follow-up: 5 weeks from baseline, and 8 weeks following patient death • Sample size statistical power: Achieved	**Results** • Results reported at Time 3: 8 weeks after the patient's death • Mixed Model repeated measure analysis (ITT, accounting for missing data without resorting to casewise deletion) • Note: General Health Questionnaire (GHQ) scores were found to have a significant departure from a normal distribution, $p<0.001$ by a joint test of skew and kurtosis. Square root transformation (no longer statistically significant, $p=0.23$), on this basis the square root of the GHQ scores were used in the analyses. **Caring-related morbidity: General Health (General Health Questionnaire):** • Mean scores at Time 3 - N/R. Unable to read scores from the Figures. • Model: Significant effects of age ($p<0.001$), gender ($p=0.04$), non significant effect of time ($p=0.06$), intervention and interaction of intervention with time ($p\geq0.15$) • On average 'younger participants, and females had higher (worse) outcomes • Two intervention groups versus control **($p=0.044$),** one visit versus two visit group over time was not significant ($p=0.09$), but shows divergence not apparent at time 1	**Limitations (assessed using the Cochrane 'Risk of bias' tool for randomised trials)** • Random sequence generation: low risk • Allocation concealment - unclear risk: Not described in sufficient detail • Blinding of participants and personnel - unclear risk: Not described in sufficient detail • Blinding of outcome assessment - low risk • Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Australia **Study type** 3 groups RCT **Aim of the study** This RCT aimed to compare the effectiveness of 2 interventions, a psycho-educational intervention (deliverd either face-to-face or by telephone) versus standard care, in adult carers of people with advanced cancer receiving home-based palliative care. **Study dates** **Publication date**: 2015 **Data collection**: 2009-2011	based palliative care. **Inclusion criteria** a) primary family caregiver; b) residing with a person with advanced cancer; c) admitted to a community (home-based) palliative care service **Exclusion criteria** a) aged under 18 years: b) confronted with significant emotional distress precluding from completing questionnaires; and c) unable to understand English. Caregivers of patients with a nonmalignant diagnosis or a poor functional status were excluded, too.	**Mode of delivery** • Face-to-face • Individual • N/R		• One visit group versus control, two visit group versus control, not significant • Small to medium effects of the interventions relative to the control group (one visit 0.58, two visit 0.15), combined visit groups 0.36) • From baseline: ○ Estimated mean GHQ score rose significantly in the control group (p=0.003) ○ Estimated mean GHQ score decreased non significantly in the one visit group (p=0.33) ○ Estimated mean GHQ score increased non significantly in the two visit group (p=0.13) • Authors conclusions: ○ 'relative to the participants in the control group, the sGHQ scores of participants in the intervention conditions worsened less' ○ Suggestion of one visit superiority over two visits; possible reasons being 'final delivery of the final phase of the intervention by phone may have been more helpful is that the carers may be more able to talk freely with the FCSN and voice their concerns and needs', 'presence of the patient' at face-to-face visits, 'difficulty getting the carers to appreciate that they were there to support the carer not the patient, which was lessened when the intervention took place over the phone and the focus was on the carer' ○ 'apparent absence of negative sequelae for caregivers in the intervention group'	• Selective reporting - low risk • Other risk of bias - low risk: incomplete outcome data was unlikely to have produced bias **Overall risk of bias:** no serious **Other information** Related to interventions in RQE

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Source of funding The study was supported by the NH & MRC Grant, Commonwealth Department of Health & Aging					
Full citation Kogler, M., Brandstatter, M., Borasio, G. D., Fensterer, V., Kuchenhoff, H., Fegg, M. J., Mindfulness in informal caregivers of palliative patients, Palliative & Supportive Care, 13, 11-8, 2015 **Ref Id** 379771 **Country/ies where the study was carried out** Germany	**Sample size** N = 130 adult carers - Intervention: 73; - Control: 57 **Characteristics Carer** - Age (years) - Mean (SD): Intervention= 54.5 (13.6); C = 54.0 (13.2) - Gender (M/F): intervention: 20/53; control: 18/39 - Relationship to care recipient: parents:29; spouses: 85; daughters-sons: 5; other/undisclosed: 11:	**Intervention details:** - Name of intervention in the paper: Existential Behavioural Therapy - Name of control in the paper: TAU - Intervention (according to the protocol): Cognitive behavioural therapy - Control (according to the protocol): TAU **Mode of delivery** - Face-to-face - Group - N/R	**Details** - Randomization methods: No details about the allocation concealment and randomisation methods have been reported. - Blinding methods: No details on blinding of participant carers, personnel, or outcome assessors - Follow-up: 3, and 12 months from baseline - Sample size statistical power: N/R	**Results** - Regression analysis controlled for: age (metric), gender, relation to the patient (partner/child versus parent/other), time of death (≥6 weeks before versus <6 weeks before/during versus after intervention), use of other psychosocial support (yes/no) and group participation (yes/no). - Scales and ranges of scores: Psychological distress (Brief Symptom Inventory- subscales depression, anxiety, somatization; and Global Severity Index, BSI-GSI) range 21-80, Quality of Life (QoL-NRS, numerical rating scale) range 1-10, WHOQOL-Bref range 0-100, Satisfaction with Life (SWLS) range 1-7, Meaning in Life Evaluation (SMILE) range not stated. - Dispositional mindfulness as a predictor of adaptation and well-being T2- approximately 6 weeks from T1 (before intervention)	**Limitations (assessed using the Cochrane 'Risk of bias' tool for randomised trials)** - Random sequence generation: unclear risk: Not described in sufficient detail - Allocation concealment - unclear risk: Not described in sufficient detail - Blinding of participants and personnel - unclear risk: Not described in sufficient detail - Blinding of outcome assessment - unclear risk: Not described in sufficient detail

Outcomes	n	Pre (T1), Mean (SD)	Follow-up T2, Mean (SD)	B	CI (B)		p
					Low	High	

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>**Study type**
2 groups RCT

Aim of the study
This RCT aimed to compare the effectiveness of 2 interventions, a cognitive behavioural intervention (existential behavioural therapy) versus standard care, in adult carers of people with advanced cancer and neurological disorders -with a life expectancy < 6 months.

Study dates

Publication date: 2015

Data collection: 2008-2010</td>
<td>• Diagnosis of person being cared for: Cancer= 104; Neurological= 19; Others= 7

Carer recipient Condition:
• Palliative care patients with life expectancy <6 months

Inclusion criteria
a) relative of a PC patient (life expectancy < 6 months); b) at least 21 years old; c) without severe psychiatric disease or significant cognitive impairment; and d) sufficient knowledge of German.

Exclusion criteria
N/R - see the inclusion criteria</td>
<td></td>
<td></td>
<td>
<table>
<tr><td>Caring-related morbidity: Psychological distress; BSI (GSI)</td><td>**124**</td><td>**65.7 (10.7)**</td><td>**63.0 (11.7)**</td><td>**-4.16**</td><td>**-7.61**</td><td>**-0.71**</td><td>**0.02**</td></tr>
<tr><td>Carer quality of life: Quality of Life; QoL-NRS</td><td>123</td><td>4.0 (1.9)</td><td>5.2 (2.1)</td><td>0.71</td><td>-0.04</td><td>1.47</td><td>0.06</td></tr>
<tr><td>Carer quality of life: Quality of Life; WHOQOL-Bref</td><td>124</td><td>62.5 (11.9)</td><td>65.7 (11.7)</td><td>1.75</td><td>-1.92</td><td>5.42</td><td>0.35</td></tr>
<tr><td>Impact of caring on carer: Satisfaction with Life (SWLS)</td><td>124</td><td>3.8 (1.2)</td><td>4.1 (1.2)</td><td>0.10</td><td>-0.29</td><td>0.50</td><td>0.61</td></tr>
<tr><td>Impact of caring on carer: Meaning of Life Evaluation/ satisfaction - SMiLE</td><td>111</td><td>67.6 (18.0)</td><td>70.3 (17.9)</td><td>5.75</td><td>-1.26</td><td>12.76</td><td>0.11</td></tr>
</table>
</td>
<td>• Incomplete outcome data - unclear risk: Not described in sufficient detail (N=30 missing data, unclear in which group and methods to manage this)
• Selective reporting - low risk
• Other risk of bias - unclear risk: Insufficient information to permit judgment on sample size statistical power

Overall risk of bias: serious

Other information
Related to interventions in RQG</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Source of funding This research was supported by Deutsche Krebshilfe e.V". (107433).				- Psychological distress at T2 is 4.16 points lower if mindfulness at T1 is 1 point higher (range 1-4) T3- 3 months from end of intervention	

Outcomes	n	Pre (T1), Mean (SD)	Follow-up T3, Mean (SD)	B	CI (B)		p
					Low	High	
Caring-related morbidity: Psychological distress; BSI (GSI)	**123**	**65.7 (10.8)**	**62.9 (11.2)**	**-5.25**	**-9.12**	**-1.35**	**0.01**
Carer quality of life: Quality of Life; QoL-NRS	**121**	**4.1 (1.9)**	**5.4 (2.0)**	**1.12**	**0.31**	**1.93**	**0.01**
Carer quality of life: Quality of Life; WHOQOL-Bref	123	62.6 (11.9)	66.5 (13.4)	-0.82	-6.18	4.55	0.76
Impact of caring on carer: Satisfaction with Life (SWLS)	123	3.8 (1.2)	4.1 (1.3)	0.38	-0.09	0.84	0.11

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Impact of caring on carer: Meaning of Life Evaluation/ satisfaction - SMiLE</td><td>105</td><td>68.1 (17.5)</td><td>69.8 (20.1)</td><td>10.40</td><td>0.58</td><td>20.22</td><td>0.04</td></tr>
</table>

Psychological distress at T3 is 5.25 points lower if mindfulness at T1 is 1 point higher (range 1-4)
QoL-NRS at T3 is 1.12 (of 10 units) higher if mindfulness at T1 is 1 point higher (range 1-4)
SMiLE at T3 is 10.40 higher if mindfulness at T1 is 1 point higher (range 1-4)

T4- 12 months from end of intervention
<table>
<tr><th rowspan="2">Outcomes</th><th rowspan="2">n</th><th rowspan="2">Pre (T1), Mean (SD)</th><th rowspan="2">Follow-up T4, Mean (SD)</th><th rowspan="2">B</th><th colspan="2">CI (B)</th><th rowspan="2">p</th></tr>
<tr><th>Low</th><th>High</th></tr>
<tr><td>Caring-related morbidity: Psychological distress; BSI (GSI)</td><td>121</td><td>65.7 (10.8)</td><td>60.0 (11.2)</td><td>-2.19</td><td>-6.69</td><td>2.32</td><td>0.34</td></tr>
<tr><td>Carer quality of life: Quality</td><td>118</td><td>4.1 (1.2)</td><td>6.1 (2.1)</td><td>0.62</td><td>-0.26</td><td>1.49</td><td>0.16</td></tr>
</table>
</td><td></td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>of Life; QoL-NRS</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Carer quality of life: Quality of Life; WHOQOL-Bref</td><td>121</td><td>62.6 (12.0)</td><td>69.4 (12.4)</td><td>-0.05</td><td>-5.23</td><td>5.16</td><td>0.99</td></tr>
<tr><td>Impact of caring on carer: Satisfaction with Life (SWLS)</td><td>121</td><td>3.8 (1.2)</td><td>4.3 (1.2)</td><td>0.22</td><td>-0.25</td><td>0.69</td><td>0.35</td></tr>
<tr><td>Impact of caring on carer: Meaning of Life Evaluation/ satisfaction - SMiLE</td><td>109</td><td>67.2 (17.9)</td><td>71.8 (17.4)</td><td>11.42</td><td>4.68</td><td>18.16</td><td><0.01</td></tr>
</table>
SMiLE at T4 is 11.42 higher if mindfulness at T1 is 1 point higher (range 1-4)
<p>Mediation of long-term (T1-T4) intervention effect by mindfulness (N=118)</p>
</td><td></td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><th>Outcomes</th><th>Effect of..</th><th>B</th><th>Low CI</th><th>High CI</th><th>p</th></tr>
<tr><td>Caring-related morbidity: Psychological distress; BSI (GSI)</td><td>Intervention</td><td>1.84</td><td>-1.34</td><td>5.01</td><td>0.29</td></tr>
<tr><td></td><td>Δ Mindfulness</td><td>-7.84</td><td>-11.29</td><td>-4.39</td><td><0.01</td></tr>
<tr><td></td><td>Intervention +Δ Mindfulness</td><td>0.24</td><td>-2.90</td><td>3.37</td><td>0.88</td></tr>
<tr><td>Caring-related morbidity: Somatisation (BSI subscale)</td><td>Intervention</td><td>-0.54</td><td>-4.05</td><td>2.97</td><td>0.76</td></tr>
<tr><td></td><td>Δ Mindfulness</td><td>-6.46</td><td>-10.44</td><td>-2.47</td><td><0.01</td></tr>
<tr><td></td><td>Intervention +Δ Mindfulness</td><td>-2.14</td><td>-5.79</td><td>1.50</td><td>0.25</td></tr>
<tr><td>Caring-related morbidity: Depression (BSI subscale)</td><td>Intervention</td><td>3.27</td><td>0.15</td><td>6.39</td><td>0.04</td></tr>
<tr><td></td><td>Δ Mindfulness</td><td>-7.24</td><td>-10.60</td><td>-3.88</td><td><0.01</td></tr>
<tr><td></td><td>Intervention +Δ Mindfulness</td><td>1.57</td><td>-1.51</td><td>4.64</td><td>0.32</td></tr>
</table>
</td><td></td></tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments

Caring-related morbidity: Anxiety (BSI subscale)	Intervention Δ	1.44	-2.26	5.13	0.44
	Mindfulness	**-5.39**	**-9.46**	**-1.31**	**0.01**
	Intervention +Δ Mindfulness	-0.45	-4.19	3.29	0.81
Carer quality of life: QOL-NRS	Intervention Δ	**-1.18**	**-190**	**-0.45**	**<0.01**
	Mindfulness	**1.18**	**0.40**	**1.96**	**<0.01**
	Intervention +Δ Mindfulness	**-0.75**	**-1.47**	**-0.02**	**0.04**
Carer quality of life: WHOQOL-Bref	Intervention Δ	-3.60	-7.32	0.11	0.06
	Mindfulness	**10.71**	**7.02**	**14.39**	**<0.01**
	Intervention +Δ Mindfulness	-0.71	-4.02	2.60	0.67

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Impact of caring on Carer: Satisfaction with Life; SWLS</td><td>Intervention
Δ Mindfulness
Intervention +Δ Mindfulness</td><td>-0.31
0.50
-0.13</td><td>-0.68
0.10
-0.48</td><td>0.06
0.90
0.23</td><td>0.09
0.01
0.47</td></tr>
<tr><td>Impact of caring on Carer: Meaning of Life Evaluation/satisfaction; SMiLE</td><td>Intervention
Δ Mindfulness
Intervention +Δ Mindfulness</td><td>0.54
4.41
1.33</td><td>-5.15
-2.27
-4.62</td><td>6.22
11.09
7.27</td><td>0.85
0.19
0.66</td></tr>
</table>
Authors Conclusions:

Dispositional mindfulness (T1) was a significant predictor of adjustment for all relative in both groups.. most significant at 3 months
Mindfulness (as a state) following the EBT intervention, small but significant effect were found.. Long term effects of the EBT intervention on depression and QoL appeared to be partly mediated by mindfulness

</td><td></td></tr>
<tr><td>Full citation</td><td>Sample size
N = 271 adult carers
Intervention: 137;</td><td>Intervention details:
Name of intervention in the paper: Carer</td><td>Details
Randomization methods: The</td><td>Results</td><td>Limitations (assessed using the Cochrane ‘Risk of</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Walsh Kiri, et al.,, Reducing emotional distress in people caring for patients receiving specialist palliative care: randomised trial, British Journal of Psychiatry, 190, 142-147, 2007

Ref Id

707404

Country/ies where the study was carried out

UK

Study type
2 groups mixed-methods RCT

Aim of the study
This mixed-methods RCT aimed to compare the effectiveness of 2 interventions, a psycho-educational</td>
<td>• Control: 134

Characteristics Carer
• Age (years) - Mean (SD): Intervention= 56.4 (14.6); C = 56.1 (13.2)
• Gender-M/F): intervention: 27/107; control: 29/108
• Relationship to care recipient: parents/spouses = 172; daughters-sons= 67; other/undisclosed = 32
• Living with care recipient (yes/no): N/R

Carer recipient Condition:
• Advanced cancer, receiving palliative care.

Inclusion criteria</td>
<td>advisor intervention (covering 7 domains of carer need: a) patient care; b) physical health needs; c) need for time away from the patient in the short term and longer term; d) need to plan for the future; e) psychological health, relationships and social networks; and g) finances. finances)
• Name of control in the paper: TAU (Specialist palliative care provided by a specialist palliative care team, giving advice specialist social work support, to patients at home and their families)
• Intervention category (according to the protocol): Psycho-educational intervention</td>
<td>assignment to each intervention group was randomised by an independent statistician using a block randomisation design, stratified according to the 7 participating teams. Interviewers were masked to the block size of 12.
• Blinding methods: No details on blinding of participant carers, personnel, or outcome assessors
• Follow-up: 4, 9, and 12 weeks from baseline
• Sample size statistical power: Not achieved.</td>
<td>
<table>
<tr><td rowspan="3">Outcomes</td><td colspan="6">4 weeks follow-up from baseline</td></tr>
<tr><td colspan="3">Intervention</td><td colspan="3">Control</td></tr>
<tr><td>Mean</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer - Carer Strain (Carer Strain Index)</td><td>27.7</td><td>11.6</td><td>99</td><td>27.8</td><td>11.5</td><td>86</td></tr>
<tr><td>Carer quality of life (Caregiver Quality Of Life Index)</td><td>69.6</td><td>22.4</td><td>93</td><td>63.9</td><td>19.3</td><td>82</td></tr>
<tr><td>Caring-related morbidity - Psychological distress: General Health Questionnaire (GHQ-28)</td><td>10.5</td><td>6.3</td><td>97</td><td>11.9</td><td>6.4</td><td>85</td></tr>
</table>
<table>
<tr><td rowspan="3">Outcomes</td><td colspan="6">9 weeks follow-up from baseline</td></tr>
<tr><td colspan="3">Intervention</td><td colspan="3">Control</td></tr>
<tr><td>Mean</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
</table>
</td>
<td>bias' tool for randomised trials)
• Random sequence generation: low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - unclear risk: Not described in sufficient detail
• Blinding of outcome assessment - unclear risk: Not described in sufficient detail
• Incomplete outcome data - low risk: incomplete outcome data was unlikely to have produced bias
• Selective reporting - low risk
• Other risk of bias - unclear risk: Sample size statistical power has been not achieved, however this is unlikely to have produced bias</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>intervention (a carer advisor intervention) versus standard care (standard specialistic palliative care services), in adult carers of people with advanced cancer receiving palliative care.
Study dates
Publication date: 2007
Data collection: 2001-2003
Source of funding
The trial was funded by the former Cancer Research Campaign, now Cancer Research UK (grant number C1432/A179).</td>
<td>a) people providing informal care to patients in all new referrals to 6 of the participating specialistic palliative care teams. No further detail has been given.
Exclusion criteria
N/R - see the inclusion criteria</td>
<td>• Control (according to the protocol): TAU
Mode of delivery
• Face-to-face
• Individual
• N/R</td>
<td></td>
<td>
<table>
<tr><td>Impact of caring on carer - Carer Strain (Carer Strain Index)</td><td>26.7</td><td>11.4</td><td>73</td><td>25.1</td><td>10.1</td><td>63</td></tr>
<tr><td>Carer quality of life (Caregiver Quality Of Life Index)</td><td>69.3</td><td>22.7</td><td>71</td><td>65.2</td><td>17.0</td><td>59</td></tr>
<tr><td>Caring-related morbidity - Psychological distress: General Health Questionnaire (GHQ-28)</td><td>9.3</td><td>6.5</td><td>70</td><td>10.7</td><td>7.3</td><td>64</td></tr>
</table>
<table>
<tr><td rowspan="3">Outcomes</td><td colspan="6">12 weeks follow-up from baseline</td></tr>
<tr><td colspan="3">Intervention</td><td colspan="3">Control</td></tr>
<tr><td>Mean</td><td>SD</td><td>N</td><td>Mean</td><td>SD</td><td>N</td></tr>
<tr><td>Impact of caring on carer - Carer Strain (Carer Strain Index)</td><td>27.2</td><td>11.7</td><td>69</td><td>27.3</td><td>10.2</td><td>54</td></tr>
</table>
</td>
<td>Overall risk of bias: serious
Other information
Related to interventions in RQE</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>
<table>
<tr><td>Carer quality of life (Caregiver Quality Of Life Index)</td><td>65.2</td><td>21.3</td><td>64</td><td>62.2</td><td>19.8</td><td>52</td></tr>
<tr><td>Caring-related morbidity - Psychological distress: General Health Questionnaire (GHQ-28)</td><td>11.3</td><td>7.3</td><td>69</td><td>11.7</td><td>7.8</td><td>54</td></tr>
</table>
</td><td></td></tr>
</table>

C: Control group; CI: Confidence Intervals; F: Female; I: intervention group; ITT: Intention to treat; M: Male; N: Number; N/R: not reported; p: probablility that result was due to chance; RCT: Randomised controlled trial; RoB: Risk of Bias; SD: Standard deviation; T: Time/observation; TAU: Treatment as usual.

[1] *Zeiss A, Gallagher-Thompson D, Lovett S, et al. Self-efficacy as a mediator of caregiver coping: development and testing of an assessment model. J Clin Geropsychology 1999;5(3):221--230.*

Qualitative component of the review

Table 7: Evidence tables for the qualitative studies

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Full citation Ashton, S. E., Roe, B., Jack, B., McClelland, B., End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia - A qualitative study, Dementia, 15, 958-75, 2016 **Ref Id** 725006 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To explore the experiences of advance care planning amongst family caregivers of people living with advanced dementia. **Data collected**	**Sample size** 12 adult carers **Care recipient** Dementia **Setting** Specialist dementia unit within nursing home. North West of England. **Characteristics** Range - years: 35 - 82 parents (n): 0; spouses (n): 4; daughters-sons (n): 4; sibling (n): 1; other/undisclosed (n): 3 **Inclusion criteria** An invitation was made to all family caregivers of people living with advanced dementia within the unit; whoever responded was accepted unconditionally. **Exclusion criteria** N/R	**Details** Data was collected through (face-to-face) semi-structured interviews and analysed by content analysis **Recruitment:** Purposive sample of family caregivers within a specialist dementia unit	**Reults are summarised under the following the following themes:** • The experience of ACP • The relevance of ACP for people living with advanced dementia (it was their responsibility) • The relevance of ACP for people living with advanced dementia (it allowed them to confront the important decisions) • Content of the ACP interviews • A deviant case - not all carers will be ready and willing	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Yes

Study details	**Participants**	**Methods**	**Outcomes and Themes**	**Methodological quality**
Aug 2009 - Feb 2010 **Source of funding** N/R				**Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Briggs, Daniel, Notes on the end of life: the social interactions between patients, carers and professionals, Quality in Ageing and Older Adults, 11, 35-46, 2010 **Ref Id** 718797 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To gain an understanding of the experiences and expectations of carers of patients diagnosed	**Sample size** 20 adult carers **Care recipient** Dying people **Setting** Homes, hospices or hospitals. London. **Characteristics** Age range: 17 - 84 Relationship: N/R ("mostly young family members or partners") **Inclusion criteria** Borough-registered patients or carers aged 16 years and over **Exclusion criteria**	**Details** Data was collected through ethnographic methods (open-ended qualitative interviews and observations). The interviews examined the carer's knowledge and experiences of services. Observations were also made of patient/carer/professional interactions in some patients' home settings. Interviews were transcribed verbatim for inductive analysis and categorised thematically, with the key areas of investigation providing the overall framework for coding. **Recruitment:**	**Reults are summarised under the following the following themes:** • Patients and carers views (disjointed services) • Developing tense emotions in the course of care • The complex social relations between carers and patients, and professionals (being dismissed) • The complex social relations between carers and patients, and professionals (being labelled as 'difficult') • The complex social relations between carers and patients, and	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and**

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
with lifelimiting diseases during the last year of life **Data collected** January to April 2009. **Source of funding** The data for this paper originate from the findings of a NHS primary care trust (PCT) funded consultation in Borough	N/R (look at the inclusion criteria)	Approached through service professionals and asked if they would consent to participate.	professionals (homecare and privacy) - The complex social relations between carers and patients, and professionals (sacrifice of providing care at home) - The complex social relations between carers and patients, and professionals (going well) - The complex social relations between carers and patients, and professionals (first impressions for trust) - The complex social relations between carers and patients, and professionals (dignity)	**participants been adequately considered?** - Yes **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** – No. Fairly poor description of the analysis process, and little data given to back up conclusions **Q9: Is there a clear statement of findings?** – Partly. Not well grouped or organised. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** – Unclear. Explains the findings in the context of existing research, however makes no discussion of future research needed, or transferrability of findings to other areas. **Overall methodological limitations** - Major
Full citation Caswell, Glenys, Pollock, Kristian, Harwood, Rowan, Porock, Davina, Communication between family	**Sample size** 13 adult carers 32 care providers **Care recipient**	**Details** Field notes from observations were written up and narratives were constructed from the case	**Reults are summarised under the following the following themes:**	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study, BMC Palliative Care, 14, 2015 **Ref Id** 725889 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers. **Data collected** N/R **Source of funding** None	Older dying people. **Setting** Hospital wards. Nottingham. **Characteristics** N/R **Inclusion criteria** Inclusion criteria included relatives and carers of older patients, family members may, or may not, have provided care for the patient. **Exclusion criteria** N/R	notes accessed. Research interviews were, with the permission of the participant, recorded and then transcribed. Analytic procedures were based in the constant comparative method. **Recruitment:** The family carers of the 39 patient cases who had relatives were invited to take part in an interview.	• Perceived limitations to carers' understanding (capacity) • Perceived limitations to carers' understanding (repeat conversations) • Carers' perspectives • Receiving bad news: Clarity (Inclusion in decision) • Receiving bad news: Lacking clarity (not realising until later) • Receiving bad news: Lacking clarity (misinterpreting information) • Receiving bad news: Lacking clarity (vagueness) • Seeking a hearing • Feeling abandoned	**Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate? -** Yes **Q3 Was the research design appropriate to address the aims of the research?** – Partly. Used a mix of qualitative sources but didn't really explain why or what was significant about that. **Q4: Was the recruitment strategy appropriate to the aims of the research?** – No. Little clarity around why some patients were interviewed while others were not chosen to or didn't agree to **Q5: Were the data collected in a way that addressed the research issue?** – Partly. Several types of data were used, but irregularly. The reasons are explained in some parts but not others. **Q6: Has the relationship between researcher and participants been adequately considered?** – No. Little consideration given.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Q7: Have ethical issues been taken into consideration? - Yes **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Major
Full citation Dosser, I., Kennedy, C., Family carers' experiences of support at the end of life: Carers' and health professionals' views, International journal of palliative nursing, 18, 491-497, 2012 **Ref Id** 722967 **Country/ies where the study was carried out** UK **Study type** Qualitative study	**Sample size** 13 adult carers 26 care providers **Care recipient** Dying people **Setting** Hospital. Scotland. **Characteristics** parents (n): 0; spouses (n): 0; daughters-sons (n): 0; sibling (n): 0; other/undisclosed (n): 13 **Inclusion criteria**	**Details** Carers underwent individual semi-structured interviews, as did 3 palliative care specialists. 23 nursing staff participated in focus groups. Thematic analysis was used to analyse the data. **Recruitment:** Convenience sampling was used. 3 volunteers were approached by hospital staff. All remaining eligible carers were sent a letter explaining the study and inviting them to participate. Those who didn't	**Reults are summarised under the following the following themes:** • Valuing and respecting (accommodating carers) • Valuing and respecting (communicating to carers) • Valuing and respecting (staff's communication skills) • Valuing and respecting (nurses communication style) • Valuing and respecting (nurses communication	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** – No. The recruitment was very

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Aim of the study To investigate the current support offered to carers near the end of life in an acute hospital setting **Data collected** N/R **Source of funding** N/R	Carers were to have been bereaved for between 4 and 12 months. **Exclusion criteria** N/R (look at the inclusion criteria)	opt-out were later invited to interview, of which a further 10 were recruited.	difficulties came out of context) - Valuing and respecting (communication role)	opportunistic, with little consideration on the significance of those who may not have been enthusiastic. However they did acknowledge and explain the limitations they were under. **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** – Moderate
Full citation Dosser, I., Kennedy, C., Improving family carers' experiences of support at the	**Sample size** 24 care providers **Care recipient**	**Details** Participatory action research. Data came from a number of sources, including snapshot	**Reults are summarised under the following the following themes:**	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
end of life by enhancing communication: an action research study, International journal of palliative nursing, 20, 608-616, 2014 **Ref Id** 721077 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To improve communication between staff and carers. To improve the care environment for carers experiencing the death of the person they care for. **Data collected** N/R **Source of funding** None	Dying people **Setting** Hospital. Scotland. **Characteristics** 24 nurse participants, the entire registered nurse workforce on the ward. **Inclusion criteria** The entire registered nurse workforce on the ward participated. **Exclusion criteria** N/R (look at the inclusion criteria)	interviews and audio recordings in practice, the reflective diary of the researcher, field notes, action meetings and poster notes. Emerging data were presented to the action team where the findings were discussed and refined in an ongoing and reflexive process. The analysis aimed to describe what was done, explain why, and demonstrate the implications within the study context. **Recruitment:** The entire registered nurse workforce on the ward was recruited.	• Findings of a communication skills intervention (nurses felt more confident) • Findings of a communication skills intervention (nurses felt more competent) • Findings of an environmental intervention	**Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** – Yes Action research study for the aim of developing new practice approach. **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** – Partly. The researcher talks a lot about the positive aspects of their involvement, but isn't especially critical of the impact they may have had in influencing the reports of the staff. **Q7: Have ethical issues been taken into consideration?** - Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Q8: Was the data analysis sufficiently rigorous? - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., Rob, G., Beynon, T., Higginson, I., Harding, R., Adjusting to the caregiving role: the importance of coping and support, International journal of palliative nursing, 18, 541-5, 2012 **Ref Id** 722949 **Country/ies where the study was carried out** UK **Study type** Qualitative study	**Sample size** 20 adult carers **Care recipient** Cancer **Setting** Homes, hospices or hospitals. London. **Characteristics** Gender-M/F (N)= 9/11 Mean 55.5 years, SD 16.9 years, range 25–79 years parents (n): 4; spouses (n): 10; daughters-sons (n): 2; sibling (n): 1; other/undisclosed (n): 0 **Inclusion criteria**	**Details** Flexible, open-ended, semi-structured interviews, and a thematic analysis. **Recruitment:** Recruited from the community palliative care team	**Reults are summarised under the following the following themes:** • Support (at home from nurse) • Support (from Oncologist) • Support (from GP) • Support (from families and friends)	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Aim of the study To identify existing coping and support mechanisms among informal cancer caregivers in order to inform intervention development. **Data collected** N/R **Source of funding** Supported by a grant from Cancer Research UK	Adult informal cancer caregivers (aged 18 years or over) currently providing a combination of any physical and emotional unpaid care to a relative or friend at home **Exclusion criteria** Caregivers excluded if they were under 18 years of age, were caring for a patient who had been receiving treatment from the palliative care service for less than 2 weeks, or were unable to provide consent or understand English.			**Q6: Has the relationship between researcher and participants been adequately considered?** – Unclear. Not discussed. The researcher has some removal from the construct of interest, but this may not have been made clear to participants. **Q7: Have ethical issues been taken into consideration?** – Unclear. Ethics approved given, but not much other discussion. Participants opted in to participation so may be considered enthusiastic. **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Forbat, Liz, McManus, Elaine, Haraldsdottir, Erna, Clinical implications for supporting caregivers at the end-of-life:	**Sample size** 17 adult carers **Care recipient**	**Details** Semi-structured interview using open-ended questions, analysed inductively and thematically.	**Reults are summarised under the following the following themes:** • Relationships • Shift in lifestyle	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Findings and from a qualitative study, Contemporary Family Therapy: An International Journal, 34, 282-292, 2012 **Ref Id** 379316 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** What are the support needs of caregivers when someone is receiving palliative care. **Data collected** N/R **Source of funding** N/R	Dying from a lifelimiting illness (11 out of 16 had cancer) **Setting** Hospice. Scotland. **Characteristics** Gender-M/F (N)= 4/13 parents (n): 4; spouses (n): 10; daughters-sons (n): 2; sibling (n): 1; other/undisclosed (n): 0 **Inclusion criteria** Only relatives of out-patients were approached. **Exclusion criteria** Recently bereaved were not approached	**Recruitment:** A systematic sampling technique was used, where every fifth person was taken from the caseload of community specialists.	• Factors affecting impact • Relationship Difficulties (patient and carer) • Relationship difficulties (wider relationships) • Relationship difficulties (conceding care) • Support in the context of other family members (caring for others needs) • Support in the context of other family members (relieving others of responsibility) • Living with a Life-Limiting Illness is a Systemic Issue (it's good when practitioners recognise this) • Living with a Life-Limiting Illness is a Systemic Issue (it's bad when practitioners don't recognise this)	**Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** – Yes. Although didn't explain why almost half of those approached chose not to partake **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** – Unclear. No particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) – Unclear. Not discussed, but is UK based. **Overall methodological limitations** - Minor
Full citation Jack, Barbara A, et al.,, Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service, Journal of clinical nursing, 24, 131-140, 2015 **Ref Id** 726015 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To explore family carers' experiences with a hospice at home service	**Sample size** 20 adult carers **Care recipient** Dying people **Setting** Homes. North west England. **Characteristics** Gender-M/F (N)= 5/15 18 out of 20 were aged 50 or over parents (n): 1; spouses (n): 13; daughters-sons (n): 6; sibling (n): 0; other/undisclosed (n): 0 **Inclusion criteria** Aged over 18 years and had been the main carer of a patient who had received the service **Exclusion criteria**	**Details** Semi-structured interview, and thematic analysis. **Recruitment:** Purposive sample - open invitation through ads seeking past service users	**Reults are summarised under the following the following themes:** • Impact on the carers - a valued presence (felt they would be lost without them) • Impact on the carers - a valued presence (drew comfort from their presence) • Impact on the carers - a valued presence (encouragement that they were giving the right care) • Impact on the carers - a valued presence (better experience at the moment of passing) • Impact of the carers - in good hands (respite)	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear. No

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Data collected January–March 2013 **Source of funding** Supported by the Merseyside & Cheshire Palliative & End of Life Care Network	N/R		• Impact of the carers - in good hands (more quality time) • Impact of the carers - in good hands (qualities of the staff) • Impact of the carers - in good hands (hard to accept help) • Impact of the carers - support a normal life (family activities) • Impact of the carers - support a normal life (business activities)	particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration? -** Yes **Q8: Was the data analysis sufficiently rigorous? -** Yes **Q9: Is there a clear statement of findings? -** Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) -** Yes **Overall methodological limitations -** Minor
Full citation Nelson, D., Mansfield, P., Kane, R., Carers of people affected by cancer and other long-term conditions at end of life: A qualitative study of providing a bespoke package of support in a rural setting, Palliative Medicine, 31, 158-161, 2017 **Ref Id** 723444	**Sample size** 10 adult carers **Care recipient** Dying people **Setting** Homes. Lincolnshire. **Characteristics** Gender-M/F (N)= 2/8 8 out of 10 were over 65 parents (n): 0; spouses (n): 8; daughters-sons (n): 0; sibling (n): 0; other/undisclosed (n): 2	**Details** Interviews, analysed thematically. **Recruitment:** 20 invitations sent out, from a range of demographics, to those who'd reported especially good or bad experiences - from pool of 400 users.	**Reults are summarised under the following the following themes:** • Awareness and advertising. • Focus of support on the carer. • Modes of communication.	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research? -** Yes **Q2: Was a qualitative methodology appropriate? -** Yes **Q3 Was the research design appropriate to address the aims of the research? -** Yes **Q4: Was the recruitment strategy appropriate to the**

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Country/ies where the study was carried out UK **Study type** Qualitative study **Aim of the study** Explore the experiences of carers of patients dying in their own homes. **Data collected** 22 August to 19 September 2014 **Source of funding** Funded by Macmillan Cancer Support.	**Inclusion criteria** People using a home care support service, most were currently still caring. **Exclusion criteria** N/R			**aims of the research?** – No. Only approached those who had previously spoken up with praise of grievances. Not clear about who the others were, or a typical experience **Q5: Were the data collected in a way that addressed the research issue?** – Unclear. Used 'in-depth interviews, but isn't really clear what that means. **Q6: Has the relationship between researcher and participants been adequately considered? -** Unclear. No particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** – Unclear. Approved by a board, and brief mention of consent, but no other details or discussion **Q8: Was the data analysis sufficiently rigorous?** – No. Very little detail about the analysis process. And no quotes or real reference to the process or the original data in the findings.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Q9: Is there a clear statement of findings? – Yes. Although not a lot of detail given. **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** – Unclear. Crudely discussed in the context of the aims and intervention only. **Overall methodological limitations** – Major
Full citation Newbury Jenny, The drama of end of life care at home, Nursing Times, 22.3.11, 20-21, 2011 **Ref Id** 717730 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study**	**Sample size** 15 adult carers **Care recipient** Dying people **Setting** Homes. South west england. **Characteristics** Age Range 27-87 parents (n): 0; spouses (n): 11; daughters-sons (n): 4; sibling (n): 0; other/undisclosed (n): 0 **Inclusion criteria** People using a specialist palliative care service.	**Details** Qualitative approach, interviewed before and after death, using grounded theory methodology. **Recruitment:** Not reported	**Reults are summarised under the following the following themes:** • Performance • Setting and props • Script • Directors • Supporting cast • Audience	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** – Unclear. Didn't really discuss why they took the approach they did. **Q4: Was the recruitment strategy appropriate to the aims of the research?** – No.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Describe the experiences of carers in receipt of the bespoke support package. **Data collected** N/R **Source of funding** N/R	**Exclusion criteria** N/R			Unsure as very little information about the recruitment process. **Q5: Were the data collected in a way that addressed the research issue?** – No. Unsure as very little information given on how the data was collected. **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear. No particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** – Unclear. Approved by a board, but no other details or discussion. **Q8: Was the data analysis sufficiently rigorous?** – Unclear. Little detail about the methodology. No mention of other opinions or reflexiveness or self-reflection. **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** – Unclear.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Some mention, just not very detailed. **Overall methodological limitations** - Major
Full citation O'Brien, Mary R., Preston, Harriet, Family carer perspectives of acute hospital care following a diagnosis of motor neuron disease: a qualitative secondary analysis, BMJ supportive & palliative care, 5, 503, 2015 **Ref Id** 725372 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** Explore the experiences of hospitalisation that occurred after a diagnosis of MND was made.	**Sample size** 21 adult carers **Care recipient** Motor Neuron Disease **Setting** Hospitals. Lancashire. **Characteristics** Gender-M/F (N)= 10/11 parents (n): 1; spouses (n): 18; daughters-sons (n): 2; sibling (n): 0; other/undisclosed (n): 0 **Inclusion criteria** Family carers of people with MND resident in Northwest England **Exclusion criteria** N/R	**Details** Secondary analysis 2 sets of narrative-style interviews, and a consensus based thematic analysis **Recruitment:** Purposive sampling of family carers of people with MND resident in Northwest England	**Reults are summarised under the following the following themes:** • Lack of knowledge (having to step in) • Lack of knowledge (the right ward) • Basic care • Reluctance for admission • Final memories	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** – Unclear. Not really discussed, refers to previous papers that sources were drawn from. **Q4: Was the recruitment strategy appropriate to the aims of the research?** – Unclear. The population were drawn from 2 other studies, without much discussion of how appropriate they were to be analysed for this aim - except that previous authors had discussed it.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Data collected 2008–2009 **Source of funding** Some of the data presented in this article are based on independent research funded by the National Institute for Health Research				**Q5: Were the data collected in a way that addressed the research issue?** – Unclear. Dependent on the previous 2 studies **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear. Secondary data analysis, so this is dependent on the previous studies. **Q7: Have ethical issues been taken into consideration?** – Yes. Ethical approval was extended to this study, and the data was already in existence **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** – Partly. They express their own doubts, but contextualise the findings as much as possible. **Overall methodological limitations** - Major

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Full citation Payne, S., Turner, M., Seamark, D., Thomas, C., Brearley, S., Wang, X., Blake, S., Milligan, C., Managing end of life medications at home--accounts of bereaved family carers: a qualitative interview study, BMJ supportive & palliative care, 5, 181-188, 2015 **Ref Id** 725339 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To explore how family members manage delivering end of life medications **Data collected** December 2011 to August 2012 **Source of funding**	**Sample size** 59 adult carers **Care recipient** Dying people **Setting** Homes. North west and south west England **Characteristics** Gender-M/F (N)= 18/41 Median 72, Range 44–90 parents (n): 0; spouses (n): 43; daughters-sons (n): 15; sibling (n): 1; other/undisclosed (n): 0 **Inclusion criteria** Family carers of older deceased people (aged 50 years +) from any cause, occurring in the home **Exclusion criteria** More than 24mths bereaved, cognitively impaired, or otherwise unable or unwilling to give consent	**Details** Single face-to-face interviews conducted, and for analysis a constant comparative approach was utilised until saturation of themes was achieved. **Recruitment:** Recruited through GP practices - staff identified carers who met criteria, and posted information packs.	**Reults are summarised under the following the following themes:** • Decision-making processes in managing end of life medication at home (strategies) • Taking responsibility • Disagreements with staff about medication • Carers’ anxiety about medications • Perceptions about the effects of morphine • Rewards in managing end of life medications at home	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** – Partly. They gave aims in terms of the program, but not really the study. **Q2: Was a qualitative methodology appropriate? -** Yes **Q3 Was the research design appropriate to address the aims of the research? –** Unclear. Not discussed, other than to say the design mirrored research from abroad. **Q4: Was the recruitment strategy appropriate to the aims of the research? –** Yes. Although didn't explain why almost half of those approached chose not to partake. **Q5: Were the data collected in a way that addressed the research issue? -** Yes **Q6: Has the relationship between researcher and participants been adequately considered? -** Unclear. No

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
None				particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** – Unclear. Approved by a board, but no other details or discussion. **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Minor
Full citation Percival, J., Lasseter, G., Purdy, S., Wye, L., "Earthly Angels"? A qualitative study of the domiciliary care worker role in meeting the needs of families caring for those dying at home, Palliative & supportive care, 12, 445-453, 2014 **Ref Id** 720666	**Sample size** 42 adult carers 6 care providers **Care recipient** Dying people **Setting** Homes. England. **Characteristics** N/R	**Details** In-depth face-to-face interviews and observations of practice, analysed by thematic and content analysis **Recruitment:** Not reported	**Reults are summarised under the following the following themes:** • Sensitivity • Consistency • Proactive and Family-Centered Approaches • Allocation of Sufficient Time to Meet Physical and Emotional Needs of Patients and Family Caregivers	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** – Yes. This paper presented the qualitative part of a mixed methods approach to evaluation.

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
Country/ies where the study was carried out UK **Study type** Qualitative study **Aim of the study** Examine the aspects of domiciliary care perceived to be of most value **Data collected** N/R **Source of funding** N/R	**Inclusion criteria** Family carers **Exclusion criteria** N/R			**Q3 Was the research design appropriate to address the aims of the research?** – Partly. The study was mainly quantitatively focused, so these parts are a little less well thought out. **Q4: Was the recruitment strategy appropriate to the aims of the research?** – Unclear. Not clear how they were recruited. The population are clearly relevant but not sure why these participants were picked over others. **Q5: Were the data collected in a way that addressed the research issue?** – Partly. It says what they did but doesn't justify why. **Q6: Has the relationship between researcher and participants been adequately considered? -** Partly. No particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** – No. This is not mentioned. **Q8: Was the data analysis sufficiently rigorous? -** Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Q9: Is there a clear statement of findings? - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - Moderate
Full citation Public Health England (PHE) prepared by Solutions Research, Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report, 71, 2016 **Ref Id** 724159 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To understand the following: the awareness and knowledge	**Sample size** 69 adult carers and their dying relatives **Care recipient** Dying people **Setting** Homes, hospices or hospitals. England. **Characteristics** N/R (reported to be primarily spouses and adult children) **Inclusion criteria** Dying adults and their carers, or else bereaved carers **Exclusion criteria** N/R	**Details** Interviewed some in groups, dyads or individually. The qualitative analysis comprised a variety of approaches, primarily in the form of theme-discussion and development. **Recruitment:** Recruited by professional market research recruiters	**Reults are summarised under the following the following themes:** • Carers' needs (spouses, adult child influencers and the bereaved) • Case studies covering support for carers and bereaved people	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes **Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** – No. Recruited by a market research company, not clear how. **Q5: Were the data collected in a way that addressed the research issue?** – Yes. Although it says interviews were

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
of community end of life care across a number of key audiences; their perceptions of community end of life care; their experiences of end of life care and any community initiatives; any improvements that could be made to community end of life care. **Data collected** July 2015 **Source of funding** Research commissioned by Public Health England (PHE)				by phone or in person and doesn't say how that was arranged. **Q6: Has the relationship between researcher and participants been adequately considered?** – No. Unclear, including who ran interviews and where. **Q7: Have ethical issues been taken into consideration?** - Yes **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological limitations** - moderate
Full citation Seamark, D., Blake, S., Brearley, S. G., Milligan, C., Thomas, C., Turner, M., Wang, X., Payne, S., Dying at home: A qualitative study of family carers' views of support provided by GPs community	**Sample size** 59 adult carers **Care recipient** Dying people **Setting**	**Details** In-depth semi-structured interviews conducted, an inductive approach to analysis was informed by the principles of grounded-theory methods	**Reults are summarised under the following the following themes:** • Personal continuity (same carers) • Personal continuity (changes were draining)	**Limitations (assessed using the CASP checklist for qualitative studies)** **Q1: Was there a clear statement of the aims of the research?** - Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
staff, British Journal of General Practice, 64, e796-e803, 2014 **Ref Id** 720576 **Country/ies where the study was carried out** UK **Study type** Qualitative study **Aim of the study** To elicit family carers' views about the community support that made death at home possible. **Data collected** December 2011 to August 2012 **Source of funding** Supported by a grant from Marie Curie Cancer Care	Homes. East Devon, North Lancashire, and Cumbria. **Characteristics** Gender-M/F (N)= 18/41 parents (n): 0; spouses (n): 43; daughters-sons (n): 15; sibling (n): 1; other/undisclosed (n): 0 **Inclusion criteria** Family carers of older deceased people (aged 50 years +) from any cause, occurring in the home **Exclusion criteria** More than 24mths bereaved, cognitively impaired, or otherwise unable or unwilling to give consent	**Recruitment:** Recruited through GP practices - staff identified carers who met criteria, and posted information packs.	• Personal continuity (GP in regular contact) • Personal continuity (ideal scenario) • Informational continuity (pleasant surprise when it works) • Informational continuity (insensitive when it fails) • Informational continuity (frustrating when it fails) • Informational continuity (unprepared carers) • Organisational continuity (organising care) • Organisational continuity (knowing who to call) • Organisational continuity (out of hours)	**Q2: Was a qualitative methodology appropriate?** - Yes **Q3 Was the research design appropriate to address the aims of the research?** - Yes **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes **Q5: Were the data collected in a way that addressed the research issue?** - Yes **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear. No particular issues apparent, but not really discussed. **Q7: Have ethical issues been taken into consideration?** – Unclear. Approved by a board, but no other details or discussion. **Q8: Was the data analysis sufficiently rigorous?** - Yes **Q9: Is there a clear statement of findings?** - Yes **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes

Study details	Participants	Methods	Outcomes and Themes	Methodological quality
				Overall methodological limitations - Minor

F: Female; M: Male; MND: Motor Neuron Disease; N/n: Number/number in subgroup; N/A: not applicable; N/R: not reported.

Appendix E – Forest plots

Forest plots for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

No meta-analysis was undertaken for this review and so there are no forest plots.

Appendix F – GRADE and GRADE-CERQual tables

GRADE tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Training to provide practical support [Relating to RQE]

Table 8: Evidence profile for psychoeducational Interventions versus control

Quality assessment							Number of patients		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psychoeducational interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Anxiety (The Hospital Anxiety and Depression Scale) at 5 weeks follow-up from baseline (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	40	35	-	MD 0.3 lower (2.01 lower to 1.41 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Anxiety (The Hospital Anxiety and Depression Scale) at 8 weeks follow-up from patient death (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	20	25	-	MD 0.2 higher (2.09	VERY LOW	CRITICAL

										lower to 2.49 higher)		
Caring-related morbidity: Psychological distress (General Health Questionnaire, GHQ-28) at 4 weeks follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	97	85	-	MD 1.4 lower (3.25 lower to 0.45 higher)	LOW	CRITICAL
Caring-related morbidity: General Health (GHQ) at 1 week post intervention (5 weeks post recruitment) follow-up (Better indicated by lower values)												
1[6]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[7]	none	150[11]	148	-	See narrative results in appendix D	MODERATE	CRITICAL
Caring-related morbidity: Psychological distress (General Health Questionnaire, GHQ-28) at 9 weeks follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	70	64	-	MD 1.4 lower (3.75 lower to 0.95 higher)	LOW	CRITICAL
Caring-related morbidity: Psychological distress (General Health Questionnaire, GHQ-28) at 12 weeks follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	69	54	-	MD 0.4 lower	LOW	CRITICAL

										(3.1 lower to 2.3 higher)		
Caring-related morbidity: General Health (GHQ) at 8 weeks after the patient's death follow-up (Better indicated by lower values)												
1[8]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[7]	none	150[11]	148	-	See narrative results in appendix D	MODERATE	CRITICAL
Carer knowledge/ confidence or efficacy: Self efficacy- Respite (Instrument developed by Zeiss 1999) at 5 weeks follow-up from baseline (Better indicated by higher values)												
1[1]	randomised trials	very serious[2,9]	no serious inconsistency	no serious indirectness	serious[3]	none	40	35	-	MD 0.56 higher (0.55 lower to 1.67 higher)	VERY LOW	CRITICAL
Carer knowledge/ confidence or efficacy: Self efficacy- Rewarding interaction (Instrument developed by Zeiss 1999) at 5 weeks follow-up from baseline (Better indicated by higher values)												
1[1]	randomised trials	very serious[2,9]	no serious inconsistency	no serious indirectness	serious[3]	none	40	35	-	MD 0.07 higher (0.88 lower to 1.02 higher)	VERY LOW	CRITICAL
Carer knowledge/ confidence or efficacy: Rewards (Rewards of Caregiving Scale) at 5 weeks follow-up from baseline (Better indicated by higher values)												

1[1]	randomised trials	very serious[2,10]	no serious inconsistency	no serious indirectness	serious[3]	none	40	35	-	MD 0.27 higher (0.14 lower to 0.68 higher)	VERY LOW	CRITICAL
Carer knowledge/ confidence or efficacy: Rewards (Rewards of Caregiving Scale) at 1 week post intervention (5 weeks post recruitment) follow-up (Better indicated by higher values)												
1[6]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[7]	none	150[11]	148	-	See narrative results in appendix D	MODERATE	CRITICAL
Carer knowledge/ confidence or efficacy: Rewards (Rewards of Caregiving Scale) at 8 weeks follow-up from patient death (Better indicated by higher values)												
1[1]	randomised trials	very serious[2,10]	no serious inconsistency	no serious indirectness	no serious imprecision	none	20	25	-	MD 0.46 higher (0.02 to 0.9 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Strain (Carer Strain Index) at 4 weeks follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	99	86	-	MD 0.1 lower (3.44 lower to 3.24 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Strain (Carer Strain Index) at 9 weeks follow-up from baseline (Better indicated by lower values)												

1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	73	63	-	MD 1.6 higher (2.01 lower to 5.21 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Strain (Carer Strain Index) at 12 weeks follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	69	54	-	MD 0.1 lower (3.98 lower to 3.78 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Quality of Life (Caregiver Quality of Life Index) at 4 weeks follow-up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	93	82	-	MD 5.7 higher (0.48 lower to 11.88 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Quality of Life (Caregiver Quality of Life Index) at 9 weeks follow-up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	71	59	-	MD 4.1 higher (2.73 lower to 10.93 higher)	LOW	CRITICAL
Impact of caring on carer: Carer Quality of Life (Caregiver Quality of Life Index) at 12 weeks follow-up from baseline (Better indicated by higher values)												

1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	64	52	-	MD 3 higher (4.5 lower to 10.5 higher)	LOW	CRITICAL
Impact of caring on carer: Family inventory of need (Part Scale B) at 1 week post intervention (5 weeks post recruitment) follow-up (Better indicated by lower values)												
1[6]	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[7]	none	150[11]	148	-	See narrative results in appendix D	MODERATE	CRITICAL

1 Hudson 2005
2 The quality of the evidence has been downgraded by 2 levels due to attrition bias, selective outcome reporting and sample size statistical power not being achieved.
3 Non-significant result (Any statistically significant change was considered to be important to carers- for any outcome where published MIDs were not identified)
4 Walsh 2007
5 The quality of the evidence has been downgraded by 1 level for an unclear risk of blinding (participants/personnel/outcome assessment). Sample size statistical power has not been achieved, however this is unlikely to have produced bias.
6 Hudson 2013
7 Imprecision was downgraded by 1 because results were presented as model outputs without reporting Means and SD and so imprecision could not be assessed.
8 Hudson 2015
9 The Self-efficacy scale was adapted to the study's population: Item 7 was change to 'Get enough sleep almost every night'- deemed implausible to expect caregivers of dying patients to get at least 7hrs/night. Item 8: perceived capacity for caregivers to get out of the house were reduced to 2 hours (6 hours seen as too much to expect given the context of care).
10 The Rewards of Caregiving Scale was adapted to the study's population: 4 of the 15 items focused on caregivers of the aged and were excluded. Item 4 also removed as it related to nursing home resident care
11 Participants received a psychoeducational intervention under two similar experimental arms of the same study. One arm (n = 57) received 2 face-to-face visits and 2 telephone calls, the other arm (n = 93) received 1 face-to-face visits and 3 telephone calls (see appendix D). Means and SDs were not reported and so results are also described in appendix D.

Psychological and emotional support (Relating to RQG)

Table 9: Evidence profile for psychological/ emotional interventions versus control

Quality assessment							Number of patients		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Psychological/ emotional support interventions**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Subjective experience of caring (Inventory of Daily Widowed Life, IDWL) - Oscillation Balance at 2 weeks follow-up from baseline (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	9	10	-	MD 5.41 higher (2.11 lower to 12.93 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Hope (Herth Hope Index, HHI) at 2 weeks follow-up from baseline (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	9	10	-	MD 0.7 higher (4.58 lower to 5.98 higher)	VERY LOW	CRITICAL
Impact of caring on carer: Satisfaction with Life (SWLS) at 6 weeks from baseline, 3 & 12 months from intervention follow-up (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	CRITICAL

Impact of caring on Carer: Meaning of Life Evaluation/ satisfaction (SMiLE) Impact of caring on carer: Satisfaction with Life (SWLS) at 6 weeks from baseline, 3 & 12 months from intervention follow-up (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	CRITICAL
Caring-related morbidity: Psychological distress (BSI-GSI) at 6 weeks from baseline, 3 & 12 months end of intervention follow-up (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	CRITICAL
Caring-related morbidity: Somatisation (BSI subscale) at 12 months follow-up from the end of intervention (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	CRITICAL
Caring-related morbidity: Depression (BSI subscale) at 12 months follow-up from the end of intervention (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	CRITICAL
Caring-related morbidity: Anxiety (BSI subscale) at 12 months follow-up from the end of intervention (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in	LOW	CRITICAL

										appendix D		
Carer quality of life: QOL-NRS Impact of caring on carer: Satisfaction with Life (SWLS) at 6 weeks from baseline, 3 & 12 months from intervention follow-up (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	IMPORTANT
Carer quality of life: WHOQOL-Bref Impact of caring on carer: Satisfaction with Life (SWLS) at 6 weeks from baseline, 3 & 12 months from intervention follow-up (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	73	57	-	See narrative results in appendix D	LOW	IMPORTANT

1 Holtslander 2016

2 The quality of the evidence has been downgraded by 2 levels due to unclear allocation concealment, unclear blinding of participants/personnel and outcome assessment, attrition bias and for the sample size statistical power not being achieved.

3 Non-significant result (Any statistically significant change was considered to be important to carers- for any outcome where published MIDs were not identified)

4 Kogler 2015

5 The quality of the evidence has been downgraded by 1 level for an unclear risk of randomization, allocation concealment, blinding of participants/personnel and outcome assessment, unclear incomplete outcome data and insufficient information to permit judgment on sample size statistical power.

6 Imprecision was downgraded by 1 because results were presented as model outputs without reporting Means and SD and so imprecision could not be assessed.

GRADE - CERQual tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Table 10: Summary of evidence (GRADE-CERQual), Theme 1: Interacting with carers at the end of life, having difficult discussions with carers

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Carers may struggle to comprehend information							
3(Caswell 2015; Dosser 2012; Ashton 2016)	2: Semi-structured interviews, 1: Mixed qualitative methods	Carers can find it difficult to comprehend and accept the seriousness of the patient's condition. Understanding that the person they care for is dying and taking in details may be difficult. It will often require more than one conversation. Some reach a state of denial and feel reluctant to 'give up'.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Very minor concerns	MODERATE
Relaying difficult news should be done clearly as well as sensitively							
1(Caswell 2015)	1: Mixed qualitative methods	Carers need to be told things sensitively and given time to process, however it is also important to use clear language and avoiding being vague or euphemistic. This can prevent misunderstandings later on.	No or very minor concerns[5]	Very minor concerns	Moderate concerns[1]	Serious concerns[3]	LOW
Frequent verbal updates from a professional are appreciated							
2(Epiphaniou 2012;	2: Semi-structured interviews	Carers value receiving further information about the patient's condition and the end of life	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[4]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Seamark 2014)		process directly from professional care staff. Frequent face-to-face updates with professionals when at units, or by phone with GPs when at home, has a big impact.					
Written information is not well engaged with							
1(Newbury 2011)	1: Semi-structured interviews	At the end of life carers do not engage well with further information from books, leaflets or websites.	Moderate concerns[5]	Moderate concerns	Moderate concerns[2]	Serious concerns[3]	VERY LOW
Non-specialist staff may be reluctant to dicuss death with families							
1(Dosser 2012)	1: Semi-structured interviews	Unlike specialist hospice or acute care staff, ward nurses may be hesitant to talk with families and carers about the end of life. They do not see it as their role, and felt families may appreciate conversations with more senior or specialist staff, even though families often come to them. Many also felt underconfident in their skills and ability to have difficult conversations.	Moderate concerns[6]	Very minor concerns	Moderate concerns[1]	Serious concerns[3]	LOW
Non-specialist staff feel more able to discuss dying with families following training							
1(Dosser 2014)	1: Mixed qualitative methods	Following communication training ward nurses felt confident in their ability to offer	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[3]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		help and have difficult conversations. Families greatly appreciated having this extra support available.					

1 Evidence was downgraded due to applicability of evidence as the data was based in only a hospital setting but considered to apply generally
2 Evidence was downgraded due to applicability of evidence as the data was based in only a home setting but considered to apply generally
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
4 Evidence was downgraded due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
5 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
6 Evidence was downgraded as it was based on 1 study that was rated as having moderate methodological limitations following assessment with the CASP assessment tool

Table 11: Summary of evidence (GRADE-CERQual), Theme 2: Interacting with carers at the end of life, valuing carers

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Carers often feel dismissed or undervalued by staff and services							
3(Briggs 2010; Forbat 2012; Nelson 2017)	1: Open-ended interviews and observations, 1: Semi-structured interviews, 1: Interviews (unspecified)	Carers often feel that support services don't pay them consideration and ignore their significant role, knowledge and experience. This is an oversight given the levels of care they provide as well as the personal and condition-specific knowledge they have.	Moderate concerns[1]	Moderate concerns[2]	No or very minor concerns	No or very minor concerns	LOW
Carers are afraid of being labelled as 'difficult'							
1(Briggs 2010)	1: Open-ended interviews and observations	Some carers feel wary that they should not push or assert themselves too much in their demands with care staff. They	Moderate concerns[1]	Moderate concerns	Very minor	Serious concerns[3]	VERY LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		fear they may be labled as ‘difficult’ and this will damage their relationship with professionals. They beleive this will be detrimental to the support that they and the person they care for receive.					
Feeling appreciated and included in decision-making helped the experience							
1(Caswell 2015)	1: Mixed qualitative methods	Carers that feel included in decisions and processes subsequently feel better towards the service they received and happier with the end of life process overall.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW

1 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to coherence issues with as studies made claims without backing it up with sufficient quotes or examples
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review’s findings (offering poor data

Table 12: Summary of evidence (GRADE-CERQual), Theme 3: Challenges for carers at end of life, impacts of being a carer

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Impact upon themself							
1(Forbat 2012)	1: Semi-structured interviews	Carers feel highly responsible for the person they care for and their care. Providing care impacts them and takes a toll on their lifestyle – however this toll is somewhat mediated	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		by their own life-stage (job status, health etc).					
Being strong as a coping strategy							
1(Newbury 2011)	1: Semi-structured interviews	Carers feel determined they have to be 'strong' and maintain the appearance that everything is 'fine'.	Moderate concerns[1]	Moderate concerns	Moderate concerns[2]	Serious concerns[3]	VERY LOW
Strain on their interaction with the patient							
1(Forbat 2012)	1: Semi-structured interviews	Being a carer for a dying person puts a strain upon that relationship. Carers may become snappy or irritated towards them due to the pressure of burden. Patients may act demandingly, complacently or entitled towards their carer. Carers feel unhappy that their relationship can become soured by this towards the end of the person's life.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW
Presence of family can bring support							
2(Forbat 2012; Epiphaniou 2012)	2: Semi-structured interviews	Close family networks usually rally around patients and carers towards the end of life and offer support.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[4]	MODERATE
Presence of family can add to the workload							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
1(Forbat 2012)	1: Semi-structured interviews	Carers sometimes feel pressured to look after their family members as well as the dying person - including to act like everything is fine in front of them, consoling them, and taking on extra responsibilities in order that other family members don't also feel strained.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW

1 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to applicability of evidence as the data was based in only a home setting but considered to apply generally
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
4 Evidence was downgraded due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 13: Summary of evidence (GRADE-CERQual), Theme 4: Challenges for carers at end of life, advanced care plans (ACPs) at end of life

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Benefits of an advanced care plan							
1(Ashton 2016)	1: Semi-structured interviews	Carers of people who may lack capacity now or in future (in this case, people living with dementia) agreed ACPs are appropritate. ACPs allow them to confront important and inevitable decisions at a calmer, less stressful time.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW
A sensitive and person-centered approach to ACPs							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
1(Ashton 2016)	1: Semi-structured interviews	Advanced care planning is an uncomfortable experience. Open and honest but sensitive discussions were appreciated. It is important to remember that they are a person with a life history, and not only a dying patient.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW

1 Evidence was downgraded due to applicability of evidence as the data was based in only a hospital setting but considered to apply generally
2 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 14: Summary of evidence (GRADE-CERQual), Theme 5: Challenges for carers at end of life, managing medication at end of life

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Strategies for managing medication							
Payne (2015)	1: Semi-structured interviews	Carers come up with their own strategies for how to manage medication. These need to be understood and worked with.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW
Carers worry about medication at end of life							
Payne (2015)	1: Semi-structured interviews	The responsibility of managing medication gives carers concerns. They are especially worried about making mistakes such as giving too much, not enough, or forgetting to give it at all.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW
Carers may disagree with practitioners about medication							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Payne (2015)	1: Semi-structured interviews	Carers are anxious about challenging medical practitioners about their instructions if they disagreed with them.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW
Drug side effects (especially morphine) at the end of life							
Payne (2015)	1: Semi-structured interviews	Some drugs (especially morphine) are important for pain relief but can also make the patient lose their composure and dignity. When a patient is on the edge of dying, some carers recalled fondly how they brought the patient off their drugs in the final hours and were able to make final precious memories as they regained lucidity.	No or very minor concerns	No or very minor concerns	Moderate concerns[1]	Serious concerns[2]	LOW

1 Evidence was downgraded due to applicability of evidence as the data from 1 study was based in only on a population with only 1 specific condition
2 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 15: Summary of evidence (GRADE-CERQual), Theme 6: Challenges for carers at end of life, bad experiences with professional services

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Staff may lack knowledge or training about specific conditions							
2(O'Brien 2015;	1: Interviews (unspecified), 1:	In homecare or hospital settings carers sometimes had	Moderate concerns[4]	No or very minor concerns	Moderate concerns[1]	Moderate concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Seamark 2014)	Semi-structured interviews	to deal with professionals that don't have specialist knowledge or training about the condition. Carers had to fill in these knowledge gaps, often repeatedly to different staff. This was especially true with rare conditions or special cases and can lead to frustration and occasionally conflict.					
Staff may lack knowledge or training about communication							
1(Briggs 2010)	1: Open-ended interviews and observations	Professionals sometimes failed to understand when a patient had communication difficulties – and this was undignifying to the patient and made them less autonomous.	Moderate concerns[4]	Moderate concerns	Very minor	Serious concerns[3]	VERY LOW
The importance of getting it right first time							
2(O'Brien 2015; Briggs 2010)	1: Interviews (unspecified), 1: Open-ended interviews and observations	Bad experiences can do unreversible damage to carers' perceptions and relationships with professionals. Bad experiences may be detrimental to the final memories the carer has with the person they care for. It may also stop them from	Moderate concerns[4]	No or very minor concerns	Moderate concerns[1]	Moderate concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
		feeling willing to seek help in future when it's necessary.					

1 Evidence was downgraded due to applicability of evidence as the data from 1 study was based in only on a population with only 1 specific condition
2 Evidence was downgraded due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
4 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool

Table 16: Summary of evidence (GRADE-CERQual), Theme 7: Receiving support at home at end of life, arranging for help at home at end of life

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Making the arrangements for care at home is overwhelming							
2(Seamark 2014; Nelson 2017)	1: Semi-structured interviews, 1: Interviews (unspecified)	Carers feel overwhelmed and vulnerable at this time, and find organizing care at home highly taxing. Carers report being given a long list of phone numbers but still feeling unsure who to call. Arranging for out-of-hours help was especially distressing.	Moderate concerns[1]	Moderate concers	No or very minor concerns	Moderate concerns[3]	LOW
Organising services was detrimental to their limited time							
2(Seamark 2014; Briggs 2010)	1: Semi-structured interviews, 1: Open-ended interviews and observations	Filling out forms and striving to see what help they qualify for added further stress to carers, when they wanted to make the most of the time they had with the person they care for.	Moderate concerns[1]	Moderate concerns	No or very minor concerns	Moderate concerns[3]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Carers would prefer that most of the arranging was done for them							
1(Newbury 2011)	1: Semi-structured interviews	Carers want to have some input but ideally the arrangements for homecare would mostly be arranged and directed by professionals	Moderate concerns[1]	Moderate concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
Organising help at home in a rural setting							
1(Nelson 2017)	1: Interviews (unspecified)	Carers in a rural settings that want to remain in their own homes acknowledge that it's harder to get support to them. Receiving help, assistance and reassurance over the phone was acceptable but it needed to be regular. Also it helped if they got to meet the professionals face-to-face at least once.	Moderate concerns[1]	Moderate concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
Communication and cordination between services							
2(Seamark 2014; Briggs 2010)	1: Semi-structured interviews, 1: Open-ended interviews and observations	There is often a lack of strategic communication between agencies. Carers commonly report negative experiences. In one example a patient died and the care agency – not having been informed of this - continued to send carers. Carers were pleasantly surprised on the	Moderate concerns[1]	Moderate concerns	No or very minor concerns	Moderate concerns[3]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		occasions when communication did work.					

1 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
3 Evidence was downgraded due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 17: Summary of evidence (GRADE-CERQual), Theme 8: Receiving support at home at end of life, experiences of receiving support at home at end of life

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Carers are grateful for help and support at home at end of life							
3(Jack 2015; Epiphaniou 2012; Percival 2014)	2: Semi-structured interviews, 1: formal & informal interviews, and observation sessions	Support at home could be a very valued presence. Competent professional staff made carers feel comforted and supported, and better able to enjoy their final time with the person they care for.	No or very minor concerns	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH
Home carers were a lifeline							
2(Jack 2015; Briggs 2010; PHE 2016)	1: Semi-structured interviews; 1: Open-ended interviews and observations, 1: Interviews (unspecified)	Home care staff help out domestically as well as with care tasks. This gave carers a chance for some respite, and often enabled them to keep their jobs and own livlihoods. Above all it improved the quality of the time and	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		interaction they had with dying person.					
Encouragment and reassurance for carers							
2(Jack 2015; Newbury 2011)	2: Semi-structured interviews	Carers value the praise and encouragement they get from professional home care staff. Where they doubt themselves or the actions they are taking as carers, professionals could guide them or reassure them that the care they're giving is adequate and appropriate.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	MODERATE
Accepting help can be hard to do							
4(Jack 2015; Forbat 2012; Briggs 2010; PHE 2016)	2: Semi-structured interviews; 1: Open-ended interviews and observations, 1: Interviews (unspecified)	Carers find the decision to accept help at home very difficult. Carers often give up work or social lives to avoid or reduce the need for outside help.	No or very minor concerns	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH
Accepting help at home can feel invasive							
2(Newbury 2011; Briggs 2010)	1: Semi-structured interviews; 1: Open-ended interviews and observations	Carers find it hard to adjust to outsiders coming into the home, often several times per day and often varying people. Accepting help in the home can feel very invasive. The same applied to medical equipment brought in to the	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		home. Introducing new workers and equipment to the home must be done sensitively.					
Continuity is very important to carers at end of life							
2(Seamark 2014; Percival 2014)	1: Semi-structured interviews, 1: formal & informal interviews, and observation sessions	Having continuity with the staff who visit their house is very important to carers. Being introduced to new staff and having to repeat information and preferences is distressing for both the carer and the patient.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[2]	MODERATE
Make home care person centered							
1(Percival 2014)	1: formal & informal interviews, and observation sessions	Receiving help at home was most beneficial when it was flexible and when visitng care staff weren't rushed. Being able to adapt as the situation changes, and give more or less time as necessary, was greatly appreciated.	Moderate concerns[4]	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW

1 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
4 Evidence was downgraded by 1 as it was based on 1 study that was rated as having moderate methodological limitations following assessment with the CASP assessment tool

Table 18: Summary of evidence (GRADE-CERQual), Theme 9: Carers needs at a hospital/care unit setting, making a supportive environment for carers at end of life

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Accomodating family at the end of life							
3(Dosser 2012; Dosser 2014; Caswell 2015)	1: Semi-structured interviews, 2: Mixed qualitative methods	Having calm side-bedrooms for patients who are dying was greatfly appreciated compared to being on a ward. This allowed family to have intimate moments in peace, as well as avoid being distressed or selfconscious that they were disturbing neighbours. Similarly, having quiet side rooms with seating, kettles, microwaves etc where	No or very minor concerns	No or very minor concerns	No or very minor concerns	No or very minor concerns	HIGH
Not being forgotten							
1(Caswell 2015)	1: Mixed qualitative methods	Carers who are keeping vigil with a dying relative appreciate being occasionally checked up on by staff, even though they are going through a sensitive personal time.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 19: Summary of evidence (GRADE-CERQual), Theme 10: Carers needs at a hospital/care unit setting, meeting needs

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Basic care							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
1(O'Brien 2015)	1: Interviews (unspecified)	Carers find it highly distressing when dying patients, especially those with severe disabilities such as MND, are left without having their personal basic care and hygene needs met.	Moderate concerns[1]	No or very minor concerns	Serious concerns[2]	Serious concerns[3]	VERY LOW
Staff on hand							
1(Caswell 2015)	1: Mixed qualitative methods	Carers at hospital units sometimes find it difficult to find any member of staff to ask questions to.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[3]	LOW

1 Evidence was downgraded due to half or more of the studies being rated as having major methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to applicability of evidence as the data was based in only on a population with only 1 specific condition
3 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 20: Summary of evidence (GRADE-CERQual), Theme 11: Support following bereavement, carers support needs following bereavement

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Support with legal and logistical issues							
1(PHE 2016)	1: Interviews (unspecified)	Carers feel the need for support navigating legal and logistical tasks (funerals and death certification) after the person they care for has passed away.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
Formal and informal emotional support							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
1(PHE 2016)	1: Interviews (unspecified)	Carers feel a need to talk and grieve with others once the person they care for has passed. This may become especially apparent when coming to terms with the gap in their life that had previously been filled by caring. For some this may involve opening up to informal support networks, but for others seeing a counsellor was considered very helpful.	Moderate concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

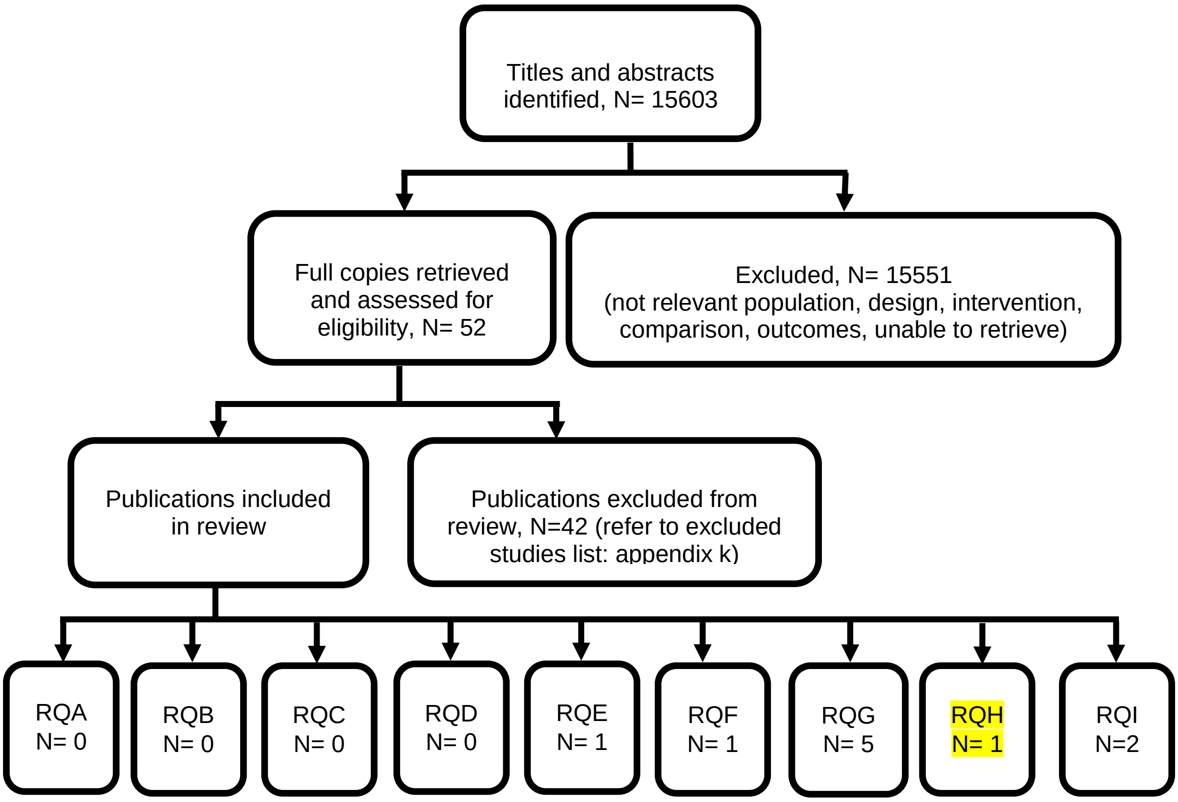
1 Evidence was downgraded by 1 as it was based on 1 study that was rated as having moderate methodological limitations following assessment with the CASP assessment tool
2 Evidence was downgraded due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. As shown in Figure 4 below, 1 economic study was identified which was applicable to this review question.

Figure 4: Study selection flow chart



Appendix H – Economic evidence tables

Economic evidence tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Table 21: Economic evidence tables

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
Pham 2014 Canada Cost utility analysis **Conflict of interest**: none **Funding:** Health Quality Ontario	i) Improving family conferences for relatives of patients dying in an intensive care unit – a conference between members of the ICU team and carers to mitigate the effects of bereavement ii) Multicomponent psychological education provided by advanced practice nurses with	**Population:** Ontarian decedents and their main informal carers **Sources of data:** • Systematic reviews of EoL care interventions undertaken by Health Quality Ontario • Health administration databases at Institute for Clinical Evaluative Sciences (ICES) • Experts on an EoL care advisory panel • EoL survey data from services in Ontario hospices and hospitals	**Costs:** Annual fee-for-service payment per specialist full-time equivalent, nurse practitioner annual salary, registered nurse annual salary, bioethicist annual salary, social worker annual salary, registered nurse hourly rate 3 (1–5) years of experience, social worker hourly rate **Incremental costs:** ○ Improving family conferences: 56 CAD ○ Multicomponent psychological education: 4,766 CAD	**ICERs** Improving family conferences: 41,690 CAD per QALY Multicomponent psychological education: 479,509 CAD per QALY Supportive interventions for carers: 87,205 CAD per QALY **Sensitivity analysis** Probabilistic sensitivity analysis – probability cost-effective using a cost-effectiveness threshold of 50,000 CAD per QALY ○ Improving family conferences: 52%	**Perspective**: Health payer **Currency:** CAD Cost year: 2013 **Time horizon**: 1 year Discounting: None **Applicability:** partially applicable **Quality:** minor limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	training in speciality care in palliative care with the patient and their care Supportive interventions for carers such as breaks from caring, providing programmes that assist problem solving and enhancing well-being through counselling, relaxation or psychotherapy	• Summary characteristics in-home palliative expert consult teams based on 11 such teams based in Ontario • Planning documents obtained from the Ontario Long-Term Care Association • Ontario Association of Community Care Access Centres • Bridgepoint Active Healthcare facility • Rouge Valley Health System on ethics consultation services Certain model inputs were derived from additional literature searches of published and unpublished studies	○ Supportive interventions for carers: 196 CAD **Incremental quality adjusted life days (QALD)** ○ Improving family conferences - Total: 0.49 ○ Multicomponent psychological education - Patient: 1.98 - Carer: 1.65 - Total: 3.63 ○ Supportive interventions for carers Total: 0.82	○ Multicomponent psychological education: 26% ○ Supportive interventions for carers: 28%	

C: Control group; EQ-5D: EuroQol 5 Dimensions; F: Female; I: intervention group; ICER: Incremental cost-effectiveness ratio; N/A: not applicable; N/R: not reported; QALY: Quality-adjusted life year; RCT: Randomised controlled trial; SD: Standard deviation; TAU: Treatment as usual.

a: When cost–utility analysis was done using the QALYs for dyads (i, e. carers and care recipients) showed that the intervention to be borderline cost-effective (ICER = £26,648/QALY, with a 51.4% probability of being below £30,000 per QALY gained)

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Table 22: Economic evidence profiles

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
Pham 2014 Canada	Minor limitations	Partially applicable[1]	Cost utility analysis Outcome measure: QALYs	○ Improving family conferences: 56 CAD ○ Multicomponent psychological education: 4,766 CAD ○ Supportive interventions for carers: 196 CAD	○ Improving family conferences - Total: 0.49 QALD ○ Multicomponent psychological education - Patient: 1.98 QALD - Carer: 1.65 QALD - Total: 3.63 QALD ○ Supportive interventions for carers Total: 0.82 QALD	○ Improving family conferences: 41,690 CAD per QALY ○ Multicomponent psychological education: 479,509 CAD per QALY ○ Supportive interventions for carers: 87,205 CAD per QALY	Cost-effectiveness was assessed on the basis that QALY maximisation was the objective of the interventions but this may not be the case for end of life interventions.

1. Canadian costs may not be applicable to NHS and England social care setting, a strong assumption of constant relative responsiveness between diseases specific HRQoL measures and generic scales such as EuroQOL 5 dimensions (EQ-5D)

Appendix J – Economic analysis

Economic evidence analysis for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

List of excluded studies for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers who are caring for people at the end of life, and after the person receiving care dies?

Quantitative component of the review

Table 23: Excludies studies from the quantitative component of the review

Study	Reason for Exclusion
Allen, R. S., Harris, G. M., Burgio, L. D., Azuero, C. B., Miller, L. A., Shin, H. J., Eichorst, M. K., Csikai, E. L., DeCoster, J., Dunn, L. L., Kvale, E., Parmelee, P., Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial, Journal of Pain & Symptom Management, 48, 590-601, 2014	Setting to exclude: no Country of interest.
Aoun, Sm, Grande, G, Howting, D, Deas, K, Toye, C, Troeung, L, Stajduhar, K, Ewing, G, The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial, PLoS ONE, 10, 2015	No intervention of interest: not support interventions for adult carers.
Bakitas, M., Dionne-Odom, J. N., Pamboukian, S. V., Tallaj, J., Kvale, E., Swetz, K. M., Frost, J., Wells, R., Azuero, A., Keebler, K., Akyar, I., Ejem, D., Steinhauser, K., Smith, T., Durant, R., Kono, A. T., Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: Results of the ENABLE CHF-PC pilot clinical trial, BMC Palliative Care, 16 (1) (no pagination), 2017	Setting to exclude: no Country of interest.
Barrett, M., Wheatland, B., Haselby, P., Larson, A., Kristjanson, L., Whyatt, D., Palliative respite services using nursing staff reduces hospitalization of patients and improves acceptance among carers, International Journal of Palliative Nursing, 15, 389-95, 2009	Not an RCT.
Candy, B., Jones, L., Williams, R., Tookman, A., King, M., Interventions for supporting informal caregivers of patients in the terminal phase of a disease, Cochrane Database of Systematic Reviews, (1) (no pagination), 2009	Not an RCT.
Carson, Ss, Cox, Ce, Wallenstein, S, Hanson, Lc, Danis, M, Tulsky, Ja, Chai, E, Nelson, Je, Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness: a Randomized Clinical Trial, JAMA, 316, 51-62, 2016	Setting to exclude: no Country of interest.
Chol, Y. K., The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients, Journal of Music Therapy, 47, 53-69, 2010	Setting to exclude: no Country of interest.

Study	Reason for Exclusion
Clayton, Jm, Butow, Pn, Tattersall, Mh, Devine, Rj, Simpson, Jm, Aggarwal, G, Clark, Kj, Currow, Dc, Elliott, Lm, Lacey, J, Lee, Pg, Noel, Ma, Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care, Journal of clinical oncology, 25, 715-723, 2007	Not relevant the PICO question.
Dionne-Odom, J. N., Azuero, A., Lyons, K. D., Hull, J. G., Prescott, A. T., Tosteson, T., Frost, J., Dragnev, K. H., Bakitas, M. A., Family Caregiver Depressive Symptom and Grief Outcomes From the ENABLE III Randomized Controlled Trial, Journal of Pain and Symptom Management, 52, 378-385, 2016	Setting to exclude: no Country of interest.
Dionne-Odom, Jn, Azuero, A, Lyons, Kd, Hull, Jg, Tosteson, T, Li, Z, Li, Z, Frost, J, Dragnev, Kh, Akyar, I, Hegel, Mt, Bakitas, Ma, Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: outcomes From the ENABLE III Randomized Controlled Trial, Journal of Clinical Oncology, 33, 1446-1452, 2015	Setting to exclude: no Country of interest.
Fegg, Mj, Brandstätter, M, Kögler, M, Hauke, G, Rechenberg-Winter, P, Fensterer, V, Küchenhoff, H, Hentrich, M, Belka, C, Borasio, Gd, Existential behavioural therapy for informal caregivers of palliative patients: a randomised controlled trial, Psycho-Oncology, 22, 2079-2086, 2013	This RCT was published before 2014 (Psychosocial support).
Grande, Ge, Farquhar, Mc, Barclay, Si, Todd, Cj, Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death, Journal of Palliative Care, 20, 69-77, 2004	Not an RCT.
Greene, A., Aranda, S., Tieman, J. J., Fazekas, B., Currow, D. C., Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: community facilitator pilot, Palliative Medicine, 26, 917-23, 2012	Not an RCT.
Hamilton, G, Gallagher, M, Pierson, K, Lowes, S, Lin, Py, Ortega, R, Palliative care for dementia: a randomized controlled study of a replicable and financially viable model for organizations providing caregiver support, Journal of Pain and Symptom Management, 401-401, 2017	Conference abstract.
Harding, R, Higginson, Ij, Leam, C, Donaldson, N, Pearce, A, George, R, Robinson, V, Taylor, L, Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service, Journal of Pain and Symptom Management, 27, 396-408, 2004	Not an RCT.
Holdsworth, L. M., Gage, H., Coulton, S., King, A., Butler, C., A quasi-experimental controlled evaluation of the impact of a hospice rapid response community service for end-of-life care on achievement of preferred place of death, Palliative Medicine, 29, 817-825, 2015	Not an RCT.

Study	Reason for Exclusion
Holland, Jm, Currier, Jm, Gallagher-Thompson, D, Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers, Psychology and Aging, 24, 190-202, 2009	Setting to exclude: no Country of interest.
Hudson, Peter, A critical review of supportive interventions for family caregivers of patients with palliative-stage cancer, Journal of Psychosocial Oncology, 22, 77-92, 2004	Review study, which is an excluded study design. References have been handsearched for relevant studies.
Hughes, M, Sulmasy, D, Yenokyan, G, Kub, J, Terry, P, Astrow, Ab, Johnson, J, Ho, G, Nolan, M, The tailored study: a randomized controlled trial to improve surrogate decision making, Journal of general internal medicine., 31, S435, 2016	Not an RCT.: conference abstract.
Kissane, Dw, McKenzie, M, Bloch, S, Moskowitz, C, McKenzie, Dp, O'Neill, I, Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement, American Journal of Psychiatry, 163, 1208-1218, 2006	This RCT was published before 2014 (Psychosocial support).
Lee, K. C., Yiin, J. J., Chao, Y. F., Effect of integrated caregiver support on caregiver burden for people taking care of people with cancer at the end of life: A cohort and quasi-experimental clinical trial, International Journal of Nursing Studies, 56, 17-26, 2016	Setting to exclude: no Country of interest.
McDonald, J., Swami, N., Hannon, B., Lo, C., Pope, A., Oza, A., Leighl, N., Krzyzanowska, M. K., Rodin, G., Le, L. W., Zimmermann, C., Impact of early palliative care on caregivers of patients with advanced cancer: cluster randomised trial, Annals of Oncology, 28, 163-168, 2017	Although carer received various kinds of support (social, emotional, training), attendance at palliative care not compulsory for them. Intervention primarily for care recipient.
McMillan, Sc, Small, Bj, Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial, Oncology Nursing Forum, 34, 313-321, 2007	Setting to exclude: no Country of interest.
McMillan, Sc, Small, Bj, Weitzner, M, Schonwetter, R, Tittle, M, Moody, L, Haley, We, Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial, Cancer, 106, 214-222, 2006	Setting to exclude: no Country of interest.
Mosher, C. E., Secinti, E., Johns, S. A., O'Neil, B. H., Helft, P. R., Shahda, S., Jalal, S. I., Champion, V. L., Examining the effect of peer helping in a coping skills intervention: a randomized controlled trial for advanced gastrointestinal cancer patients and their family caregivers, Quality of Life Research, 1-14, 2017	Setting to exclude: no Country of interest.
Nappa, U, Lundgren, A-B, Axelsson, B, The effect of bereavement groups on grief, anxiety, and depression - A controlled, prospective intervention study, BMC Palliative Care, 15, 2016	Not an RCT.
Sulmasy, D. P., Hughes, M. T., Yenokyan, G., Kub, J., Terry, P. B., Astrow, A. B., Johnson, J. A., Ho, G., Nolan, M. T., The Trial of Ascertaining Individual Preferences for	Setting to exclude: no Country of interest.

Study	Reason for Exclusion
Loved Ones' Role in End-of-Life Decisions (TAILORED) Study: A Randomized Controlled Trial to Improve Surrogate Decision Making, Journal of Pain and Symptom Management, 54, 455-465, 2017	
Treasure, Janet, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, 125-137, 2016	Study only describes intervention (same as Treasure et al. 2008).
Yun, Yh, Lee, Mk, Park, S, Lee, Jl, Park, J, Choi, Ys, Lim, Yk, Kim, Sy, Jeong, Hs, Kang, Jh, Oh, Hs, Park, Jc, Kim, Sy, Song, Hs, Ro, J, Lee, Ks, Heo, Ds, Hong, Ys, Use of a decision aid to help caregivers discuss terminal disease status with a family member with cancer: a randomized controlled trial, Journal of clinical oncology, 29, 4811-4819, 2011	Setting to exclude: no Country of interest.

Qualitative component of the review

Table 24: Excludies studies from the qualitative component of the review

Study	Reason for exclusion
The national survey of bereaved people (VOICES) 2014	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Palliative and Supportive Care; Investigators at Curtin University Report New Data on Palliative and Supportive Care (Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial), 1979, 2015	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Akiyama, Akiko, Numata, Kumiko, Mikami, Hiroshi, Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement, Archives of Gerontology and Geriatrics, 50, 175-178, 2010	The study was not conducted in the UK.
Aneshensel, Carol S., Botticello, Amanda L., Yamamoto-Mitani, Noriko, When Caregiving Ends: The Course of Depressive Symptoms After Bereavement*, Journal of Health and Social Behavior, 45, 422-40, 2004	The study was not conducted in the UK.
Baldwin, Paula K., Villagran, Melinda M., Family Communication Patterns, Resilience and Social Support among Hospice Family Caregivers, AAI3506242	Full text is a dissertation.
Beland, P., Implications for carers of terminally ill patients dying at home, Nursing standard (Royal College of Nursing (Great Britain) : 1987), 28, 40-45, 2013	Not a qualitative study design.
Bennett Kate M, et al.,, "Well if he could see me now": the facilitators and barriers to the promotion of instrumental independence following spousal bereavement, Journal of Gerontological Social Work, 53, 215-234, 2010	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.

Study	Reason for exclusion
Bennett, Dora, Death and people with learning disabilities: Empowering carers, British Journal of Learning Disabilities, 31, 118-122, 2003	Population - was not about carers of people who were dying.
Berry, M., Brink, E., Harris, J., Sleeman, K. E., Supporting relatives and carers at the end of a patient's life, BMJ, 356, j367, 2017	Not a qualitative study design.
Betts Adams Kathryn, Sanders Sara, Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed method analysis, Dementia: The International Journal of Social Research and Practice, 3, 195-210, 2004	The study was not conducted in the UK.
Boston, Patricia H., Mount, Balfour M., The Caregiver's Perspective on Existential and Spiritual Distress in Palliative Care, Journal of Pain and Symptom Management, 32, 13-26, 2006	The study was not conducted in the UK.
Broady, Timothy R., Carers' Experiences of End-of-Life Care: A Scoping Review and Application of Personal Construct Psychology, Australian Psychologist, 52, 372-380, 2017	Review study, which is an excluded study design. References have been handsearched for relevant studies.
Cain, R., MacLean, M., Sellick, S., Giving support and getting help: informal caregivers' experiences with palliative care services, Palliative & supportive care, 2, 265-72, 2004	The study was not conducted in the UK.
Calvete, E., De Arroyabe, E. L., Depression and grief in Spanish family caregivers of people with traumatic brain injury: The roles of social support and coping, Brain Injury, 26, 834-843, 2012	The study was not conducted in the UK.
Carlander, I., Sahlberg-Blom, E., Hellstrom, I., Ternestedt, B. M., The modified self: family caregivers' experiences of caring for a dying family member at home, Journal of clinical nursing, 20, 1097-105, 2011	The study was not conducted in the UK.
Caron, Chantal D., Griffith, Jennifer, Arcand, Marcel, End-of-life decision making in dementia: the perspective of family caregivers, Dementia, 4, 113-136, 2005	The study was not conducted in the UK.
Caron, Chantal D., Griffith, Jennifer, Arcand, Marcel, Decision Making at the End of Life in Dementia: How Family Caregivers Perceive Their Interactions with Health Care Providers in Long-Term-Care Settings, The Journal of Applied Gerontology, 24, 231-247, 2005	The study was not conducted in the UK.
Caserta, Michael S., Lund, Dale A., Utz, Rebecca L., Tabler, Jennifer Lyn, "One Size Doesn't Fit All" - Partners in Hospice Care, an Individualized Approach to Bereavement Intervention, Omega, 73, 107, 2016	The study was not conducted in the UK.
Chen, Wan-Yi, Lukens, Ellen, Well Being, Depressive Symptoms, and Burden Among Parent and Sibling Caregivers of Persons With Severe and Persistent Mental Illness, Social Work in Mental Health, 9, 397-416, 2011	The study was not conducted in the UK.
Clark, David, Evans, Anne, Hughes, Philippa, Ingleton, Christine, Morgan, Jana, Noble, Bill, Carer satisfaction with end-of-life care in Powys, Wales: a cross-sectional survey, Health and Social Care in the Community, 12, 43-52, 2004	The study was not conducted in the UK.
Clark, Paul G., Brethwaite, Drucilla S., Gnesdiloff, Sabine, Providing Support at Time of Death From Cancer: Results	The study was not conducted in the UK.

Study	Reason for exclusion
of a 5-Year Post-Bereavement Group Study, Journal Of Social Work In End-Of-Life & Palliative Care, 7, 195-215, 2011	
Corden, Anne, Hirst, Michael, Partner care at the end-of-life: identity, language and characteristics, Ageing & Society, 31, 217-242, 2011	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Crowther, Jacqueline, Dementia: what care do patients and carers need in the last year of life and time surrounding death?: an exploratory qualitative study, 10069138, 2011	Full text is a dissertation.
Davies, Nathan, Rait, Greta, Maio, Laura, Iliffe, Steve, Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study, Palliative Medicine, 31, 726-733, 2017	General focus on carers caring for people with dementia with no specific focus on providing practical support for carers.
Dumont, Isabelle, Dumont, Serge, Mongeau, Suzanne, End-of-Life Care and the Grieving Process: Family Caregivers Who Have Experienced the Loss of a Terminal-Phase Cancer Patient, Qualitative health research, 18, 1049-1061, 2008	The study was not conducted in the UK.
Dumont, S., Fillion, L., Gagnon, P., Bernier, N., A new tool to assess family caregivers' burden during end-of-life care, Journal of Palliative Care, 24, 151-61, 2008	The study was not conducted in the UK.
Edwards, A., Pang, N., Shiu, V., Chan, C., Review: The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research, Palliative Medicine, 24, 753-70, 2010	Review study, which is an excluded study design. References have been handsearched for relevant studies.
Felicity, H., Allison, S., Mary, W., George, K., Dorry, M., Barbara, W., Barbara, C., Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease, Journal of Palliative Care, 25, 157-163, 2009	General focus on carers caring for people with COPD with no specific focus on providing practical support for carers.
Ford, James L., Linde, Brittany D., Gigliotti, Christina, Kim, Kye Y., Grief experiences of 3 caregiving wives of veterans with dementia, American Journal of Hospice & Palliative Medicine, 30, 137-145, 2013	The study was not conducted in the UK.
Frank, Jacquelyn B., Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis, American Journal of Alzheimer's Disease and other Dementias, 22, 516-527, 2008	The study was not conducted in the UK.
Gao, Xin, Prigerson, Holly G., Diamond, Eli L., Zhang, Baohui, Wright, Alexi A., Meyer, Fremonta, Maciejewski, Paul K., Minor Cognitive Impairments in Cancer Patients Magnify the Effect of Caregiver Preferences on End-of-Life Care, Journal of Pain and Symptom Management, 45, 650-659, 2013	The study was not conducted in the UK.
Gordon, Theresa A., Good Grief: Exploring the Dimensionality of Grief Experiences and Social Work Support, Journal Of Social Work In End-Of-Life & Palliative Care, 9, 27-42, 2013	The study was not conducted in the UK.
Grande, G. E., Ewing, G., Informal carer bereavement outcome: relation to quality of end of life support and	Not qualitative data.

Study	Reason for exclusion
achievement of preferred place of death, Palliative Medicine, 23, 248-56, 2009	
Grande, Gunn E., Farquhar, Morag C., Barclay, Stephen I., Todd, Chris J., Caregiver Bereavement Outcome: Relationship With Hospice at Home, Satisfaction With Care, and Home Death, Journal of Palliative Care, 20, 69-77, 2004	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Greer, S., Bereavement care: some clinical observations, Psycho-Oncology, 19, 1156-60, 2010	Not a qualitative study design.
Haley, William E., Bergman, Elizabeth J., Roth, David L., McVie, Theresa, Gaugler, Joseph E., Mittelman, Mary S., Long-Term Effects of Bereavement and Caregiver Intervention on Dementia Caregiver Depressive Symptoms, Gerontologist, 48, 732-740, 2008	The study was not conducted in the UK.
Harrop, Emily J., Byrne, Anthony, Morgan, Fiona, Nelson, Annmarie, The bereavement experiences and support needs of family carers: a supplementary qualitative analysis of free text data from the peolcpsp research priority setting exercise, BMJ supportive & palliative care, 6, 393, 2016	Full text is an abstract.
Hasson, Felicity, Kernohan, W. George, McLaughlin, Marian, Waldron, Mary, McLaughlin, Dorry, Chambers, Helen, Cochrane, Barbara, An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease, Palliative Medicine, 24, 731-736, 2010	General focus on carers caring for people people with Parkinsonâ€ ™s disease with no specific focus on providing practical support for carers.
Hebert Randy S, et al.,, Preparing family caregivers for the death of a loved one: implications for hospital social workers, Journal of Social Work in End-of-Life and Palliative Care, 4, 269-285, 2008	The study was not conducted in the UK.
Hirano, Yuko, Yamamoto-Mitani, Noriko, Ueno, Mari, Takemori, Shiho, Kashiwagi, Masayo, Sato, Izumi, Miyata, Noa, Kimata, Mari, Fukahori, Hiroki, Yamada, Masako, Home Care Nurses' Provision of Support to Families of the Elderly at the End of Life, Qualitative health research, 21, 199-213, 2011	The study was not conducted in the UK.
Horsfall, Debbie, Leonard, Rosemary, Rosenberg, John P., Noonan, Kerrie, Home as a place of caring and wellbeing? A qualitative study of informal carers and caring networks lived experiences of providing in-home end-of-life care, Health & Place, 46, 58, 2017	The study was not conducted in the UK.
Horsfall, Debbie, Noonan, Kerrie, Leonard, Rosemary, Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities, Health Sociology Review, 21, 373-382, 2012	The study was not conducted in the UK.
Jacinto, George A., The Self-Forgiveness Process of Caregivers After the Death of Care-Receivers Diagnosed With Alzheimer's Disease, Journal of Social Service Research, 36, 24-36, 2010	The study was not conducted in the UK.
Jones, L., Candy, B., Davis, S., Elliott, M., Gola, A., Harrington, J., Kupeli, N., Lord, K., Moore, K., Scott, S., Vickerstaff, V., Omar, R. Z., King, M., Leavey, G., Nazareth, I., Sampson, E. L., Development of a model for integrated care at the end of life in advanced dementia: A whole	Not a qualitative study design.

Study	Reason for exclusion
systems UK-wide approach, Palliative Medicine, 30, 279-95, 2016	
Kwak, Jung, Salmon, Jennifer R., Acquaviva, Kimberly D., Brandt, Katherine, Egan, Kathleen A., Benefits of Training Family Caregivers on Experiences of Closure During End-of-Life Care, Journal of Pain and Symptom Management, 33, 434-445, 2007	The study was not conducted in the UK.
Lander, Dorothy, Graham-Pole, John, Love medicine for the dying and their caregivers: the body of evidence, Journal of Health Psychology, 13, 201-212, 2008	The study was not conducted in the UK.
Magill, L., The spiritual meaning of pre-loss music therapy to bereaved caregivers of advanced cancer patients, Palliative & Supportive Care, 7, 97-108, 2009	The study was not conducted in the UK.
Magill, Lucanne, Hesser, Barbara, The spiritual meaning of music therapy after the death of a loved one: A qualitative study of surviving caregivers, 3247763, 205, 2007	The study was not conducted in the UK.
McKay, E. A., Taylor, A. E., Armstrong, C., "What she told us made the world of difference": carers' perspectives on a hospice at home service, Journal of Palliative Care, 29, 170-7, 2013	Non-Uk study.
McLaughlin, D., Sullivan, K., Hasson, F., Hospice at home service: the carer's perspective, Supportive Care in Cancer, 15, 163-70, 2007	Low richness postal survey rather than qualitative study.
Morbey Hazel, et al.,, Age UK: supporting older carers of those nearing the end of life, 61, 2013	No discernible qualitative analysis.
National Council For Palliative, Care, Who cares? Support for carers of people approaching the end of life: a discussion based on a conference held on 6th November 2012, 20, 2013	Not a qualitative study design.
Newbury, Margaret J., The carerâ€ ™s initiation: a qualitative study of the experience of family care of the dying, U601111, 1, 2009	General focus on carers caring for dying renal patients with no specific focus on providing practical support for carers.
O'Connor, L., Gardner, A., Millar, L., Bennett, P., Absolutely fabulous--but are we? Carers' perspectives on satisfaction with a palliative homecare service, Collegian: Journal of the Royal College of Nursing, Australia, 16, 201-9, 2009	Non-UK study.
O'Kelly Allison, et al.,, Advance planning for end of life care, Journal of Dementia Care, 23, 30-33, 2015	Not a qualitative study design.
Orzeck Pam, Silverman Marjorie, Recognizing post-caregiving as part of the caregiving career: implications for practice, Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community, Welfare and the Community, 211-220, 2008	Not a qualitative study design.
Palliative,, End Of Life Care Priority Setting, Partnership, Palliative and end of life care Priority Setting Partnership (PeolcPSP): putting patients, carers and clinicians at the heart of palliative and end of life care research, 28, 2015	Not a qualitative study design.
Papadatou, Danai, Caregivers in Death, Dying, and Bereavement Situations: International Work Group on	The study was not conducted in the UK.

Study	Reason for exclusion
Death, Dying, and Bereavement, Death Studies, 30, 649-663, 2006	
Peacock, S., Duggleby, W., Koop, P., The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia, Palliative & supportive care, 12, 117-26, 2014	The study was not conducted in the UK.
Pearce, Michelle J., Singer, Jerome L., Prigerson, Holly G., Religious coping among caregivers of terminally ill cancer patients: main effects and psychosocial mediators, Journal of Health Psychology, 11, 743-760, 2006	The study was not conducted in the UK.
Peel, E., 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': representations of dementia in print media and carer discourse, Sociology of health & illness, 36, 885-901, 2013	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Phillips, Linda R., Reed, Pamela G., End-of-Life Caregiver's Perspectives on their Role: Generative Caregiving, The Gerontologist, 50, 204-214, 2010	The study was not conducted in the UK.
Piemonte, Nicole Marie, Fisher, Carla, The Contradictions of Caregiving, Loss, and Grief during Emerging Adulthood: An Autoethnography and Qualitative Content Analysis, 1483446, 143, 2010	Full text is a dissertation.
Pleschberger, Sabine, Wosko, Paulina, From neighbour to carer: An exploratory study on the role of non-kin-carers in end-of-life care at home for older people living alone, Palliative Medicine, 31, 559-565, 2017	The study was not conducted in the UK.
Preston, H., Fineberg, I. C., Callagher, P., Mitchell, D. J., The preferred priorities for care document in motor neurone disease: views of bereaved relatives and carers, Palliative Medicine, 26, 132-8, 2012	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Proot, Ireen M., Abu-Saad, Huda Huijer, Crebolder, Harry F., Goldsteen, Minke, Luker, Karen A., Widdershoven, Guy A., Vulnerability of family caregivers in terminal palliative care at home: Balancing between burden and capacity, Scandinavian Journal of Caring Sciences, 17, 113-121, 2003	The study was not conducted in the UK.
Reyniers, Thijs, Houttekier, Dirk, Cohen, Joachim, Pasman, H. Roeline, Deliens, Luc, The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers, Health and Place, 27, 77-83, 2014	The study was not conducted in the UK.
Richardson, Virginia E., Length of Caregiving and Well-Being among Older Widowers: Implications for the Dual Process Model of Bereavement, Omega, 61, 333, 2010	The study was not conducted in the UK.
Riley Jaqueline, Fenton Gaynor, A terminal diagnosis: the carers' perspective, Counselling and Psychotherapy Research, 7, 86-91, 2007	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Roberts, Louise, Ending care relationships: carer perspectives on managing 'endings' within a	Population to exclude: adult carers of young people (16<)

Study	Reason for exclusion
part-time fostering service, Adoption and Fostering, 35, 20-28, 2011	
Ross, L., Austin, J., Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers, Journal of nursing management, 23, 87-95, 2015	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Rowland, Christine, Hanratty, Barbara, Pilling, Mark, van den Berg, Bernard, Grande, Gunn, The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures, Palliative Medicine, 31, 346-355, 2017	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Russell, Cherry, Middleton, Heather, Shanley, Chris, Dying with dementia: The views of family caregivers about quality of life, Australasian journal on ageing, 27, 89-92, 2008	The study was not conducted in the UK.
Sammut Anne, Teaching family carers about dying, death and grief, Journal of Dementia Care, 13, 24-25, 2005	Not a qualitative study design
Sanders Sara, Caregiver grief in end-stage dementia: using the Marwit and Meuser Caregiver Grief Inventory for assessment and intervention in social work practice, Social Work in Health Care, 46, 47-65, 2007	The study was not conducted in the UK.
Sanders, S., VOICES OF THE DYING AND THEIR CAREGIVERS : QUALITATIVE ACCOUNTS OF PSYCHOLOGICAL, EMOTIONAL, RELATIONAL AND SPIRITUAL EXPERIENCES, The Gerontologist, 44, 69, 2004	The study was not conducted in the UK.
Sanders, Sara, Ott, Carol H., Kelber, Sheryl T., Noonan, Patricia, The Experience of High Levels of Grief in Caregivers of Persons with Alzheimer's Disease and Related Dementia, Death Studies, 32, 495-523, 2008	The study was not conducted in the UK.
Sano, T., Maeyama, E., Kawa, M., Shirai, Y., Miyashita, M., Kazuma, K., Okabe, T., Family caregiver's experiences in caring for a patient with terminal cancer at home in Japan, Palliative & supportive care, 5, 389-95, 2007	The study was not conducted in the UK.
Sautter, J. M., Tulsky, J. A., Johnson, K. S., Olsen, M. K., Burton-Chase, A. M., Lindquist, J. H., Zimmerman, S., Steinhauser, K. E., Caregiver experience during advanced chronic illness and last year of life, Journal of the American Geriatrics Society, 62, 1082-90, 2014	The study was not conducted in the UK.
Schroepfer Tracy A, Social relationships and their role in the consideration to hasten death, Gerontologist, 48, 612-621, 2008	The study was not conducted in the UK.
Schroepfer Tracy A, N. O. H. Hyunjin, Terminally ill elders' anticipation of support in dying and death, Journal of Social Work in End-of-Life and Palliative Care, 6, 73-90, 2010	The study was not conducted in the UK.
Scottish Partnership For Palliative, Care, Living and dying with advanced heart failure: a palliative care approach, 49p., 2008	Not a qualitative study design
Selman, L., Beynon, T., Higginson, I. J., Harding, R., Psychological, social and spiritual distress at the end of life in heart failure patients, Current Opinion in Supportive & Palliative Care, 1, 260-6, 2007	Review study, which is an excluded study design. References have been handsearched for relevant studies.

Study	Reason for exclusion
Seow, H., Bainbridge, D., Bryant, D., Guthrie, D., Urowitz, S., Zwicker, V., Marshall, D., The CaregiverVoice Survey: A Pilot Study Surveying Bereaved Caregivers to Measure the Caregiver and Patient Experience at End of Life, Journal of Palliative Medicine, 19, 712-719, 2016	The study was not conducted in the UK.
Shanley, Chris, Russell, Cherry, Middleton, Heather, Simpson-Young, Virginia, Living through end-stage dementia, Dementia: The International Journal of Social Research and Practice, 10, 2011	The study was not conducted in the UK.
Shin, Dong Wook, Cho, Juhee, Kim, So Young, Chung, Ik Joo, Kim, Sam Soo, Yang, Hyung Kook, Ahn, Eunmi, Park, Bo Ram, Seo, Hongwan, Park, Jong-Hyock, Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices, Psycho - Oncology, 24, 212, 2015	The study was not conducted in the UK.
Silverberg, Eleanor, Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, assess and assist, Omega: Journal of Death and Dying, 54, 215-235, 2007	The study was not conducted in the UK.
Singer, Yoram, Bachner, Yaacov G., Shvartzman, Pesach, Carmel, Sara, Home death-The caregivers' experiences, Journal of Pain and Symptom Management, 30, 70-74, 2005	The study was not conducted in the UK.
Small, N., Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S., Dying, death and bereavement: A qualitative study of the views of carers of people with heart failure in the UK, BMC Palliative Care, 8 (no pagination), 2009	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Smith, Paula, The family caregivers journey in end-of-life care: Recognizing and identifying with the role of carer, International Journal on Disability and Human Development, 8, 67-73, 2009	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Social Care Institute For, Excellence, Moriarty Jo, et al.,, SCIE research briefing 40: end of life care for people with dementia living in care homes, 24p., 2012	Not a qualitative study design.
Stafford, Mai, Bendayan, Rebecca, Tymoszuk, Ula, Kuh, Diana, Social support from the closest person and sleep quality in later life: Evidence from a British birth cohort study, Journal of Psychosomatic Research, 98, 1, 2017	Not a qualitative study design.
Stajduhar, K. I., Martin, W., Cairns, M., What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients, Palliative and Supportive Care, 8, 277-289, 2010	The study was not conducted in the UK.
Stajduhar, Kelli I., Funk, Laura, Outcalt, Linda, Family caregiver learning-how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets, Palliative Medicine, 27, 657-664, 2013	The study was not conducted in the UK.
Strang, John, Manning, Victoria, Mayet, Soraya, Titherington, Emily, Offor, Liz, Semmler, Claudia, Williams, Anna, Family carers and the prevention of heroin overdose	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of

Study	Reason for exclusion
deaths: Unmet training need and overlooked intervention opportunity of resuscitation training and supply of naloxone, Drugs: Education, Prevention & Policy, 15, 211-218, 2008	life, and after the death, of the person receiving care.
Sundar, Vidyalakshmi, Fox, Susan W., Phillips, Kimberly G., Transitions in caregiving: Evaluating a person-centered approach to supporting family caregivers in the community, Journal of Gerontological Social Work, 57, 750-765, 2014	Not a qualitative study design.
Taylor, Sandra Loraine, Transcending death by living: Needs of rural Manitoba women caregivers providing care for their spouses (common law or life partners) with terminal cancer at home, AAIMR49074, 3302	Full text is a dissertation.
Turner Mary, et al.,, Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences, Age and Ageing, 45, 421-426, 2016	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Ventura Mde, M., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Sao Paulo Medical Journal = Revista Paulista de MedicinaSao Paulo Med J, 134, 93-4, 2016	Not a qualitative study design.
Vlachogianni, A., Efthymiou, A., Potamianou, D., Sakka, P., Orgeta, V., Life after care: psychological adjustment to bereavement in family carers of people with dementia, International Psychogeriatrics, 28, 815-23, 2016	The study was not conducted in the UK.
Waldrop, Deborah P., Kusmaul, Nancy, The Living-Dying Interval in Nursing Home-Based End-of-Life Care: Family Caregivers' Experiences, Journal of Gerontological Social Work, 54, 768, 2011	The study was not conducted in the UK.
Ward-Griffin, Catherine, McWilliam, Carol L., Oudshoorn, Abram, Relational experiences of family caregivers providing home-based end-of-life care, Journal of Family Nursing, 18, 491-516, 2012	The study was not conducted in the UK.
Weibull, A., Olesen, F., Neergaard, M. A., Caregivers' active role in palliative home care - To encourage or to dissuade? A qualitative descriptive study, BMC Palliative Care, 7 (1) (no pagination), 2008	The study was not conducted in the UK.
Wheeler, C., Anstey, S., Lewis, M., Jeynes, K., Way, H., The effect of education on community nursing practice in improving the patient-carer experience at the end of life, British journal of community nursing, 19, 284-290, 2014	Study did not relate to the phenomenon of interest - the support needs of adult carers at the end of life, and after the death, of the person receiving care.
Whitehead, B., O'Brien, M. R., Jack, B. A., Mitchell, D., Experiences of dying, death and bereavement in motor neurone disease: A qualitative study, Palliative Medicine, 26, 368-378, 2012	General focus on carers caring for people with Motor Neurone Disease with no specific focus on providing practical support for carers.
Williams, Sharon W., Zimmerman, Sheryl, Williams, Christianna S., Family Caregiver Involvement for Long-Term Care Residents at the End of Life, Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 67B, 595-604, 2012	The study was not conducted in the UK.

Study	Reason for exclusion
Wiszniak, Debra, Geller, Gloria, A qualitative study exploring quality of life of informal caregivers caring for someone with a terminal illness, MQ82643, 197, 2003	Full text is a dissertation.
Woodman, C., Baillie, J., Sivell, S., The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence, BMJ supportive & palliative care, 6, 418-429, 2016	Review study, which is an excluded study design. References have been handsearched for relevant studies.
Yektatalab, Sh, Kaveh, M. H., Sharif, F., Khoshknab, M. Fallahi, Petramfar, P., Characteristics of Care and Caregivers of Alzheimer's Patients in Elderly Care Homes: A Qualitative Research, Iranian Red Crescent Medical Journal, 14, 294-299, 2012	The study was not conducted in the UK.
Young Amanda J, Rogers Angie, Addington-Hall Julia M, The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: a retrospective survey of surviving family and friends using the Views of Informal carers Evaluation of Services questionnaire, Health and Social Care in the Community, 16, 419-428, 2008	Not a qualitative study design: survey
Yun, Y. H., Lee, M. K., Chang, Y. J., You, C. H., Kim, S., Choi, J. S., Lim, H. Y., Lee, C. G., Choi, Y. S., Hong, Y. S., Kim, S. Y., Heo, D. S., Jeong, H. S., The life-sustaining treatments among cancer patients at end of life and the caregiver's experience and perspectives, Supportive Care in Cancer, 18, 189-96, 2010	The study was not conducted in the UK.

Economic component of the review

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. The table below is a list of excluded studies across the entire guideline and studies listed were not necessarily identified for this review question.

Table 25: Excludies studies from the economic component of the review

Study	Reason for Exclusion
Arksey Hilary, et al.,, Review of respite services and short-term breaks for carers for people living with dementia: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation	Study design: This report is a review, and reviews are excluded. References could not be hand-searched as there was no reference list included in the report.
Arts, E. E., Landewe-Cleuren, S. A., Schaper, N. C., Vrijhoef, H. J., The cost-effectiveness of substituting physicians with diabetes nurse specialists: a randomized controlled trial with 2-year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	Population of interest: the study focus is primarily on patients.
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial:	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lowson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised controlled trial with resource use and cost study, Age & AgeingAge Ageing, 38, 2009	This cost analysis is focused primarily on patients.
Gardiner, Clare, Brereton, Louise, Frey, Rosemary, Wilkinson-Meyers, Laura, Gott, Merryn, Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review, Health & Social Care in the Community, 24, 519-531, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Gitlin LN, Hodgson N, Jutkowitz E, Pizzi L. The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: the tailored activity program. Am J Geriatr Psychiatry 2010;18(6):510-9.	Economic evaluation conducted in the USA.
Gomes, B., Calanzani, N., Curiale, V., McCrone, P., Higginson, I. J., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Cochrane Database of Systematic Reviews, 2016 (3) (no pagination), 2013	Study design - this review of HE studies has been excluded for this guideline - but its references have been checked for any relevant HE study.
Gomes, Barbara, Calanzani, Natalia, Higginson, Irene J., Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers, JAMA: Journal of the American Medical Association, 311, 1060-1061, 2014	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Heslin, M., Forster, A., Healey, A., Patel, A., A systematic review of the economic evidence for interventions for family carers of stroke patients, Clinical Rehabilitation, 30, 119-33, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE study.
Hoefman, R. J., van Exel, J., Brouwer, W. B., Measuring Care-Related Quality of Life of Caregivers for Use in Economic Evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US, PharmacoEconomics, 35, 469-478, 2017	No intervention of interest.
Huter, K., Kocot, E., Kissimova-Skarbek, K., Dubas-Jakobczyk, K., Rothgang, H., Economic evaluation of health promotion for older people-methodological problems and challenges, BMC Health Services Research, 16 Suppl 5, 328, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones Carys, Edwards Rhiannon Tudor, Hounsome Barry, A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones, C., Edwards, R. T., Hounsome, B., Health economics research into supporting carers of people living with dementia:	Study design - this review of HE studies has been excluded for this guideline - but its references have

Study	Reason for Exclusion
A systematic review of outcome measures, Health and Quality of Life Outcomes, 10 (no pagination), 2012	been hand-searched for any relevant HE studies.
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, Value in Health, 13, 720-5, 2010	Economic evaluation conducted in the USA.
Kenealy, T. W., Parsons, M. J., Rouse, A. P., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K., Masson, S. C., Rea, H. H., Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation, PLoS ONE [Electronic Resource], 10, e0116188, 2015	Population of interest: the study focus is primarily on patients.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, American Journal of Managed Care, 15, 521-528, 2009	Population of interest: the study focus is primarily on patients.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people living with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial (Structured abstract), Bmj, 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijsbers, H. J., Hendriks, E. J., Bartelink, M. L., de Bie, R. A., Teijink, J. A., The ClaudicatioNet concept: design of a national integrated care network providing active and healthy aging for patients with intermittent claudication, Vascular Health & Risk Management, 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, Supportive Care in Cancer, 21, 3461-9, 2013	Not the intervention of interest: This study estimates lost productivity and informal caregiving and associated costs among partner caregivers of localized prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and costs of the informal carers in patients with tele-monitoring of pacemakers: the PONIENTE study, Clinical Research in Cardiology, 105, 307-313, 2016	Not the intervention of interest: aim of this study was to assess the burden borne by and the costs to informal carers of patients with remotely monitored pacemakers.
Magnusson, L., Hanson, E., Supporting frail older people and their family carers at home using information and communication technology: cost analysis, Journal of advanced nursing, 51, 645-57, 2005	This cost analysis uses a case study methodology involving 5 families, cost and resource usage are not reported separately for carers and patients.
Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., Glendinning, C., A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people	Study design - this review of HE studies has been excluded for this guideline (but its references have

Study	Reason for Exclusion
and their carers, Health Technology Assessment (Winchester, England), 11, 1-157, iii, 2007	been hand-searched for any relevant HE studies.
Mason, Anne, Weatherly, Helen, Spilsbury, Karen, Golder, Su, Arksey, Hilary, Adamson, Joy, Drummond, Michael, The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People, Journal of the American Geriatrics Society, 55, 290-299, 2007	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Menn P, Holle R, Kunz S, Donath C, Lauterberg J, Dementia care in the general practice setting: a cluster randomized trial on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	Population of interest: no primary focus on carers.
Morgan, R. O., Bass, D. M., Judge, K. S., Liu, C. F., Wilson, N., Snow, A. L., Pirraglia, P., Garcia-Maldonado, M., Raia, P., Fouladi, N. N., Kunik, M. E., A break-even analysis for dementia care collaboration: Partners in Dementia Care, Journal of General Internal Medicine, 30, 804-9, 2015	Population of interest: the study focus is primarily on patients.
Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	This economic evaluation was conducted in the USA.
Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs. J Am Geriatr Soc. 2017 May;65(5):931-936	This economic evaluation was conducted in the USA.
Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E. D., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I. T., de Waal, H., Woods, R. T., Orrell, M., Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial, Health Technology Assessment (Winchester, England), 19, 1-108, 2015	Population of interest: the study focus is primarily on patients.
Patel, A., Forster, A., Young, J., Nixon, J., Chapman, K., Knapp, M., Mellish, K., Holloway, I., Farrin, A., Cluster randomised trial evaluation of a patient and carer centred system of longer-term stroke care (the LoTS care trial): Economic evaluation, Cerebrovascular Diseases, 35, 584, 2013	Conference abstract.
Pickard, Linda, The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission, 2004	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Quinn, C., Anderson, D., Toms, G., Whitaker, R., Edwards, R. T., Jones, C., Clare, L., Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and cost-effectiveness of a self-management group intervention (the SMART study), Trials [Electronic Resource], 15, 74, 2014	Research protocol.

Study	Reason for Exclusion
Romeo, R., Knapp, M., Banerjee, S., Morris, J., Baldwin, R., Tarrier, N., Pendleton, N., Horan, M., Burns, A., Treatment and prevention of depression after surgery for hip fracture in older people: cost-effectiveness analysis, Journal of Affective Disorders, 128, 211-9, 2011	Population of interest: no adult carers.
Sandberg, M., Jakobsson, U., Midlov, P., Kristensson, J., Cost-utility analysis of case management for frail older people: effects of a randomised controlled trial, Health Economics Review, 5 (1) (no pagination), 2015	Population of interest: no adult carers.
Schepers, J., Annemans, L., Simoens, S., Hurdles that impede economic evaluations of welfare interventions, Expert Review of Pharmacoeconomics & Outcomes Research, 15, 635-42, 2015	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Søgaard R, Sørensen J, Waldorff FB, Eckermann A, Buss DV, Early psychosocial intervention in Alzheimer's disease: cost utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	Population of interest: no primary focus on carers.
Sogaard, R., Sorensen, J., Waldorff, F. B., Eckermann, A., Buss, D. V., Waldemar, G., Private costs almost equal health care costs when intervening in mild Alzheimer's: a cohort study alongside the DAISY trial, BMC Health Services Research, 9, 215, 2009	Study findings updated by a more recent HE study (Søgaard 2014)
Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., Scott, S., Costs and caregiver consequences of early supported discharge for stroke patients, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on patients.
Toseland RW, Smith TL. The impact of a caregiver health education program on health care costs. Research on Social Work Practice 2006;16(1):9–19.	This economic evaluation was conducted in the USA.
Vicente, C., Sabapathy, S., Formica, L., Maturi, B., Piwko, C., Cost-utility analysis of tocilizumab in the treatment of active systemic juvenile idiopathic arthritis, Value in Health, 16 (3), A225, 2013	Not the intervention of interest: The objective of this HE study is to determine the cost-effectiveness of tocilizumab with or without methotrexate compared to placebo with methotrexate for the treatment of juvenile idiopathic arthritis.
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S., Mugford, M., Befriending carers of people living with dementia: a cost utility analysis, International Journal of Geriatric Psychiatry, 24, 610-23, 2009	Duplication (Charlesworth 2008).
Wittenberg, E., Prosser, L. A., Disutility of illness for caregivers and families: A systematic review of the literature, Pharmacoeconomics, 31, 489-500, 2013	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.

Study	Reason for Exclusion
Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., Gao, J., The effect of telephone support groups on costs of care for veterans with dementia, Gerontologist, 50, 623-31, 2010	Population of interest: no adult carers.

Appendix M – Quotes extracted from the included papers, which support the qualitative review findings

Ashton 2016

- **“The experience of ACP”** - ‘‘I wasn’t sure what she meant at first and thought it was some sort of agreement to stop any treatment. But Xxxxx explained it to me that it was to find out what XXX would have preferred at the end of his life. I must say I was a bit upset at first to be talking about this. I did not want XXX to think I wanted him to die but he didn’t know anyway. It did feel a bit uncomfortable”. (Wife 3)
- **“The relevance of ACP for people with advanced dementia (it was their responsibility)”** - ‘‘I would say, it removed a lot of the uncertainty, that perhaps hadn’t the advance planning been done, all of a sudden you’ll be faced with a decision, it would be at a time perhaps when you’re not emotionally prepared for it, and it would be a bit too much at that stage. At least if you’ve planned it, I thought it helped, in my case, I discussed what was going to happen, how best end of life can be dealt with in terms of making her life as easy as possible really”. (Son 2)
- **“The relevance of ACP for people with advanced dementia (it allowed them to confront the important decisions)”** - ‘‘I wonder about doing the right thing as I did not have a lot of contact with her up until she became ill so I try and think about what she would have wanted when she was younger or what I would have liked. I also think about how our parents died. I suppose you just have to do the best you can”. (Brother 1)
- **“Content of the ACP interviews”** - ‘‘We talked about drips and tubes and pain relief. XXXXX was as blunt as she could be without making it sound as though she was trying to influence our decisions. We talked about if withholding treatment would make her suffer”. (Niece 1)
- **“Content of the ACP interviews”** - ‘‘We have been saying goodbye to grandma for over 10 years because my grandma’s gone! You get little glimpses of her but she’s not there anymore. You know? She doesn’t play her music anymore she doesn’t play her Black Sabbath at full volume and dance round the kitchen like she use to ... and that’s at 80 ... She can’t get on the back of the boys bikes anymore ... ‘‘She’s not there’’. Which is sad?’’ (Granddaughter 1)
- **“A deviant case - not all carers will be ready and willing”** - ‘‘Oh that (ACP), she tried to say it was some scheme they were involved in and that I needed to talk about what XXXX would want if he became very ill. He is going to get very ill if he stays like this. I don’t know what she was talking about. I think XXXX is getting depressed in there. I don’t want to talk about it, that would be like giving up and I haven’t given up”. (Wife 4)

Jack 2015

- **“Impact on the carers - a valued presence (felt they would be lost without them)”** - If I didn’t have that service...I would probably feel very, well more vulnerable than what I felt – although I did feel vulnerable – a lot more vulnerable, and a lot more anxious, and probably very alone and lost, and isolated”. (Respondent 4, Husband aged 50–59)
- **“Impact on the carers - a valued presence (drew comfort from their presence)”** - "And I kind of knew when they were there, that she would be fine”. (Respondent 20, Daughter aged 40–49)"

- **“Impact on the carers - a valued presence (encouragement that they were giving the right care)”** - Made me feel that we were doing everything we should do, there’s always a doubt in your mind that “oh, what if?”, “should I do this; should I do that?”, but they allowed you to stand back and think “actually, there isn’t anything else that we can do; this is the best it is....” (Respondent 1, Wife aged 60–69)
- **“Impact on the carers - a valued presence (better experience at the moment of passing)”** - I valued that somebody was here the night he died, because the nurse called us when she thought it was time, so my daughter and I were with him”. (Respondent 18, Wife aged 80–89)
- **“Impact of the carers - in good hands (respite)”** - "They saved my life... I could go out without worrying”. (Respondent 12, Wife aged 60–69)
- **“Impact of the carers - in good hands (respite)”** - “I was just very grateful that somebody could come and give me you know a bit of a lift really and give me some time to just have a sleep and time to just get out into the fresh air and see normal people”. (Respondent 10, Wife aged 70–79)"
- **“Impact of the carers - in good hands (more quality time)” -** "The [HAH] night girl, she did the ironing for me – it sounds like such a simple little thing – but it meant the next day instead of sitting doing the ironing I took mum out for the day, and just being able to do that was just ... it was just so nice. And it’s one of my favourite memories as well, and she did that a few times for us... it just meant that we made the most of that time”. (Respondent 3, Daughter aged 20–29)"
- **“Impact of the carers - in good hands (qualities of the staff)”** - I mean, I had the comfort of knowing that she was with somebody... of sufficient experience ... to know what to do if anything turned out for the worst you know, and it was good to know that I was going out for a couple of hours to get the shopping and what not and they, that person was here with her which was a of comfort to me and her as well”. (Respondent 5, Husband aged 70–79)
- **“Impact of the carers - in good hands (hard to accept help)”** - "I should be doing this, the whole point of bringing her home was you know, I should be doing this”. (Respondent 16, Daughter aged 50–59)
- **“Impact of the carers - in good hands (hard to accept help)”** - It’s very difficult to let go of what you think is your responsibility”. (Respondent 16 daughter aged 50–59)"
- **“Impact of the carers - support a normal life (family activities)”** - "That’s the thing, ‘cause there was always the tug, you know between rugby practice or going and looking after M – and obviously M would win out every time – but it meant that the boys could carry on with their activities”. (Respondent 2, Daughter-in-Law aged 50–59)"
- **“Impact of the carers - support a normal life (business activities)”** - "Without them I probably would have lost, you know I would have had to give up work or something and then being self-employed and it being your own business...it’s not something you can get back”. (Respondent 20, Daughter aged 40–49)"

Briggs 2010

- **“Patients and carers views (disjointed services)” -** ‘[Have there been] improvements? Reverse the drift of NHS policy. I think much of the recent reforms have been counter productive in this direction because they try to open up to private companies so they loosened the connection between patient and practice but if [the] patient registered with

[a] doctor it would be better. The result has broken the relationship between GP and patient. When… bureaucratic systems are prioritised, the patient suffers – this is my experience of how the NHS works.' GP

- **"Developing tense emotions in the course of care"** - 'time that was left' 'fighting'
- **"The complex social relations between carers and patients, and professionals (being dismissed)"** - '[They are] so focused in care for that person [the carer] and a lot of knowledge they have can get dismissed because they are seen as not medical or not qualified but sometimes if they do ask a lot or challenge, they will almost get labelled as the difficult family.' Shirley
- **"The complex social relations between carers and patients, and professionals (being labelled as 'difficult')"** - 'You feel that you can't say too much in case you are perceived as someone who is creating too much fuss and they don't want to have anything to do with you. I know they tell you a lot of things but there needs to be openness.'
- **"The complex social relations between carers and patients, and professionals (homecare and privacy)"** - 'It is too much, you have no privacy, no control over what is happening and if you have control, you have to fight for what you want and this is the situation.' Monique
- **"The complex social relations between carers and patients, and professionals (sacrifice of providing care at home)"** - 'I could cope up to a point with the care and the job but then it got too difficult and I decided to take the pay severance. They didn't really give me much choice but what can you do, it is just me, I am the only son, Dad is dead so, I just stopped working.' Jack
- **"The complex social relations between carers and patients, and professionals (going well)"** - 'It is reassuring that I can live my life knowing that my dad is being cared for. While I want to be around him as much as possible, it is not always healthy… that's not to say I don't want to be with him but the carer and the responsibility they have takes a lot of that away from me.' Henry (2)
- **"The complex social relations between carers and patients, and professionals (first impressions for trust)"** - 'There is no rehearsal. We have a one-off shot to get it right and unfortunately services just don't understand that and what happens is the patients, once you have not turned up for an appointment or turned up two hours late, you have lost trust in that patient and family. They then tend not to trust anyone else.'
- **"The complex social relations between carers and patients, and professionals (dignity)"** - 'some carers used to go with him and engage with him, treat him like he was normal but others just thought "this person is not going to get it" because he was in a wheelchair and found it difficult to communicate'

Caswell 2015

- **"Perceived limitations to carers' understanding (capacity)"** - We know you come to a medical consultation and you remember twenty percent of it, you may remember the doctor's face, you may remember a sentence of what the doctor said…you may remember nothing at all. You go and dutifully write it all down in the notes and the relatives have a completely different recollection of what was said". (Consultant, Ash)
- **"Perceived limitations to carers' understanding (repeat conversations)"** - I think there's probably levels of acceptance, and maybe as nurses and practitioners and

doctors, we think, because we've had one conversation where we've said very clearly, He's coming to the end of his life, and it could just be a matter of days now…and they nod and they say Yes, okay, that doesn't mean to say that that's been fully accepted or processed by them…you might need to have the conversation again, but obviously, nurses and doctors don't want to have that conversation every day, and you think if it's happened once, why would you go there with someone? (Staff Nurse, Oak)

- **"Carers' perspectives"** - When the dying patient was placed in a side room it was easier for their family to spend time with them without being disturbed by the routine work of the ward. However, when patients remained in the open bay visiting, it was potentially distressing for family members, some of whom were also concerned about being a source of discomfort for other people on the ward.
- **"Receiving bad news: Clarity"** - And the doctor had pre-warned me that the end of somebody's life through fibrosis isn't pleasant both for any party…on the night that he was dying, I thought they were very, very good…when we came, obviously, they knew when we came in, what the situation was". (Daughter of PNCO206, an 86 year old male patient)
- **"Receiving bad news: Clarity (Inclusion in decision)"** - And dad hadn't been eating and drinking for a long while and there was problems again with his aspiration so he, he (consultant) felt really that he was at the end of his life so we, we took a decision to withdraw… any sort of feeding… you know, it was dad's time, and really, it was dad's time". (Daughter of PNCO203, an 85 year old male patient)
- **"Receiving bad news: Lacking clarity (not realising until later)"** - I'm not too sure when I actually realised it, when it hit me when I was on my way back to the house, but I'm not sure quite when I realised it, yeah. I think they did actually. I think they did. Because I had a little chat with them at one point. And, (…) I think they did tell me that actually … (Male partner of PNCA401, a 96 year old female patient).
- **"Receiving bad news: Lacking clarity (misinterpreting information)"** - (she said, he's) 'really poorly'. I said, 'Yes, clearly, I realise that, we've been through this many times before.' And she said 'Well, we don't think he'll pull through this time.' So, that was a shock… So, anyway, about three o'clock in the morning, he kept waking up, and was sitting holding his hand and he was squeezing my hand really hard and I thought, No, this isn't what a dying man is, he's too strong, he's fighting this again". (Wife of PNCA403, a 63 year old male patient)
- **"Receiving bad news: Lacking clarity (vagueness)"** - When there was a lack of clarity in communication, whether through the use of euphemistic or vague language, this could lead carers to develop or perpetuate expectations which health professionals would realise were unrealistic
- **"Seeking a hearing"** - Only because, you could never get hold of anybody. I mean, they were so busy. I mean, sometimes you'd think, 'Where are they?' (Daughter of PNCO206, an 86 year old male patient)
- **"Feeling abandoned"** - But he didn't take more than like, less than a minute, less than half a second, so I pulled the curtain round and I sit with him for five minutes til he completely take the last breath. But the problem is, what irritates me, because I couldn't find anybody. Because the time …at that time, I just need somebody to be there". (Partner of PNCO205, a 68 year old male patient)

Dosser 2014

- **“Findings of a communication skills intervention (nurses felt more confident)” -** "‘Usually on a Friday night I would go home, open a bottle of wine and moan to my husband about how awful the week had been. This time I still opened the wine but said what a great week I had and how proud I was of myself for trying out new [interpersonal] skills with patients and families, which had been a great success.’ Staff nurse 5"
- **“Findings of a communication skills intervention (nurses felt more competent)”** - "In the past I believed I needed time to get to know a patient before being able to have meaningful conversation but this time, while assisting in her personal care I was able to ask how her and her family were coping with the bad news received the previous day. This led to a lengthy conversation in which the patient discussed her life and her acceptance that she had led a fulfilling life. I felt able to listen and notfeel scared which I might not have done prior the course.’"
- **“Findings of an environmental intervention”** - ‘A patient died at the weekend in the night and being able to take his wife to sit quietly in the new room, was wonderful.’ Care support worker 1

Dosser 2012

- **“Valuing and respecting (accommodating carers)”** - ‘People themselves [the nurses] are fantastic .. it’s just the system. Even if there had been an ensuite bathroom. There was just the day room for patients. There was a sink in the [patient’s] room but there was no way I was going to [wash and change]. It was a big lack I thought. I know I wanted time on my own, whenever I wasn’t in [the patient’s room] I was in the [patient] day room.’ Carer (C) 4
- **“Valuing and respecting (communicating to carers)”** - I found that period really hard, and maybe the hospital could have given me a bit more support at that point. You’re faced with your husband in that state, but nobody sort of said: “He won’t get well.”’ C3
- **“Valuing and respecting (staff's communication skills)”** - ‘I’ve seen patients maybe trying to ask something about their prognosis and they say .. not blank them off but say .. “Oh no you’re fine, you’re fine”, but they’re not fine, but rather than [have the conversation] .. they sort of hide it from the patient.’ Focus group 2, ward A, staff nurse 1 (FG1 A SN1)
- **“Valuing and respecting (nurses communication style)”** - ‘There is a view that you don’t actually go in and have “that conversation” it’s only maybe if you are in the room dealing with the patient that you do try to have a conversation with the relative.’ FG2 A SN1
- **“Valuing and respecting (nurses communication difficulties came out of context)”** - You know that you should be putting the time and effort into speaking to relatives but you know you’ve not got the time to do it unfortunately .. quite often you don’t know who they are because they haven’t asked to speak to you.’ FG1 A SN1
- **“Valuing and respecting (communication role)”** - ‘Because the family want to hear it from the doctor not the nurses.’ FG1 A SN2

Epiphaniou 2012

- **“Support (at home from nurse)”** - ‘Our palliative nurse tries to do her best. Her encouragement is fantastic. She is such a nice lady to us so we are happy. Whenever she comes we are happy.’ (Ca 15)
- **“Support (from Oncologist)”** - ‘.. we are very lucky because the consultant was very good, very chatty, told us what was going on all the time and they are good.’ (Ca 20)
- **“Support (from GP)”** - ‘I was quite fortunate that my GP helped me a lot and gave me information but without that help I would not know what to do ..’ (Ca 5)
- **“Support (from families and friends)” -** "‘I am lucky I have my family behind me, my husband, my daughters, I got people around me, and my sisters call every week.’ (Ca 3)
- **“Support (from families and friends)” -** ‘I have good friends, two really, really good friends I could rely on and that is what I need.’ (Ca 13)"

Forbat 2012

- **“Relationships”** - It’s pretty much all-consuming really. I mean, it’s not just debilitating for her but it’s debilitating, it’s very difficult for the, for the whole family but especially the ones closely there with her”. (12)
- **“Shift in lifestyle”** - Well, you just feel it’s a massive responsibility, originally I had lived abroad and I more or less came back because my mum wasn’t so well because I didn’t want to be abroad, and my own health wasn’t as good either … I’m not so able because my illnesses are getting worse”. (7)
- **“Factors affecting impact”** - "Interviewer How your wife’s illness has affected both you and your family … what effect that has had on you? Interviewee Eh … it hasn’t … being retired it’s not as though is it, would have affected me in terms of any trauma or any job I had to do”. (6)"
- **“Relationship Difficulties (patient and carer)” -** "At times I think that my husband just sees me as the carer, and I can’t remember what I said once but when he answered me I said, ‘Excuse me, I am your wife first and then your carer!’ (4)
- **“Relationship Difficulties (patient and carer)” -** I turned to mummy and I just swore at her, I said, ‘For so and so’s sake, don’t fucking get a chest infection, because I can’t take it’, and she went, ‘Well, I don’t want one and if I get one it’s not my fucking fault,’ … and I don’t want to speak to my mother like that”. (7)"
- **“Relationship difficulties (wider relationships)” -** [My sister] said ‘You’re not gentle, the girl [paid carer] who’d just left she’s so gentle, you’re not gentle,’ you know, and I was just like, I just, I never do it, I never and, I just went out and I just slammed the door behind me, because you know, I literally go there every morning”. (12)
- **“Relationship difficulties (conceding care)”** - I find it very difficult to leave [daughter] with anybody”. (2)
- **“Support in the context of other family members (caring for others needs)”** - I have got three brothers and there’s times when he’s really low and they’re there and you ask them to help to do something with them and they’re standing there like maybe there’s … he [father] goes through phases where he’s maybe vomiting and [I’ll say] ‘Can you give me a hand to hold him up?’ and they’re standing and they have tears down their face and I’m standing there and I’m looking, thinking ‘For God’s sake, he’s only being sick […] Why,

[laughs], why do my brothers not think like this? Why am I thinking like this? Why [laughs], can I not have a full weekend away? (1)

- **“Support in the context of other family members (relieving others of responsibility)”** - My family’s quite local but they’re not in this town but they’re not far away, if you know what I mean. And they’re, they’re very supportive … but I don’t want to, you know…I don’t want to play on them…We want them to enjoy their lives, we don’t want them sort of stuck. I don’t want them on my doorstep every day. They’ve got to have their own life”. (2)
- **“Living with a Life-Limiting Illness is a Systemic Issue (it's good when practitioners recognise this)”** - He [GP] asks the patient things … I know that he probably thinks that it’s not his job to think of the family … But it’s only once you’ve got someone who is really ill like my husband or with cancer or even in an alcoholic … that the illness affects not just the person, it affects the close friends and family to that person and unless you actually put your hand up and say, ‘I’ve had enough of this.’ (4)
- **“Living with a Life-Limiting Illness is a Systemic Issue (it's bad when practitioners don't recognise this)”** - Doctors tend to talk to the patient … now this is, must be a thing that has come out … I don’t know if it’s been through the … they don’t tend to talk to the carer or the partner or the person looking after them”. (5)

Nelson (2017)

- **“Modes of communication.” - ‘**Several respondents felt that it was important to meet the support worker face-to-face in their own home. All those interviewed emphasised the importance of continual contact whether this is face-to-face or via telephone.’
- **“Modes of communication.” -** ‘Many of the participants acknowledged the difficulty of delivering the service in a predominantly rural county.’
- **“Performance”** - ‘Pretending to be strong and fine was a big part of carers coping strategy’

Newbury 2011

- **“Performance”** - Nicola (current): "You've got to be strong. Strong is the best thing. Don't be weak. Try not to cry and just try and laugh. On the telephone you;ve got to try not to crack up because they can tell it in your voice."
- **“Setting and props”** - Stephen (current): "It wasn't Sarah's wish I knew, but at one stage Ifelt it was being imposed on us.. to be put downstairs in a hospital bed was not what she considered to be hospice at home. Hospice at home was to be as close to me as she could at night, which actually made it easier for me and still does."
- **“Script”** - Naomi (current): "Diane [community palliative care nurse] gave us a couple of leaflets.. the ones on coping with dying were hard to read. It's difficult to accept what it is saying.. but I would rather know so at least it is not unexpected."
- **“Directors” - ‘**Carers wanted professionals to be the 'directors of their performance'.’
- **“Supporting cast”** - Sharon (current): "I've just changed agencies.. I find the whole care thing totally traumatic, very stressful.. they were just, they weren't giving him very much time. The quality of what they were doing was very poor.. the company was a total shambles."
- **“Audience”** - Stephen (current): "Several people in [hospice] have actually told the family that I'm doing a goodjob. Well at least I don't have to blow my own trumpet."

O'Brien 2015

- **“Lack of knowledge”** - The staff need an awful lot more training in how to deal with people suffering MND. They’ve just, there are so many little incidences which show lack of understanding”. (ID215)
- **“Lack of knowledge (having to step in)”** - I was up at the hospital seeing to him and I was directing one or two of the nurses, you can understand how I felt about this, because expert I am not, but I was experienced with him where the nurses were not. So I wasn’t filled with anything except absolute terror really (ID304/ID2)
- **“Lack of knowledge (the right ward)”** - The system doesn’t cater for special cases, or it doesn’t seem to cater for special cases. If you get to the right ward, yes, that’s fine but it’s getting to that ward, that’s the problem and when you go in, in an ambulance, you automatically go in an assessment ward…I think anybody who has got MND should actually be sent to the… [neurology ward] even if it’s to lie on a trolley, at least the nurses there know how to treat them”. (I305/ID7)
- **“Basic care”** - It was filthy… he didn’t have a wash or a shave, for two days, he couldn’t help himself, couldn’t do anything for himself until I went at visiting time the day after and gave him a wash and shave, it wasn’t how you would want your loved one to be looked after”. (ID306)
- **“Reluctance for admission”** - that was another thing, I kept thinking if I look as if I can’t cope they will have him in hospital”. (ID306)
- **“Final memories”** - The last few days, they’ll haunt me for the rest of my life and the thing that pisses me off is it could have been prevented if people had done their job properly and made an effort”. (ID6)

Payne 2015

- **“Decision-making processes in managing end of life medication at home (strategies)” -** ‘I made a copy of all the tablets and the different times he was to have them and which ones […] I made a chart on the computer and just printed it out each time, and that was very helpful.’ [A11 SW Female 60]
- **“Taking responsibility” -** ‘It’s a very big responsibility and I felt helpless because I felt that some things needed increasing and the nurses weren’t there to do it, but at the same time I don’t think it would have been right for me to have total control over it because my head was all over the place. [B01 NW Female 77]
- **“Disagreements with staff about medication” -** ‘I think [the nurses] need to listen to what the carer is saying; they did mostly but generally when I said she needs more sedation and they said ‘well she’s on such and such a dose’, which apparently was quite a big dose but it still wasn’t enough for her.’ [B02 NW Female 57]
- **“Carers’ anxiety about medications”** - ‘I was really anxious just to follow the instructions and I wrote everything down carefully that I had given her. I didn’t attempt to give her an overdose, ‘[B14 NW Male 72]
- **“Perceptions about the effects of morphine” -** "‘I had my arms around him and he was talking to me normal whereas before he’d said some really horrible things, that’s the morphine.’ [A03 SW Female 76]

- **“Perceptions about the effects of morphine”** - ‘[I gave him Oramorph] when he asked for it, I didn’t like to give him all…just when I thought he needed it, which was probably every day. At first I thought ‘Oh shall I use it or not?’ [B15 NW Female 63]"
- **“Rewards in managing end of life medications at home” -** ‘When all the medications ceased, he did become quite rational for about… oh… an hour. He was quite back to his old self and I sat with him and we talked (chuckles). And it was so lovely because he hadn’t known me. And just in that hour he did. And then he drifted off and he wasn’t really conscious anymore after that. [B13 NW Female 83]

Percival 2014

- **“Sensitivity” -** "I couldn’t have managed without them, without the confidence that I knew they were coming in (...) and the people themselves, they must have been trained, they were splendid (...) they were respectful, and gave [husband] all the kindness (...) and he had to be washed by them, and not once did he find it embarrassing or awkward. He accepted it all, because of their attitude; they were treating him gently, and knowing that he was a real true gentleman, with respect, right up until the end. [Mrs. MP]
- **“Sensitivity” -** I think the continuity of the same people coming all the time is good (...) it’s a much smaller team so everybody’s got to know each other. [Mr. NG]."
- **“Consistency” -** I think the continuity of the same people coming all the time is good (...) it’s a much smaller team so everybody’s got to know each other. [Mr. NG].
- **“Proactive and Family-Centered Approaches” -** And I was asked, would you like more help in the evening, just to get him undressed, you see? And I could manage, actually, but it made it easier, made it easier for me (...) we used to call them our earthly angels, because they were, and I couldn’t have coped without them. [Mrs. MP]
- **“Allocation of Sufficient Time to Meet Physical and Emotional Needs of Patients and Family Caregivers” -** I felt with some of the people there [private care agency], that they were so rushed—this was a job, and they wanted to get it done as quickly as possible, and then on to the next job. [Mrs. MV]

PHE 2016

- **“Carers’ needs (spouses, adult child influencers and the bereaved)” -** ‘For me, just to have someone else, another adult that would truly understand what she’s going through and what her needs are, to be able to come and give me a break on a daily basis and I know that I could trust that person that would be a massive thing for me.’ (Carer of person with dementia)
- **“Carers’ needs (spouses, adult child influencers and the bereaved)” -** Carers often thought only of the person with the condition’s needs, or how some of the practical aspects of the care they provided could be supported – eg ‘someone else to get the shopping’. Some also expressed the belief that the carer should 'do it myself' or share needs within the family rather than looking for external help, and seeking external help could sometimes, for some, lead to feeling guilty or a sense of failure
- **“Carers’ needs (spouses, adult child influencers and the bereaved)” -** For others, reported needs focused around the legal and logistical issues related to death eg certification, funeral directors – more support was called for at this stage to help navigate through the process.

- **“Case studies covering support for carers and bereaved people” -** ‘When I was caring for Dad I knew I would miss the old him when he went, but it was awful near the end so I thought I would at least enjoy having my own free time again. I was surprised at what a gulf there was, and how unoccupied my days felt. I actually had to go to counselling over it, and I’ve since taken up volunteering.’ (Bereaved, cared for someone with dementia)

Seamark (2014)

- **“Personal continuity (same carers)” -** "‘Yeah, and most of them we knew because they’d been into my mum quite a lot, and so it’s quite nice when you do know them rather than strangers, though even strangers they’re always very nice. It’s always nicer to have a bit of personal contact.’ (B03 ref1)
- **“Personal continuity (same carers)”** ‘She didn’t like the personal care people very much, erm … and this would be my second criticism really, that there was somebody different virtually every day, you know, and this was quite personal [chuckles] and I mean I certainly didn’t like it.’ (B14 ref1)"
- **“Personal continuity (changes were draining)” -** we had already organised for some helpers to come in, but I left it because I knew [G] would hate it. He would have hated it for the simple reason, when you are very ill, there is something you can’t cope with, having every time somebody else coming, and that would have been the case. And that really was the reason why I felt I didn’t want [G] to put up with this …’ (B17 ref5)
- **“Personal continuity (GP in regular contact)” -** ‘Well [GP1] was absolutely brilliant, he was always on the end of a phone and you know erm whenever we were bothered and troubled by anything and worried because we didn’t know what to do, just ring the surgery, and yeah I mean something would always happen so yeah I can’t speak highly enough of them.’ (A09 ref1)
- **“Personal continuity (ideal scenario)” -** ‘We are looking here about how things could be improved, and one way it could be improved is, if somebody in her position had a personal carer, who perhaps at the initial stage might just come for half an hour a day, but could then perhaps come a bit more as required and that was one person that she got on with, you know, and accepted.’ (B14 ref2)
- **“Informational continuity (pleasant surprise when it works)” -** ‘I rang the emergency doctor. It was a weekend and they said, “Oh yes we were expecting a call from you.” They had all his details there so our GP must have. And that very impressed me, I was extremely impressed, and within half an hour a doctor was at his bedside. And they said, “Oh yes, he needs morphine” and he said, “I’ll arrange it.”’ (B07 ref6)
- **“Informational continuity (insensitive when it fails)” -** ‘And I said you know, “He’s dead”, and she said, “He can’t be.” She said, “I should have heard” and that you know. I mean she sort of stayed for 10 minutes and then went and I never seen her since.’ (A06 ref2)
- **“Informational continuity (frustrating when it fails)” -** ‘I got a little bit exasperated with community nurses, what we used to call district nurses, I think, and somebody’d want to come … big questionnaire — fair enough, to try and assess the needs. Then somebody from Marie Curie came — another questionnaire — and she went away. Then somebody from the hospice came and another one … and it went on like this.’ (B14 ref2)

- **“Informational continuity (unprepared carers)” -** ‘And dozens of different people, and some of them left the company and then new people would come who were as green as grass and would come for so-called training, which wasn’t training. And they knew nothing about the case. They would come and I would say, “Did they explain to you what he is suffering from?” “No, they didn’t say anything.” “Well, he’s suffering from Parkinson’s disease.” “Oh, yes?” you know … didn’t mean a thing to them.’ (B21 ref3)
- **“Organisational continuity (organising care)” -** ‘I found that a bit hard actually to deal with because you get a list of caring companies but they aren’t all what they say they are you know, some of them are just day care centres, some of them are not what you are looking for and it’s quite hard to, sometimes they never rang back when you asked them to, but eventually we did get a company to come and we sorted it out and they came.’ (A01 ref2)
- **“Organisational continuity (knowing who to call)”** - ‘In fact, that’s another thing: they could make clearer in a way at the beginning what’s their job and what isn’t, because I’d never had help before and I didn’t know, I really didn’t know what they were there to do in the beginning. I mean I’d cared for himself, and it was … I still wanted to do it, you know, I was … and it took me a while to realise that’s their job, you leave them alone, you know … washing him and, you know, things like that. I used to try and get him toileted before they came because I thought it’s not a nice job to ask anyone to do, and then I found out, you know, that was on their rota and they didn’t mind it at all. So it would be nice if you knew at the beginning, you know.’ (B13 ref8)
- **“Organisational continuity (out of hours)”** - I have a reluctance to ring the doctor at weekend but the support you get nowadays from out-of-hours doctors doesn’t seem to be, well certainly our experience, and my daughter-in-law, it seems to be a thing that I’d avoid, is ringing the doctor at a weekend if you possibly can.’ (B03 ref2)