

End of life care for adults: service delivery

[G] Evidence review: Involving carers

NICE guideline NG142

Evidence review

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Final

*Developed by the National Guideline Centre,
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1 Barriers and facilitators to the involvement of carers

1.1 Review question: What are the barriers and facilitators to the involvement of carers of (or people important to) those in their last year of life in planning and decision making?

1.2 Introduction

The General Medical Council states ‘The people close to a patient can play a significant role in ensuring that the patient receives high-quality care as they near the end of life, in both community and hospital settings’ and the RCGP (Involving and Supporting Carers and Families 2014) reinforced this, ‘Recognising that carers often know the people they care for better than anyone else and that information from carers about the symptoms of the person they are caring for may provide vital clues to diagnosis.

Both organisations recognise that involving carers, and other people important to people at the end of life, may further enable the person to make choices and communicate their wishes. . As many carers are directly involved in providing treatment and carerespecting the carer’s role in care and support is important I. Such respect is beneficial to the wellbeing of the person entering the last year of life and their carers.

Lack of trust and concerns about confidentiality can get in the way of involving carers in end of life decision making. The Caldicott Principles state ‘The duty to share information can be as important as the duty to protect patient confidentiality. Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these Principles’. The National Council for Palliative Care (Involving and supporting carers in end of life care in acute hospital, 2010 project) suggests we should listen to carers and ‘not forget they know the patient well and have important information about them.’

Some people will have lost capacity to make their own choices at end of life.

Carers may have been granted decision making powers through a Lasting Power of Attorney, to be used when the person has lost the capacity to make their own choices. Even if a carer does not have power of attorney they may be the only person who understands what the wishes and needs of the person are.

The National End of Life Care Strategy, 2008 states ‘Carers are central to the team that cares for somebody at the end of life and they should be treated as “co-workers” with the health and social care team.’ This chapter reviews the qualitative evidence about barriers and facilitators to the involvement of carers in decision making in the last year of life.

1.3 PICO table

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	To determine how services can be improved and what works well to support the involvement of carers of (or those important to) those in their last year of life in planning and decision making.
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Population and setting	Carers of (or those important to) adults with progressive life-limiting conditions thought to be entering their last year of life. <ul style="list-style-type: none"> • Includes young carers (<18 years)
Context	Any type of barriers and facilitators to the involvement of carers (or people important to) people in their last year of life in planning and decision making described by studies (for example regarding discharge, transition in settings or advance care planning). <p>For example:</p> <ul style="list-style-type: none"> • Level of involvement • Timing or setting of involvement • Facilitators • Barriers • Financial and benefits support • Transportation geographical separation from patients/services
Review strategy	Synthesis of qualitative research: Thematic analysis - information synthesised into main review findings. Results presented in a detailed narrative with accompanying diagrams and in table format with summary statements of main review findings.

1.4 Qualitative evidence

1.4.1 Included studies

**Twenty three qualitative studies (reported in 24 papers) were included in the review²⁴,
39, 40, 52, 55, 71, 81, 92, 96, 103, 109, 118, 127, 134, 141, 142, 147-149, 180, 181, 186, 190⁸, these are
summarised in Please see the table below:**

Table 2 below. Key findings from these studies are summarised in Table 2 below. See also the study evidence tables in Appendix D.

1.4.2 Excluded studies

See the excluded studies list in Appendix E.

1.4.3 Summary of studies included in the evidence review

Please see the table below:

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Ates 2018 ⁸	Face-to-face in-depth interview to gain narrative data, with thematic qualitative analysis.	Family caregivers looking after people with cancer, chronic obstructive pulmonary disease or chronic heart failure. Integrated Palliative Care initiative Networks in Belgium, Germany, Hungary, The Netherlands, UK N=156	To examine the burdens and rewards associated with family caregiving and the effects of the Integrated Palliative Care initiative Networks on caregivers support systems.	
Caron 2005 ²⁴	Face-to-face in-depth interview to gain narrative data, with thematic qualitative analysis.	Family caregivers involved in the care decisions for an older family member with late-stage dementia, as documented in the patient's medical record. N=24 Canada	To examine the experience and preoccupations of family caregivers about end-of-life issues, and more specifically, about treatment decision-making processes in the context of advanced dementia.	
Dening 2012 ³⁹	Structured focus group (nominal group technique) with thematic qualitative analysis.	Carers – relatives or friends who had provided care on a regular, unpaid basis to people who had died with dementia. N=7 UK	To identify barriers to people dying with dementia and their carers receiving good end-of-life care, and to identify good practice that might inform improvements in care.	Study also recorded views of HCP
Dening 2013 ⁴⁰	Structured focus group (nominal group technique) with thematic qualitative analysis.	People with dementia; carers and dyads of people with dementia and carers; and carers attending memory assessment services (recruited from the Memory Service in Barnet, Enfield and Haringey Mental Health National Health Service). N=17	To examine: how people with dementia define their wishes and preferences for their end-of-life care; how family carers define preferences for their own end-of-life care; and whether the expression of the wishes and preferences of the person with	Study also collated themes and scored the individual ranked items.

Study	Design	Population	Research aim	Comments
		UK	dementia is facilitated or inhibited by the carer being present.	
Forbes 2000 ⁵² Gessert 2001 ⁵⁵	Structured focus group (nominal group technique) with thematic qualitative analysis.	Family members of residents at four purposefully selected nursing homes in Kansas City. Investigators selected residents with moderately-severe dementia. Participants described their institutionalized relatives as having moderate to advanced cognitive impairment. N=28 USA	To examine families end of life decision making and their interactions with health professionals.	Residents with moderately-severe dementia selected with the assumption they or their carers would have, or would soon be making end of life decisions. Family members took part in four focus groups.
Holley 2009 ⁷¹ ;	Face-to-face semi-structured interviews with thematic qualitative analysis.	People aged 65 and older; enrolled in Medicare Part B; with an existing University of Chicago affiliation; homebound as defined by Medicare; limited life expectancy defined by patient's primary care provider as "not being surprised if the patient died in the next year." N=13 USA	To evaluate the clinical component of the Palliative Access Through Care at Home (PATCH) after one year of service.	PATCH is an urban, home-based geriatric palliative care program which was designed to address healthcare system gaps to provide relief and comfort for patients and their caregivers Mixed methods study, but qualitative data separate.
Jackson 2012 ⁸¹	Face-to-face semi-structured interviews with thematic qualitative analysis.	Family members who had lost a loved one in a long-term-care facility during the prior 3 to 18 months. N=19 USA	The objective of this study was to explore family perspectives of end-of-life care in long-term-care settings from interviews of family members who have had a loved one die in a long-term-care facility.	
Kryworuchko 2012 ⁹²	Face-to-face semi-structured interviews with thematic qualitative analysis.	Family members of critically ill patients in the ICU. 6 family members of 3 patients participated.	To explore family involvement in decisions about life support interventions in the intensive care.	

Study	Design	Population	Research aim	Comments
		N=6 Canada		
Lamahewa 2017 ⁹⁶	Face-to-face semi-structured interviews with thematic qualitative analysis.	Former and current family carers of people with experience of end of life care for a person with dementia. N=10 UK	To explore difficulties in decision making for practitioners and family carers at the end of life for people with dementia.	
Lind 2013 ¹⁰³	Face-to-face single narrative-inducing question interviews, followed semi-structured interviews with thematic qualitative analysis.	Families of deceased patients from four Norwegian ICUs. Patients were terminally ill, alert and competent intensive care patients. N=11 Norway	To explore how relatives of terminally ill, alert and competent intensive care patients perceive their involvement in the EOLC decision making process.	
MacDonald 2011 ¹⁰⁹	Face-to-face semi-structured interviews with thematic qualitative analysis.	Family caregivers previously involved in end-of-life decision-making. N=20 Canada	To provide insight into how the clinical ethicist can effectively support family caregivers when making end-of-life healthcare decisions.	
Michael 2014 ¹¹⁸	Focus groups and face-to-face semi-structured interviews with thematic qualitative analysis.	Patients from the lung and gastrointestinal tumour streams with a prognosis of four or less weeks, and their carers. N=18 Australia	To examine how cancer caregivers view advance care planning (ACP) to inform an ACP program in an Australian cancer centre.	
Muders 2015 ¹²⁷	Cross-sectional survey containing open-ended questions that were analysed using qualitative methods	Family members of dementia patients who had died. N=310 Germany	To explore and document the needs of family caregivers of patients dying with dementia and to identify how healthcare professionals can adequately support them	

Study	Design	Population	Research aim	Comments
O'Hare 2017 ¹³⁴	Face-to-face semi-structured interviews with thematic qualitative analysis.	Family members and friends of patients with advanced kidney disease. N=17 USA	To learn about the experiences of family members and friends of patients with advanced kidney disease.	
Preston 2012 ¹⁴¹	Face-to-face semi-structured interviews with thematic qualitative analysis.	Bereaved relatives or primary carers of patients with MND know to the MND Care and Research Centre as identified by its database. N=11 UK	To examine MND patients' bereaved relatives experiences of using the Preferred Priorities for Care (PPC) document, a patient-held record promoted by the End of Life Care Strategy as an ACP tool to promote discussion and communication amongst patients, family and health care professionals.	All patients completed a PPC. Limitations to implementation of PPC reported barriers
Ray 2014 ¹⁴²	Face-to-face semi-structured interviews with thematic qualitative analysis.	Carers, whose family member had a confirmed diagnosis of MND. N=29 UK + Australia	To examine the ways, family caregivers of people living with motor neurone disease (MND) experienced the dying of their relative and to identify how health practitioners can better prepare families for end-of-life care.	
Robinson 2000 ¹⁴⁷	Face-to-face semi-structured interviews with thematic qualitative analysis.	Wives of patients with advanced Alzheimer's who had undergone a medial crisis. N=12 USA	To describe what it was like for surrogate decision makers to live through implementation of the treatment decisions that they made for their loved ones who suffered from advanced Alzheimer's disease.	
Rosemond 2017 ¹⁴⁸	Face-to-face semi-structured interviews with inductive, descriptive qualitative approach	Family decision makers whose relative with advanced dementia died after participating in the goals of care intervention. N=16 USA	To understand how family decision makers experienced goal-based decision-making in advance of the death of the relative	This qualitative study was conducted as part of the goals of care randomised clinical trial.

Study	Design	Population	Research aim	Comments
Royak-Schaler 2006 ¹⁴⁹	Face-to-face/telephone semi-structured interviews with thematic qualitative analysis.	Spouses and first-degree relatives of deceased patients with cancer who had been treated at the cancer centre from 2000-2002. N=24 USA	To assess healthcare provider communication about end-of-life (EOL) and hospice care with patients with terminal cancer and their families, from the perspective of the family members.	
Waldrop 2011 ¹⁸⁰	Face-to-face semi-structured interviews with thematic qualitative analysis.	Caregivers of nursing home residents who had died 2 months previously. N=31 USA	To explore family members' experiences with a dying nursing home resident.	
Washington 2012 ¹⁸¹	Semi-structured interviews with thematic qualitative analysis.	Friends and family members who provided unpaid care for a home hospice patient receiving services from one of two hospice agencies. N=76 USA	To discover which specific intervention processes impacted informal hospice caregivers who participated in a problem-solving intervention.	The problem-solving intervention was the ADAPT problem-solving method, a psycho-educational intervention, which was used to address a specific challenge they had when caring for a dying family member or friend.
Wilson 2011 ¹⁸⁶	Face-to-face semi-structured interviews with thematic qualitative analysis.	Family members who had made end-of-life treatment decisions for a person close to them N=10	To identify the factors that are important to families who must decide to either prolong or end treatment for patients who are seriously ill.	
Wittich 2013 ¹⁹⁰	Face to face semi-structured interviews with thematic qualitative analysis	Next of kin of deceased patients of the VAMC. N=78 USA	To examine the ways that next of kin knew veterans' end-of-life preferences, and their ways of knowing whether those preferences were honoured in Veteran Affairs Medical Centre (VAMC) inpatient settings.	

1.4.4 Qualitative evidence synthesis

Table 3: Review findings

Main findings	Statement of finding
Lack of knowledge <ul style="list-style-type: none"> Decision-making Access to knowledgeable practitioners 	Caregivers felt they had a lack of knowledge impeding decision-making or decisions were made without an adequate knowledge base. Carers appreciated having access to knowledgeable practitioners to guide their decisions.
Informing the patient	Caregivers felt it was their role to inform the patient.
Inability to see overall view	Caregivers were more focused on the smaller day-to-day decisions and failed to see the overall picture to guide end-of-life decisions.
When to make decisions	Caregivers found it hard to identify when they needed to make decisions. Some were comfortable, others were not. They had to have acceptance before they could make decisions.
Emotional burden	Family caregivers had significant emotional burden in the role of decision maker. They often found it hard to discuss end-of-life discussions.
Access to health care providers	Many caregivers had difficulty reaching their primary care provider. Easier access was associated with more positive experience.
Improving transitions of care	Caregivers had multiple problems regarding transitions of care including transfer problems and insufficient communication between institutions.
Control	Carers wanted control over quality of care at the end of life.
Advance care planning <ul style="list-style-type: none"> Patient's wishes Problems When to complete 	Carers were tasked with identifying, addressing and upholding their loved one's wishes. Advanced care plans could help in decision-making but it could still be difficult and cause discomfort. Advanced care plans were thought best earlier, before decline.
Communication with healthcare professionals	Caregivers involved in dialogue had higher satisfaction than those who had less involvement. Communication was important to caregivers but was variable in quality and lack of consistent communication.
Trust in health care providers	Trust in the health care provider was an important facilitator in decision-making but was often found to be lacking.

1.4.4.1 Narrative summary of review findings

Review finding 1: Lack of knowledge

Lack of knowledge: decision-making

One study²⁴ found that lack of knowledge was a key barrier to decision making. Some caregivers thought that they were making decisions based on a lack of knowledge,^{52,103} and without patient-family communication.¹⁰³ Some family members did not know what questions to ask the Health Care Provider.⁹² They would have liked to be informed earlier and more comprehensively about general and specific issues,¹²⁷ and wished for more information about: the diagnosis; changes in state of health; outpatient support services;¹⁰⁹ stage of disease; treatment decisions and care options including hospice care.¹⁴⁹ Knowing the

seriousness of their relative's illness and having any available sufficient and accurate information helped them make informed decisions about care and treatment;^{109,149} which they could feel comfortable with their loved ones care, even when the final outcome was death.¹⁴⁹

Lack of knowledge: access to knowledgeable practitioners

Caregivers' appreciated easy access to a knowledgeable practitioner,^{109,71} trained in geriatrics, palliation and end-of-life care.^{8, 71} They gained knowledge via observations of medical staff performing comfort care and through interactions with clinical staff.¹⁹⁰ Some healthcare providers were able to facilitate decision making by providing information and support to the family members. In contrast there were other healthcare providers who acted as barriers to the decision-making process. One participant recalled how she was not informed that her mother had been taken off the list for an organ transplant.¹⁸⁶ Participants expressed a great deal of frustration related to trying to get information about their family member's condition¹⁰⁹ or with healthcare professionals who failed to explain disease progression.¹⁴⁹

Review finding 2: Informing the patient

Caregivers saw their role as supportive by being physically present at the bedside and able to repeat the information to the patient.¹⁰³ Caregivers often did not know how much information the patient had received, so could not judge whether they were informed enough.¹⁰³

Review finding 3: Inability to see overall view

Caregivers were unable to synthesise information into a larger conceptual framework to guide end-of-life decisions.⁵² They envisioned death as a big event and did not see day-to-day decisions as having a direct effect on their relative's death. Decisions were made 'piece by piece' or 'in the moment' without considering the 'big picture'.⁵²

Review finding 4: When to make decisions

Many were comfortable making decisions when needed to but could not identify when they were required to.⁵² Some caregivers suggested that discussions about the dying process or the death event were associated with loss of hope, negative attitudes or seen as unnecessary.¹⁴² All participants discussed the need to accept the impending death of their loved one, which included an acknowledgment of futility of the family member's condition. Until this acceptance was achieved, there could be no decision to terminate curative treatment.¹⁸⁶ However often there was a lack of alternative options, and fast decisions had to be made.⁹²

Review finding 5: Emotional burden

There were significant emotional burdens experienced by family members in their roles as decision makers and carers^{8, 52} Family member caregivers were able to discuss their current burdens, guilt and losses but found it difficult to discuss dying or end-of-life discussions.⁵² The experience of acting on the behalf of the patient could be a source of embarrassment or discomfort for family members and friends.¹³⁴ Carers expressed benefit from support where this was available. - Carers like 'having [someone] listen' or 'having the opportunity to talk to somebody', as part of the ADAPT intervention.¹⁸¹ A problem solving intervention¹⁸¹ gave caregivers the chance to reflect on challenges they were facing, allowing them to think things through. The PATCH intervention gave them relief as they often felt uncertain about the care they were providing.⁷¹

Review finding 6: Access to health care providers

In one study⁷¹ many caregivers had difficulty reaching their primary care provider (prior to PATCH) and went through to an answering service or voicemail which would not be relayed. The PATCH service was a 24-hour access to a practitioner, with timely call-backs. Participants believed that having better access to the healthcare professionals involved in their loved ones care contributed to positive experiences⁸, whereas, participants who perceived the healthcare team to be less accessible had negative comments. Some participants believed that the staff were too busy to explain their loved ones health status or too busy to provide adequate care.¹⁴⁹

Review finding 7: Improving transitions of care:

Holley (2009)⁷¹ found that caregivers had multiple problems regarding transitions of care before enrolling on PATCH, including transfers in and out of hospitals, sub-acute nursing facilities and LTC facilities without sufficient communication between institutions, often in the face of mounting medical problems. They did not understand different levels of care and recognising when the transition to end-of-life care should begin. The PATCH intervention was more 'in tune with 'patients' conditions and helped to next level of care. They had a consistent place to turn even with multiple sites of healthcare delivery. PATCH could provide anticipatory guidance to patients and caregivers and help transitions toward the end of life occur more smoothly.

Review finding 8: Control

Carers hoped for control over good quality care at the end of life.⁴⁰ They found an increased confidence and control over problems from one problem-solving intervention.¹⁸¹ They felt 'reassured' after working through the steps as it brought focus to their efforts and found many benefits of making progress toward solving a problem. Denig (2012)³⁹ found there was scepticism about whether an ACP would allow them to retain control.

Review finding 9: Advance care planning

Advance care planning: Patient's wishes

During the living-dying interval, caregivers were charged with identifying, addressing, and upholding their loved ones wishes when they were unable to express themselves but had uncertainty over how best to meet the needs of their relative.^{96,180} Some family caregivers had prior knowledge of a loved one's wishes; others did not.¹⁸⁰ Knowing the wishes of the family member aided in the surrogates decision making for care and treatment.^{109,186} This communication involved more than just the existence of advance directives. Those who had not had discussions struggled with decision making.¹⁸⁶ The process of knowing a loved one's preferences regarding end of life care appeared to unfold over time¹⁹⁰ and to be facilitated by hearing about the patient's preferences, seeing their care, and interacting with the patient and the clinical staff. They did not always have to involve formal goals of care discussions; they were dynamic and allowed for shifts in goals of care over time.¹⁴⁸ Listening to loved ones as he or she expresses preferences or listening to EOLC conversations with clinicians helped carers know what they wanted.¹⁹⁰ A study of bereaved wives found some were guided in their treatment decisions by extrapolating their husband's values from various statements or situations throughout their married lives. Many mentioned the aspect of considering their family members best interest, whether or not they knew their wishes.¹⁰⁹ Advance care planning was thought to ease the burden of decision making for family who may otherwise struggle to make best interest decisions.^{96,81}

Advance care planning: problems

However, even with the presence of ADs, there were still grey areas about healthcare such as making the decision to sign a DNR, and decisions about feeding tubes, fluids and other interventions. Some participants had difficulties and discomfort in implementing a palliative care treatment plan, despite clear directives and affirmation from health care professionals.^{81,147,180} Carers experienced feelings of guilt at carrying through a treatment decision that

would end their loved one's life,¹⁴⁷ or having to uphold wishes that they did not agree with.¹⁸⁰ In some cases there was a conflict between carer and provider decisions on the behalf of the patient¹⁸⁰. Denning (2012)³⁹ found carers had scepticism about the ACP process, as it may be open to misinterpretation by professionals. One study¹⁴¹ found that health care professionals were unaware of a patient-held ACP tool, for aiding discussion and communication amongst patients, family and health care professionals. Advance care discussions required trust in the health care providers, however two studies^{141,148} found that often the patients' preferences and wishes were ignored or the document was not understood by the HCPs, leading to confusion as to the intentions of goals of care and carers role as decision-makers. Advance care plans were most likely shown to family and friends than healthcare staff.¹⁴¹

Advanced care planning: when to complete

The carers felt it was difficult to plan ahead and anticipate what may or may not happen.⁴⁰ Many thought that advanced care plans should be completed whilst patients were still able to talk or sign the document themselves. Families believed that early discussions were important in advocating for their loved ones wishes at the end of life. Families advised others to find a good facility and have good healthcare staff to guide them through the process. Having advanced directives written down and in place prior to decline was noted by most as essential.⁸¹

Review finding 10: Communication with healthcare professionals

Families who were strongly involved in the dialogue between doctors, nurses and patient or who acted as surrogates had higher satisfaction with the communication.¹⁰³ Families that did not participate in the doctor-patient dialogue, had limited communication with nurses and were allowed less time with the patient than they desired, knew less of how much and what kind of information the patient had received. They felt that important issues between the patient and themselves remained unresolved.¹⁰³ Family-clinician communication varied in quality, with information by assigned nurse often vague.¹⁰³ There was a lack of consistent communication with a specific healthcare provider.⁵² Family members and friends described multiple sources of tension in their interactions with patients and the health care system.¹³⁴ They requested an open and comprehensible communication with HCPs. Family members discussed a desire to receive complete and accurate information, not wishing to have the opinion of healthcare professionals forced on them, and a wish for the HCP to view their patients in a more holistic way.¹⁰⁹ The families desired congruence between words and actions, which helped them come to terms with the seriousness of their relatives situation.¹⁰⁹

Review finding 11: Trust in health-care providers

Lack of trust fostered a negative end-of-life experience for the family members but when there was a trusting relationship with the staff, the end-of-life experience was positive.¹⁴⁴⁸ Caron (2005)²⁴ found trust with physician was an important facilitator in the decision-making process. Trust was developed through actions of healthcare providers and lack of trust had potentially far-reaching consequences. The experience of carers of people with dementia resulted in carers⁴⁰ having a general fear and uncertainty of the future where they themselves may lack decisional capacity, with a lack of trust in medical decision-making. Lind (2013)¹⁰³ found that two families in a study of ICU patients were informed of the doctors' decision to terminate treatment but were not involved. The relatives were unsure whether the patient's consent was obtained or whether they were told of the decision.. The HCPs did not want to burden the family so the family member was unsure if they were telling the truth.⁹²

1.4.5 Quality evidence summary

Table 4: Summary of evidence

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
Lack of knowledge: decision-making					
7	Face-to-face/telephone interviews (n=5), focus groups (n=1) and a cross-sectional study with open-ended questions (n=1)	Caregivers felt they had a lack of knowledge impeding decision-making or decisions were made without an adequate knowledge base.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Lack of knowledge: access to knowledgeable practitioners					
6	Face-to-face and telephone interviews	Carers appreciated having access to knowledgeable practitioners to guide their decisions.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns about adequacy	
Informing the patient					

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	Design		Criteria	Rating	Overall assessment of confidence
1	Face-to-face interviews	Caregivers felt it was their role to inform the patient.	Limitations	Very minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns about adequacy ^a	

Inability to see overall view					
1	Focus groups	Caregivers were more focused on the smaller day-to-day decisions and failed to see the overall picture to guide end-of-life decisions.	Limitations	Minor concerns about methodological limitations	VERY LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns over adequacy ^a	
When to make decisions					
4	Face-to-face interviews (n=3) and focus groups (n=1)	Caregiver found it hard to identify when they needed to make decisions. Some were comfortable, others were not. They had to have acceptance before they could make decisions.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	
Emotional burden					
5	Focus groups (n=1) and face-to-face and telephone interviews (n=4)	Family caregivers had significant emotional burden in the role of decision maker. They often found it hard to discuss end-of-life discussions.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	
Access to health care providers					

3	Face-to-face and telephone interviews	Many caregivers had difficulty reaching their primary care providers. The more access they had the more positive their experience was.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns over adequacy ^b	
Improving transition of care					
1	Telephone interviews	Caregivers had multiple problems regarding transitions of care including transfer problems and insufficient communication between institutions.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Moderate concerns over adequacy ^a	
Control					
3	Focus groups (n=2) and semi-structured interviews (n=1)	Carers wanted control over quality of care at the end of life.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	Very minor concerns about relevance	
			Adequacy	Minor concerns over adequacy ^b	

Advance care planning: patient's wishes					
7	Face-to-face interviews	Carers were tasked with identifying, addressing and upholding their loved one's wishes.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	
Advance care planning: problems					
5	Face-to-face interviews	Advance care plans could help in decision-making but it could still be difficult and cause discomfort.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	
Advance care plan: when to complete					
2	Face to face interview (n=1) and focus groups (n=1)	Advanced care plans were thought best earlier, before decline.	Limitations	Minor concerns about methodological limitations	LOW
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	Minor concerns over adequacy ^b	
Communication with healthcare professionals					

4	Focus groups (n=1) and face-to-face interviews (n=3)	Caregivers involved in the dialogue had higher satisfaction than those who had less involvement. Communication was important to caregivers but was variable in quality and lack of consistent communication.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	
Trust in health care providers					
6	Focus group (n=1) and face-to-face interviews (n=5)	Trust in the health care provider was an important facilitator in decision-making but was often found to be lacking.	Limitations	Minor concerns about methodological limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about relevance	
			Adequacy	No concerns over adequacy	

^a Evidence from one small study contributed to this finding.

^b Evidence from a limited number of small studies contributed to this finding.

See Appendix D for Qualitative evidence tables.

1.5 Economic evidence

1.5.1 Included studies

The committee agreed that health economic studies would not be relevant to this review question, and so health economic evidence relating to this question was not sought.

1.6 Resource costs

Recommendations made based on this review (see section **Error! Reference source not found.**) are not expected to have a substantial impact on resources.

1.7 Evidence statements

1.7.1 Qualitative evidence statements

- See section 1.4.4.1

1.7.2 Health economic evidence statements

- No relevant economic evaluations were identified.

1.8 The committee's discussion of the evidence

1.8.1 Interpreting the evidence

1.8.1.1 Findings identified in the evidence synthesis

Carers felt they had a lack of knowledge on which to base decisions, which were often impromptu, and they tended to focus on day-to-day decisions rather than the overall picture to guide end-of-life decisions. Some were comfortable to make decisions but found it hard to identify when they needed to make decisions. Some found it hard to bring up end-of-life discussions with the patient and found it to be a significant emotional burden. The evidence heavily suggested a lack of knowledge on which to base decisions and variation in ability to have end-of-life conversations, therefore the Committee chose to make a recommendation for provision of information which is individually tailored to the patients and carers preferences for involvement in decision-making (see recommendation 1.3.2). The Committee wished to acknowledge that this could change over the course of end-of-life care and requires to be revisited and that patient and carer needs may differ. Co-ordinators or lead health care professionals were identified as important to ensure that information provision was sufficient, as they would have the overall view of the patients' and carers' requirements.

It was often hard for carers to reach their primary care provider, and had to leave voicemail messages, which were often not returned. There were also a lot of issues with transfers between care and a lack of communication found between healthcare providers. The Committee wished to ensure that any transitions in care involved better communication, with appropriate information shared and that changes in prognosis were taken into consideration.

Carers wanted more control over end-of-life care. Those who were involved in dialogues had higher satisfaction than those who were not, and communication was variable in quality and consistency. Often they found it difficult to plan ahead and were sceptical of ACPs. Trust in the HCP was required but was often found to be lacking. The evidence indicated that it is essential that providers are able to communicate well with patients and carers about end-of-life, the Committee wished to ensure that providers are skilled in providing appropriate

information for that point in time, sensitively delivered, to patients and carers. They felt that the service needs to be configured as such to ensure that this occurs.

1.8.1.2 The quality of the evidence

Twenty three studies (of twenty four papers) were included in the review, using structured interviews and focus groups to elicit patients' and carers' views, which was then thematically analysed. The evidence was graded low to moderate quality, the studies overall were well-conducted and analysed. It was downgraded where there were minor methodological limitations and/or lack of adequacy, with too few studies reporting the finding. Due to mainly moderate quality evidence and the findings agreeing with their experience of barriers to involvement of carers in decision-making are the Guideline Committee had confidence in their recommendations.

1.8.2 Cost effectiveness and resource use

No relevant economic evaluations were identified. The committee considered that although these recommendations may have cost implications as a result of healthcare professional time and additional resource requirements to ensure carers are involved in decision making and are adequately supported, the committee felt strongly that it should be an essential part of good end-of-life care. The committee stressed that currently the majority of people caring for someone who is considered to be in the last year of life are not identified as carers and therefore do not have access to carer support services. The committee pointed out that adequately supporting carers to be able to care for someone in the community could reduce the number of avoidable hospital admissions in the last year of life which could reduce costs to the NHS and free up capacity in emergency services.

1.8.3 Other factors the committee took into account

The committee wanted to highlight that these recommendations relate to active carers and the persons most important to the patients, who may not necessarily be the next-of-kin.

The committee clarified that the recommendation on the provision of professional interpreters was to highlight that family members should not act as interpreters for the patient. Using a family member as an interpreter could result in embarrassment and distorted messages or information being withheld.

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Appendices

Appendix A: Review protocols

Table 5: Review protocol for what are the barriers and facilitators to the involvement of carers of (or people important to) those in their last year of life in planning and decision making

Question number: 17

Relevant section of Scope: Service models that provide support for the carers or those important to the people accessing end of life services

Field names are based on [PRISMA-P.](#)]

ID	Field	Content
I	Review question	What are the barriers and facilitators to the involvement of carers of (or people important to) those in their last year of life in planning and decision making?
II	Type of review question	Qualitative review. A review of health economic evidence related to the same review question was conducted in parallel with this review. For details see the health economic review protocol for this NICE guideline.
III	Objective of the review	To determine how services can be improved and what works well to support the involvement of carers of (or those important to) those in their last year of life in planning and decision making.
IV	Eligibility criteria – population / disease / condition / issue / domain	Carers of (or those important to) adults with progressive life-limiting conditions thought to be entering their last year of life. • Includes young carers (<18 years)
V	Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Any type of barriers and facilitators to the involvement of carers (or people important to) people in their last year of life in planning and decision making described by studies (for example regarding discharge, transition in settings or advance care planning). For example: Level of involvement Timing or setting of involvement Facilitators Barriers Financial and benefits support • Transportation geographical separation from patients/services
VI	Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
VII	Outcomes and prioritisation	Not applicable
VIII	Eligibility criteria – study design	Study designs to be considered: Qualitative studies (for example: interviews, focus groups, observations)

		Data synthesis Synthesis of qualitative research: Thematic analysis - information synthesised into main review findings. Results presented in a detailed narrative with accompanying diagrams and in table format with summary statements of main review findings
IX	Other inclusion exclusion criteria	Themes around clinical care
X	Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
XI	Selection process – duplicate screening / selection / analysis	Not applicable
XII	Data management (software)	Appraisal of methodological quality The methodological quality of each study will be assessed using NGC modified NICE checklists and the quality of the body of evidence as a whole will be assessed by a GRADE CerQual approach for each review finding. Endnote for bibliography, citations, sifting and reference management
XIII	Information sources – databases and dates	Clinical search databases to be used: Medline, Embase, Cochrane Library, Current Nursing and Allied Health Literature (CINAHL), PsycINFO, Healthcare Management Information Consortium (HMIC), Social Policy and Practice (SSP), Applied Social Sciences Index and Abstracts (ASSIA) Date: All years Language: Restrict to English only
XIV	Identify if an update	Not applicable
XV	Author contacts	https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
XVI	Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual.
XVII	Search strategy – for one database	For details please see Appendix B
XVIII	Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
XIX	Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables) or health economic evidence tables if applicable.
XX	Methods for assessing bias at outcome / study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the ‘Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox’ developed by the international GRADE working group http://www.gradeworkinggroup.org/

		[Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.]
XXI	Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual.
XXII	Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the separate Methods report for this guideline.
XXIII	Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. [Consider exploring publication bias for review questions where it may be more common, such as pharmacological questions, certain disease areas, etc. Describe any steps taken to mitigate against publication bias, such as examining trial registries.]
XXIV	Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
XXV	Rationale / context – what is known	For details please see the introduction to the evidence review.
XXVI	Describe contributions of authors and guarantor	A multidisciplinary committee [https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799] developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Mark Thomas in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual.
XXVII	Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXVIII	Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
XXIX	Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
XXX	PROSPERO registration number	Not registered

Table 6: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocol above. Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.)

Review question	All questions – health economic evidence
	<p>Unpublished reports will not be considered unless submitted as part of a call for evidence.</p> <p>Studies must be in English.</p>
Search strategy	<p>A health economic study search will be undertaken using population-specific terms and a health economic study filter – see Appendix G [in the Full guideline]</p>
Review strategy	<p>Studies not meeting any of the search criteria above will be excluded. Studies published before 2007, abstract-only studies and studies from non-OECD countries or the USA will also be excluded.</p> <p>Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in Appendix H of Developing NICE guidelines: the manual (2014).¹³⁰</p> <p>Inclusion and exclusion criteria</p> <p>If a study is rated as both ‘Directly applicable’ and with ‘Minor limitations’ then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile.</p> <p>If a study is rated as either ‘Not applicable’ or with ‘Very serious limitations’ then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile.</p> <p>If a study is rated as ‘Partially applicable’, with ‘Potentially serious limitations’ or both then there is discretion over whether it should be included.</p> <p>Where there is discretion</p> <p>The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in Appendix M.</p> <p>The health economist will be guided by the following hierarchies.</p> <p>Setting:</p> <ul style="list-style-type: none"> UK NHS (most applicable). OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). OECD countries with predominantly private health insurance systems (for example, Switzerland). <p>Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.</p> <p>Health economic study type:</p> <ul style="list-style-type: none"> Cost–utility analysis (most applicable). Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). Comparative cost analysis. <p>Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.</p> <p>Year of analysis:</p> <p>The more recent the study, the more applicable it will be.</p> <p>Studies published in 2007 or later but that depend on unit costs and resource data entirely or predominantly from before 2007 will be rated as ‘Not applicable’.</p>

Review question	All questions – health economic evidence
	<p>Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations.</p> <p>Quality and relevance of effectiveness data used in the health economic analysis: The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.</p>

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual 2014, updated 2017
<https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869>

For more detailed information, please see the Methodology Review. [\[Add cross reference\]](#)

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 7: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review: Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types

Database	Dates searched	Search filter used
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None
Database	Dates searched	Search filter used
Medline (Ovid)	1946 – 04 January 2019	Exclusions
Embase (Ovid)	1974 – 04 January 2019	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to Issue 1 of 12, January 2019 CENTRAL to Issue 1 of 12, January 2019 DARE, and NHSEED to Issue 2 of 4 2015 HTA to Issue 4 of 4 2016	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 04 January 2019	Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Journal Article, Meta Analysis, Randomized Controlled Trial, Systematic Review; Age Groups: All Adult; Language: English
PsycINFO (ProQuest)	Inception – 04 January 2019	Study type
HMIC. Healthcare Management Information Consortium (Ovid)	1979 – 04 January 2019	Exclusions
SPP, Social Policy and Practice	1981 – 04 January 2019	Study types
ASSIA, Applied Social Sciences Index and Abstracts (ProQuest)	1987 – 04 January 2019	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/

4.	palliat*.ti,ab.
5.	Terminally ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	**"Continuity of Patient Care"/
17.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Physician-Patient Relations/
21.	*Long-Term Care/
22.	**"Delivery of Health Care"/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter/
29.	editorial/
30.	news/
31.	exp historical article/
32.	Anecdotes as Topic/
33.	comment/
34.	case report/
35.	(letter or comment*).ti.
36.	or/28-35
37.	randomized controlled trial/ or random*.ti,ab.
38.	36 not 37
39.	animals/ not humans/
40.	exp Animals, Laboratory/
41.	exp Animal Experimentation/
42.	exp Models, Animal/
43.	exp Rodentia/
44.	(rat or rats or mouse or mice).ti.
45.	or/38-44
46.	27 not 45
47.	limit 46 to English language

48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	(commission* adj2 (support* or service* or model*)).ti,ab.
51.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
52.	Critical Pathways/
53.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
54.	Patient Care Bundles/
55.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
56.	or/50-55
57.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
58.	49 and 56 and 57
59.	gold standard*.ti,ab.
60.	49 and 59
61.	(amber adj2 bundle).ti,ab.
62.	58 or 60 or 61
63.	patient care team/
64.	interdisciplinary communication/
65.	((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
66.	((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
67.	(key adj2 work*).ti,ab.
68.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
69.	((healthcare or care) adj1 profession*).ti,ab.
70.	*Case Management/
71.	(case adj2 manage*).ti,ab.
72.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
73.	Or/63-72
74.	"referral and consultation"/
75.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
76.	(recommend* or direct*).ti,ab.
77.	or/74-76
78.	Social Welfare/ec, ed, es, eh, ma, st, sn, td [Economics, Education, Ethics, Ethnology, Manpower, Standards, Statistics & Numerical Data, Trends]
79.	Charities/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
80.	Home Care Services/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]

81.	Community Health Nursing/ec, ed, es, ma, mt, og, st, sn, sd, td, ut [Economics, Education, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
82.	Telemedicine/ec, es, ma, mt, og, st, sn, td, ut [Economics, Ethics, Manpower, Methods, Organization & Administration, Standards, Statistics & Numerical Data, Trends, Utilization]
83.	exp remote consultation/
84.	*telemedicine/ or *telepathology/ or *teleradiology/ or *telerehabilitation/
85.	(telemedicine or tele medicine or telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or telepathology or teleradiology or telerehabilitatio).ti,ab.
86.	((tele* or remote) adj2 consult*).ti,ab.
87.	Mobile Health Units/ec, es, ma, og, st, sn, sd, td, ut [Economics, Ethics, Manpower, Organization & Administration, Standards, Statistics & Numerical Data, Supply & Distribution, Trends, Utilization]
88.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
89.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
90.	(hospital adj3 (domicil* or home)).ti,ab.
91.	home hospitali*ation.ti,ab.
92.	exp Home Care Agencies/
93.	(social adj (welfare or care)).ti,ab.
94.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
95.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
96.	(community adj2 (health care or healthcare or nursing or nurse*)).ti,ab.
97.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropriate or increase* or risk*)).ti,ab.
98.	or/78-97
99.	Caregivers/
100.	Spouses/
101.	Family/
102.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
103.	Or/99-102
104.	((replacement or break* or holiday* or respite) adj3 (care* or service*)).ti,ab.
105.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*)).ti,ab.
106.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*)).ti,ab.
107.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
108.	Self-Help Groups/
109.	exp social support/
110.	Counseling/
111.	(counseling or counselling*).ti,ab.
112.	(buddy* or buddies).ti,ab.
113.	((health* or medical*) adj2 check*).ti,ab.

114.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge)).ti,ab.
115.	or/104-114
116.	49 and 103 and 115
117.	49 and (73 or 77 or 98)
118.	62 or 116 or 117

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
17.	*Patient care/
18.	*Attitude to Death/
19.	(attitude* adj3 (death* or dying*)).ti,ab.
20.	*Doctor patient relation/
21.	*Long term care/
22.	*Health care delivery/
23.	(end adj2 life).ti,ab.
24.	EOLC.ti,ab.
25.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
26.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
27.	or/1-26
28.	letter.pt. or letter/
29.	note.pt.
30.	editorial.pt.
31.	case report/ or case study/
32.	(letter or comment*).ti.
33.	or/28-32
34.	randomized controlled trial/ or random*.ti,ab.

35.	33 not 34
36.	animal/ not human/
37.	nonhuman/
38.	exp Animal Experiment/
39.	exp Experimental Animal/
40.	animal model/
41.	exp Rodent/
42.	(rat or rats or mouse or mice).ti.
43.	or/35-42
44.	27 not 43
45.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
46.	44 not 45
47.	limit 46 to English language
48.	(commission* adj2 (support* or service* or model*)).ti,ab.
49.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) adj2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)).ti,ab.
50.	*Clinical Pathway/
51.	((critical or clinic* or service* or care) adj2 path*).ti,ab.
52.	*Care Bundle/
53.	(care adj2 (bundle* or service* or package* or standard*)).ti,ab.
54.	or/48-53
55.	(assess* or criteria* or predict* or recogni* or identif* or refer*).ti,ab.
56.	47 and 54 and 55
57.	gold standard*.ti,ab.
58.	47 and 57
59.	(amber adj2 bundle).ti,ab.
60.	56 or 58 or 59
61.	interdisciplinary communication/
62.	patient care team*.ti,ab.
63.	((((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
64.	((((integrat* or network*) adj2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT).ti,ab.
65.	(key adj2 work*).ti,ab.
66.	((healthcare or care) adj2 (lead or leader or leads or facilitat*)).ti,ab.
67.	((healthcare or care) adj1 profession*).ti,ab.
68.	*Case Management/
69.	(case adj2 manage*).ti,ab.
70.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*).ti,ab.
71.	Or/61-70

72.	exp patient referral/
73.	(referral* or referred or referring or refer or refers or consult*).ti,ab.
74.	(recommend* or direct*).ti,ab.
75.	or/72-74
76.	*social welfare/
77.	*community health nursing/ or *community care/
78.	*senior center/
79.	*telemedicine/ or *telehealth/
80.	*teleconsultation/
81.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or mobile health unit*).ti,ab.
82.	*home care/ or *home health agency/ or *home monitoring/ or *home oxygen therapy/ or *home physiotherapy/ or *home rehabilitation/ or *home respiratory care/ or *respite care/ or *visiting nursing service/
83.	*health care personnel/ or *health auxiliary/ or *nursing home personnel/
84.	(telemedicine or tele medicine or telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or telepathology or teleradiology or telerehabilitatio).ti,ab.
85.	((tele* or remote) adj2 consult*).ti,ab.
86.	(mobile adj2 (health or care) adj2 unit*).ti,ab.
87.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care).ti,ab.
88.	(hospital adj3 (domicil* or home)).ti,ab.
89.	home hospitali*ation.ti,ab.
90.	(social adj (welfare or care)).ti,ab.
91.	(nurs* adj4 (home-visit* or home visit* or home-based or home based)).ti,ab.
92.	((district* or communit* or home or visit*) adj nurs*).ti,ab.
93.	(community adj2 (health care or healthcare or nursing or nurse*).ti,ab.
94.	((hospitali*ation* or admission* or readmission* or admit*) adj3 (reduc* or avoid* or prevent* or inappropriate or increase* or risk*).ti,ab.
95.	or/76-94
96.	*Caregiver/
97.	*Spouse/
98.	*Family/
99.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*).ti,ab.
100.	Or/96-99
101.	((replacement or break* or holiday* or respite) adj3 (care* or service*).ti,ab.
102.	((communit* or support* or psychosocial* or psycholog*) adj3 (service* or group* or system*).ti,ab.
103.	((group* or support* or psychosocial* or psycholog*) adj3 (selfhelp or self help or therap*).ti,ab.
104.	((psychosocial* or psycholog*) adj2 support*).ti,ab.
105.	*Self-Help/
106.	*Social support/
107.	*Counseling/

108.	(counseling or counselling*).ti,ab.
109.	(buddy* or buddies).ti,ab.
110.	((health* or medical*) adj2 check*).ti,ab.
111.	((spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) adj3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge)).ti,ab.
112.	or/101-111
113.	47 and 100 and 112
114.	47 and (71 or 75 or 95)
115.	60 or 113 or 114

Cochrane Library (Wiley) search terms

#1.	MeSH descriptor: [Palliative Care] this term only
#2.	MeSH descriptor: [Terminal Care] this term only
#3.	MeSH descriptor: [Hospice Care] this term only
#4.	palliat*:ti,ab
#5.	MeSH descriptor: [Terminally Ill] this term only
#6.	((terminal* or long term or longterm) near/2 (care* or caring or ill*)):ti,ab
#7.	((dying or terminal) near (phase* or stage*)):ti,ab
#8.	life limit*:ti,ab
#9.	MeSH descriptor: [Nursing Homes] explode all trees
#10.	((care or nursing) near/2 (home or homes)):ti,ab
#11.	MeSH descriptor: [Respite Care] this term only
#12.	((respite or day) near/2 (care or caring)):ti,ab
#13.	MeSH descriptor: [Hospices] this term only
#14.	hospice*:ti,ab
#15.	MeSH descriptor: [Patient Care Planning] this term only
#16.	MeSH descriptor: [Continuity of Patient Care] this term only
#17.	((advance* or patient*) near/3 (care or caring) near/3 (continu* or plan*)):ti,ab
#18.	MeSH descriptor: [Attitude to Death] explode all trees
#19.	(attitude* near/3 (death* or dying*)):ti,ab
#20.	MeSH descriptor: [Physician-Patient Relations] this term only
#21.	MeSH descriptor: [Long-Term Care] this term only
#22.	MeSH descriptor: [Delivery of Health Care] this term only
#23.	(end near/2 life):ti,ab
#24.	EOLC:ti,ab
#25.	((last or final) near/2 (year or month*) near/2 life):ti,ab
#26.	((dying or death) near/2 (patient* or person* or people or care or caring)):ti,ab
#27.	(or #1-#26)
#28.	(commission* near/2 (support* or service* or model*)):ti,ab
#29.	((service* or program* or co-ordinat* or co ordinat* or coordinat*) near/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)):ti,ab
#30.	MeSH descriptor: [Critical Pathways] explode all trees

#31.	((critical or clinic* or service* or care) near/2 path*):ti,ab
#32.	MeSH descriptor: [Patient Care Bundles] explode all trees
#33.	(care near/2 (bundle* or service* or package* or standard*)):ti,ab
#34.	(or #28-#33)
#35.	(assess* or criteria* or predict* or recogni* or identif* or refer*):ti,ab
#36.	#27 and #34 and #35
#37.	gold standard*:ti,ab
#38.	#27 and #37
#39.	(amber near/2 bundle):ti,ab
#40.	#36 or #38 or #39
#41.	MeSH descriptor: [Patient Care Team] explode all trees
#42.	MeSH descriptor: [Interdisciplinary Communication] explode all trees
#43.	((((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)) or MDT or IDT):ti,ab
#44.	((integrat* or network*) near/2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*)):ti,ab
#45.	(key near/2 work*):ti,ab
#46.	((healthcare or care) near/2 (lead or leader or leads or facilitat*)):ti,ab
#47.	((healthcare or care) near/1 profession*):ti,ab
#48.	MeSH descriptor: [Case Management] this term only
#49.	(case near/2 manage*):ti,ab
#50.	(co-ordinator* or coordinator* or coordinate* or co-ordinate*):ti,ab
#51.	(or #41-#50)
#52.	MeSH descriptor: [Referral and Consultation] explode all trees
#53.	(referral* or referred or referring or refer or refers or consult*):ti,ab
#54.	(recommend* or direct*):ti,ab
#55.	(or #52-#54)
#56.	MeSH descriptor: [Social Welfare] explode all trees
#57.	MeSH descriptor: [Charities] explode all trees
#58.	MeSH descriptor: [Adult Day Care Centers] explode all trees
#59.	MeSH descriptor: [Community Health Nursing] explode all trees
#60.	MeSH descriptor: [Home Care Services] explode all trees
#61.	MeSH descriptor: [Senior Centers] explode all trees
#62.	MeSH descriptor: [Telemedicine] this term only
#63.	MeSH descriptor: [Remote Consultation] explode all trees
#64.	(telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team*):ti,ab
#65.	MeSH descriptor: [Mobile Health Units] explode all trees
#66.	((community based or community dwelling home or rural) near/3 (care or health care or healthcare)):ti,ab
#67.	(hospital-based home care or HBHC or hospital-based hospice care or acute hospital care):ti,ab

#68.	((hospitali*ation* or admission* or readmission* or admit*) near/3 (reduc* or avoid* or prevent* or inappropriate or increase* or risk*)):ti,ab
#69.	(home based versus hospital based):ti,ab
#70.	(hospital near/3 (domicil* or home)):ti,ab
#71.	(home hospitali*ation):ti,ab
#72.	MeSH descriptor: [Home Care Services, Hospital-Based] explode all trees
#73.	MeSH descriptor: [Home Health Nursing] explode all trees
#74.	MeSH descriptor: [Homemaker Services] explode all trees
#75.	MeSH descriptor: [Home Care Agencies] explode all trees
#76.	MeSH descriptor: [Home Health Aides] explode all trees
#77.	(social care):ti,ab
#78.	MeSH descriptor: [Nurses, Community Health] explode all trees
#79.	(nurs* near/4 (home-visit* or home visit* or home-based or home based)):ti,ab
#80.	((district* or communit* or home or visit*) near nurs*):ti,ab
#81.	(or #56-#80)
#82.	MeSH descriptor: [Caregivers] this term only
#83.	MeSH descriptor: [Spouses] this term only
#84.	MeSH descriptor: [Family] this term only
#85.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*):ti,ab
#86.	(or #82-#85)
#87.	((replacement or break* or holiday* or respite) near/3 (care* or service*)):ti,ab
#88.	((communit* or support* or psychosocial* or psycholog*) near/3 (service* or group* or system*)):ti,ab
#89.	((group* or support* or psychosocial* or psycholog*) near/3 (selfhelp or self help or therap*)):ti,ab
#90.	((psychosocial* or psycholog*) near/2 support*):ti,ab
#91.	MeSH descriptor: [Self-Help Groups] this term only
#92.	MeSH descriptor: [Social Support] explode all trees
#93.	MeSH descriptor: [Counseling] this term only
#94.	(counseling or counselling*):ti,ab
#95.	(buddy* or buddies):ti,ab
#96.	(health or medical*) near/3 check*:ti,ab
#97.	(spouse* or wife or wives or husband* or carer* or caregiver* or care giver* or significant other* or friend* or partner* or family or families or individual* or sibling* or brother* or sister* or relative or relatives or mothers* or daughters* or father* or son or sons or uncle* or aunt* or grand mother* or grandmother* or grandfather* or grand father* or aunt* or uncle* or cousin* or niece* or nephew*) near/3 (education or educate or educating or information or literature or leaflet* or booklet* or pamphlet* or website* or knowledge):ti,ab
#98.	(or #87-#97)
#99.	#27 and #86 and #98
#100.	#27 and (#51 or #55 or #81)
#101.	#40 or #99 or #100

CINAHL (EBSCO) search terms

S1.	MH Palliative care
S2.	MH Terminal care
S3.	MH Hospice care
S4.	TI palliat* OR AB palliat*
S5.	MW Terminally ill
S6.	TI (terminal* or long term or longterm) AND TI (care* or caring or ill*)
S7.	AB (terminal* or long term or longterm) AND AB (care* or caring or ill*)
S8.	TI (dying or terminal) AND TI (phase* or stage*)
S9.	AB (dying or terminal) AND AB (phase* or stage*)
S10.	TI life limit* OR AB life limit*
S11.	MH Nursing homes
S12.	TI (care or nursing) AND TI (home or homes)
S13.	AB (care or nursing) AND AB (home or homes)
S14.	MH Respite care
S15.	TI (respite or day) AND TI (care or caring)
S16.	AB (respite or day) AND AB (care or caring)
S17.	MH Hospices
S18.	TI Hospice* OR AB Hospice*
S19.	(MH "Patient Care Plans")
S20.	MH Attitude to Death
S21.	TI attitude* AND TI (death* or dying)
S22.	AB attitude* AND AB (death* or dying)
S23.	MH Physician-Patient Relations
S24.	(MH "Long Term Care")
S25.	(MH "Health Care Delivery")
S26.	TI end AND TI life OR AB end AND AB life
S27.	TI EOLC OR AB EOLC
S28.	TI (last or final) AND TI (year or month) AND TI life
S29.	AB (last or final) AND AB (year or month) AND AB life
S30.	TI (dying or death) AND TI (patient* or person* or people or care or caring)
S31.	AB (dying or death) AND AB (patient* or person* or people or care or caring)
S32.	TI advance* AND TI (plan* or decision* or directive*)
S33.	AB advance* AND AB (plan* or decision* or directive*)
S34.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33
S35.	TI commission* AND TI ((support* or service* or model*))
S36.	AB commission* AND AB ((support* or service* or model*))
S37.	TI (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND TI (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S38.	AB (service* or program* or co-ordinat* or co ordinat* or coordinat*) AND AB (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*)
S39.	TI (critical or clinic* or service* or care) AND TI path*
S40.	AB (critical or clinic* or service* or care) AND AB path*

S41.	TI care AND TI (bundle* or service* or package* or standard*)
S42.	AB care AND AB (bundle* or service* or package* or standard*)
S43.	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42
S44.	TI (assess* or criteria* or predict* or recogni* or identif* or refer*) OR AB (assess* or criteria* or predict* or recogni* or identif* or refer*)
S45.	S34 AND S43 AND S44
S46.	TI gold standard* OR AB gold standard*
S47.	S34 AND S46
S48.	TI amber AND TI bundle
S49.	AB amber AND AB bundle
S50.	S48 OR S49
S51.	S45 OR S47 OR S50
S52.	(MH "Multidisciplinary Care Team+")
S53.	MDT OR IDT
S54.	((interdisciplin* or inter-disciplin* or interprofession* or inter-profession* or multidisciplin* or multi-disciplin* or multi-profession* or multiprofession* or transprofession* or trans-profession*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S55.	((integrat* or network*) n2 (team* or staff* or meeting* or manag* or appointment* or system* or program* or practic* or advic* or advis* or caring or intervention* or ward* or round* or panel* or forum* or fora or communicat* or collaborat* or relat*))
S56.	TI (key n2 work*) OR AB (key n2 work*)
S57.	TI (((healthcare or care) n2 (lead or leader or leads or facilitat*))) OR AB (((healthcare or care) n2 (lead or leader or leads or facilitat*)))
S58.	TI (((healthcare or care) n1 profession*)) OR AB (((healthcare or care) n1 profession*))
S59.	MH Case Management
S60.	TI (case n2 manage*) OR AB (case n2 manage*)
S61.	TI ((co-ordinator* or coordinator* or coordinate* or co-ordinate*)) OR AB ((co-ordinator* or coordinator* or coordinate* or co-ordinate*))
S62.	S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61
S63.	(MH "Referral and Consultation+")
S64.	TI (referral* or referred or referring or refer or refers or consult*) OR AB (referral* or referred or referring or refer or refers or consult*)
S65.	TI (recommend* or direct*) OR AB (recommend* or direct*)
S66.	S63 OR S64 OR S65
S67.	(MM "Social Welfare")
S68.	(MH "Charities")
S69.	(MM "Adult Day Center (Saba CCC)") OR (MM "Housing for the Elderly") OR (MM "Older Adult Care (Saba CCC)")
S70.	(MH "Community Health Nursing+") OR (MM "Community Health Centers")
S71.	(MH "Home Health Care+") OR (MM "Home Health Aides") OR (MM "Home Health Care Information Systems") OR (MM "Home Health Aide Service (Saba CCC)")
S72.	(MM "Housing for the Elderly") OR (MM "Rural Health Centers") OR (MM "Community Health Centers")
S73.	(MH "Telemedicine+") OR (MH "Telehealth+")
S74.	(MM "Remote Consultation") OR (MM "Telephone Consultation (Iowa NIC)") OR (MM "Services for Australian Rural and Remote Allied Health")

S75.	telehealth or tele health or virtual hospital* or helpline* or help line* or rapid response team* or senior center*
S76.	(MM "Rural Health Personnel") OR (MM "Mobile Health Units")
S77.	remote consultation
S78.	((community based or community dwelling home or rural) n3 (care or health care or healthcare))
S79.	hospital-based home care or HBHC or hospital-based hospice care or acute hospital care
S80.	((hospitali?ation* or admission* or readmission* or admit*) n3 (reduc* or avoid* or prevent* or inappropriate or increase* or risk*))
S81.	home based versus hospital based
S82.	(hospital n3 (domicil* or home))
S83.	home hospitali?ation
S84.	home care service*
S85.	(MM "Home Health Agencies") OR (MM "Nursing Home Personnel")
S86.	(MM "Homemaker Services") OR (MM "Health Services for the Aged")
S87.	(MH "Home Health Care+") OR (MM "Home Care Equipment and Supplies") OR (MH "Nursing Homes") OR (MM "National Association for Home Care & Hospice") OR (MM "Nursing Home Patients")
S88.	social care
S89.	(MM "Hospitals, Community")
S90.	(MM "Home Nursing") OR (MM "Home Nursing, Professional")
S91.	(nurs* n4 (home-visit* or home visit* or home-based or home based))
S92.	((district* or communit* or home or visit*) n1 nurs*)
S93.	S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92
S94.	S34 AND (S62 OR S66 OR S93)
S95.	S51 OR S94

PsycINFO (ProQuest) search terms

1.	(ti,ab(commission* NEAR/2 (support* OR service* OR model*)) OR ((service* OR program* OR co-ordinat* OR coordinat*) NEAR/2 (model* OR deliver* OR strateg* OR support* OR access* OR method* OR system* OR policies OR policy OR availab*))) AND (SU.EXACT("Palliative Care") OR SU.EXACT("Terminally Ill Patients") OR SU.EXACT("Hospice") OR ti,ab(palliat*) OR ti,ab((terminal* OR long-term OR longterm) NEAR/2 (care* OR caring OR ill*)) OR ti,ab((dying OR terminal) NEAR/1 (phase* OR stage*)) OR ti,ab(life-limit*) OR SU.EXACT("Nursing Homes") OR ti,ab((care OR nursing) NEAR/2 (home OR homes)) OR SU.EXACT("Respite Care") OR ti,ab((respite OR day) NEAR/2 (care OR caring)) OR ti,ab(hospice*) OR MJSUB.EXACT("Treatment Planning") OR MJSUB.EXACT("Continuum of Care") OR ti,ab((advance* OR patient*) NEAR/3 (care OR caring) NEAR/3 (continu* OR plan*)) OR MJSUB.EXACT("Long Term Care") OR ti,ab(attitude* NEAR/3 (death* OR dying*)) OR ti,ab(end NEAR/2 life) OR ti,ab(EOLC) OR ti,ab((last OR final) NEAR/2 (year OR month*) NEAR/2 life) OR ti,ab((dying OR death) NEAR/2 (patient* OR person* OR people OR care OR caring)))
2.	Adolescence (13-17 Yrs), Adulthood (18 Yrs & Older), Aged (65 Yrs & Older), Middle Age (40-64 Yrs), Thirties (30-39 Yrs), Very Old (85 Yrs & Older), Young Adulthood (18-29 Yrs)
3.	1 and 2
4.	Conference Proceedings, Journal Article, Peer Reviewed Journal
5.	3 and 4

HMIC (Ovid) search terms

1.	exp End of life care/
2.	(terminal* adj ill*).ti,ab.
3.	((dying or terminal) adj (phase* or stage*)).ti,ab.
4.	life limit*.ti,ab.
5.	(end adj2 life).ti,ab.
6.	EOLC.ti,ab.
7.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
8.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
9.	or/2-8
10.	(exp child/ or exp Paediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp older people/)
11.	9 not 10
12.	limit 11 to English
13.	limit 12 to (audiovis or book or chapter dh helmis or circular or microfiche dh helmis or multimedias or website)
14.	limit 12 to (audiocass or books or cdrom or chapter or dept pubs or diskettes or folio pamp or "map" or marc or microfiche or multimedia or pamphlet or parly or press or press rel or thesis or trustdoc or video or videos or website)
15.	13 or 14
16.	12 not 15
17.	euthanasia/
18.	euthanasia.ti,ab.
19.	17 or 18
20.	16 not 19

SPP (Ovid) search terms

1.	palliat*.ti,ab.
2.	((dying or terminal) adj (phase* or stage*)).ti,ab.
3.	life limit*.ti,ab.
4.	hospice*.ti,ab.
5.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
6.	living will*.ti,ab.
7.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
8.	(attitude* adj3 (death* or dying*)).ti,ab.
9.	(end adj2 life).ti,ab.
10.	EOLC.ti,ab.
11.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
12.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
13.	(nursing adj2 (home or homes)).ti,ab.
14.	(terminal* adj2 ill*).ti,ab.
15.	(respite adj2 (care or caring)).ti,ab.
16.	or/1-15
17.	(child* or infant*).ti,ab.
18.	(adult* or adolescent*).ti,ab.
19.	17 not 18
20.	16 not 19

21.	limit 20 to (journal or journal article or online resource or online report or report)
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ASSIA (ProQuest) search terms

1.	<p>palliat*.ti,ab. ((ti,ab(commission* N/2 (support* or service* or model*)) OR ti,ab((service* or program* or co-ordinat* or coordinat*) N/2 (model* or deliver* or strateg* or support* or access* or method* or system* or policies or policy or availab*))) AND ((SU.EXACT("Care" OR "Clinical nursing" OR "Community homes" OR "Community nursery nursing" OR "Community nursing" OR "Compassionate care" OR "Continuing care" OR "District nursing" OR "Family centred care" OR "Geriatric wards" OR "Group care" OR "Health visiting" OR "Home care" OR "Home from home care" OR "Home health aides" OR "Home helps" OR "Hospices" OR "Hostel wards" OR "Informal care" OR "Integrated care pathways" OR "Intentional care" OR "Intermediate care" OR "Intermediate care centres" OR "Lack of care" OR "Learning disability nursing" OR "Length of stay" OR "Liaison nursing" OR "Long stay wards" OR "Long term care" OR "Long term home care" OR "Long term residential care" OR "Nurse led care" OR "Nursing" OR "Occupational health nursing" OR "Ontological care" OR "Out of home care" OR "Outreach nursing" OR "Palliative care" OR "Paranursing" OR "Pastoral care" OR "Patient care" OR "Primary nursing" OR "Private residential care" OR "Process centred care" OR "Quality of care" OR "Radical health visiting" OR "Residential care" OR "Residential group care" OR "Respite care" OR "Shared care" OR "Social care" "Temporary care" OR "Terminal care" OR "Wards") OR (SU.EXACT("Terminally ill elderly people") OR SU.EXACT("Terminally ill fathers") OR SU.EXACT("Terminally ill elderly men") OR SU.EXACT("Terminally ill elderly women") OR SU.EXACT("Terminally ill young adults") OR SU.EXACT("Terminally ill parents") OR SU.EXACT("Terminally ill women") OR SU.EXACT("Terminally ill widowed sisters") OR SU.EXACT("Terminally ill colleagues") OR SU.EXACT("Terminally ill young girls") OR SU.EXACT("Terminally ill people") OR SU.EXACT("Terminally ill men")) OR SU.EXACT("Advance directives" OR "Do not resuscitate orders" OR "Durable power of attorney for health care" OR "Living wills" OR "Treatment preferences" OR "Treatment needs")) OR (ti,ab((advance* or patient*) N/3 (care or caring) N/3 (continu* or plan*)) or ti,ab(attitude* N/3 (death* or dying*)) or ti,ab(end N/2 life) or ti,ab(EOLC) or ti,ab((last or final) N/2 (year or month*) N/2 life) or ti,ab((dying or death) N/2 (patient* or person* or people or care or caring)))))) OR SU.EXACT("End of life decisions")</p>
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B.2 Health Economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to end of life care in NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA) with no date restrictions. NHS EED and HTA databases are hosted by the Centre for Research and Dissemination (CRD). Additional searches were run on Medline and Embase for health economics, economic modelling and quality of life studies.

Table 8: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 04 January 2019	Exclusions Health economics studies Health economics modelling studies Quality of life studies
Embase	2014 – 04 January 2019	Exclusions Health economics studies

Database	Dates searched	Search filter used
		Health economics modelling studies Quality of life studies
Centre for Research and Dissemination (CRD)	HTA - Inception – 04 January 2019 NHSEED - Inception to March 2015	None

Medline (Ovid) search terms

1.	Palliative care/
2.	Terminal care/
3.	Hospice care/
4.	palliat*.ti,ab.
5.	Terminally ill/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	Nursing Homes/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	Hospices/
14.	hospice*.ti,ab.
15.	exp Advance Care Planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care planning/
19.	**"Continuity of Patient Care"/
20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
21.	*Attitude to Death/
22.	(attitude* adj3 (death* or dying*)).ti,ab.
23.	*Physician-Patient Relations/
24.	*Long-Term Care/
25.	**"Delivery of Health Care"/
26.	(end adj2 life).ti,ab.
27.	EOLC.ti,ab.
28.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
29.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
30.	or/1-29
31.	letter/
32.	editorial/
33.	news/
34.	exp historical article/
35.	Anecdotes as Topic/

36.	comment/
37.	case report/
38.	(letter or comment*).ti.
39.	or/31-38
40.	randomized controlled trial/ or random*.ti,ab.
41.	39 not 40
42.	animals/ not humans/
43.	exp Animals, Laboratory/
44.	exp Animal Experimentation/
45.	exp Models, Animal/
46.	exp Rodentia/
47.	(rat or rats or mouse or mice).ti.
48.	or/41-47
49.	30 not 48
50.	limit 49 to English language
51.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
52.	50 not 51
53.	economics/
54.	value of life/
55.	exp "costs and cost analysis"/
56.	exp Economics, Hospital/
57.	exp Economics, medical/
58.	Economics, nursing/
59.	economics, pharmaceutical/
60.	exp "Fees and Charges"/
61.	exp budgets/
62.	budget*.ti,ab.
63.	cost*.ti.
64.	(economic* or pharmaco?economic*).ti.
65.	(price* or pricing*).ti,ab.
66.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
67.	(financ* or fee or fees).ti,ab.
68.	(value adj2 (money or monetary)).ti,ab.
69.	or/53-68
70.	exp models, economic/
71.	*Models, Theoretical/
72.	*Models, Organizational/
73.	markov chains/
74.	monte carlo method/
75.	exp Decision Theory/
76.	(markov* or monte carlo).ti,ab.
77.	econom* model*.ti,ab.
78.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
79.	or/70-78

80.	quality-adjusted life years/
81.	sickness impact profile/
82.	(quality adj2 (wellbeing or well being)).ti,ab.
83.	sickness impact profile.ti,ab.
84.	disability adjusted life.ti,ab.
85.	(qal* or qtime* or qwb* or daly*).ti,ab.
86.	(euroqol* or eq5d* or eq 5*).ti,ab.
87.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
88.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
89.	(hui or hui1 or hui2 or hui3).ti,ab.
90.	(health* year* equivalent* or hye or hyes).ti,ab.
91.	discrete choice*.ti,ab.
92.	rosser.ti,ab.
93.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
94.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
95.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
96.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
97.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
98.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
99.	or/80-98
100.	52 and (69 or 79 or 99)

Embase (Ovid) search terms

1.	*Palliative therapy/
2.	*Terminal care/
3.	*Hospice care/
4.	palliat*.ti,ab.
5.	*Terminally ill patient/
6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)).ti,ab.
7.	((dying or terminal) adj (phase* or stage*)).ti,ab.
8.	life limit*.ti,ab.
9.	*Nursing home/
10.	((care or nursing) adj2 (home or homes)).ti,ab.
11.	*Respite Care/
12.	((respite or day) adj2 (care or caring)).ti,ab.
13.	*Hospice/
14.	hospice*.ti,ab.
15.	*Patient care planning/
16.	(advance* adj2 (plan* or decision* or directive*)).ti,ab.
17.	living will*.ti,ab.
18.	*Patient care/
19.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)).ti,ab.
20.	*Attitude to Death/

21.	(attitude* adj3 (death* or dying*)).ti,ab.
22.	*Doctor patient relation/
23.	*Long term care/
24.	*Health care delivery/
25.	(end adj2 life).ti,ab.
26.	EOLC.ti,ab.
27.	((last or final) adj2 (year or month*) adj2 life).ti,ab.
28.	((dying or death) adj2 (patient* or person* or people or care or caring)).ti,ab.
29.	or/1-28
30.	letter.pt. or letter/
31.	note.pt.
32.	editorial.pt.
33.	case report/ or case study/
34.	(letter or comment*).ti.
35.	or/30-34
36.	randomized controlled trial/ or random*.ti,ab.
37.	35 not 36
38.	animal/ not human/
39.	nonhuman/
40.	exp Animal Experiment/
41.	exp Experimental Animal/
42.	animal model/
43.	exp Rodent/
44.	(rat or rats or mouse or mice).ti.
45.	or/37-44
46.	29 not 45
47.	limit 46 to English language
48.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
49.	47 not 48
50.	health economics/
51.	exp economic evaluation/
52.	exp health care cost/
53.	exp fee/
54.	budget/
55.	funding/
56.	budget*.ti,ab.
57.	cost*.ti.
58.	(economic* or pharmaco?economic*).ti.
59.	(price* or pricing*).ti,ab.
60.	(cost* adj2 (effectiv* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.

61.	(financ* or fee or fees).ti,ab.
62.	(value adj2 (money or monetary)).ti,ab.
63.	or/50-62
64.	statistical model/
65.	exp economic aspect/
66.	64 and 65
67.	*theoretical model/
68.	*nonbiological model/
69.	stochastic model/
70.	decision theory/
71.	decision tree/
72.	monte carlo method/
73.	(markov* or monte carlo).ti,ab.
74.	econom* model*.ti,ab.
75.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
76.	or/66-75
77.	quality-adjusted life years/
78.	"quality of life index"/
79.	short form 12/ or short form 20/ or short form 36/ or short form 8/
80.	sickness impact profile/
81.	(quality adj2 (wellbeing or well being)).ti,ab.
82.	sickness impact profile.ti,ab.
83.	disability adjusted life.ti,ab.
84.	(qal* or qtime* or qwb* or daly*).ti,ab.
85.	(euroqol* or eq5d* or eq 5*).ti,ab.
86.	(qol* or hql* or hqol* or h qol* or hrqol* or hr qol*).ti,ab.
87.	(health utility* or utility score* or disutilit* or utility value*).ti,ab.
88.	(hui or hui1 or hui2 or hui3).ti,ab.
89.	(health* year* equivalent* or hye or hyes).ti,ab.
90.	discrete choice*.ti,ab.
91.	rosser.ti,ab.
92.	(willingness to pay or time tradeoff or time trade off or tto or standard gamble*).ti,ab.
93.	(sf36* or sf 36* or short form 36* or shortform 36* or shortform36*).ti,ab.
94.	(sf20 or sf 20 or short form 20 or shortform 20 or shortform20).ti,ab.
95.	(sf12* or sf 12* or short form 12* or shortform 12* or shortform12*).ti,ab.
96.	(sf8* or sf 8* or short form 8* or shortform 8* or shortform8*).ti,ab.
97.	(sf6* or sf 6* or short form 6* or shortform 6* or shortform6*).ti,ab.
98.	or/77-97
99.	49 and (63 or 76 or 98)

NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Palliative Care IN NHSEED,HTA
#2.	MeSH DESCRIPTOR Terminal Care IN NHSEED,HTA
#3.	MeSH DESCRIPTOR Hospice Care IN NHSEED,HTA
#4.	(palliat*) IN NHSEED, HTA
#5.	MeSH DESCRIPTOR Terminally Ill IN NHSEED,HTA
#6.	((terminal* or long term or longterm) adj2 (care* or caring or ill*)) IN NHSEED, HTA
#7.	((dying or terminal) adj (phase* or stage*)) IN NHSEED, HTA
#8.	(life limit*) IN NHSEED, HTA
#9.	MeSH DESCRIPTOR Nursing Homes IN NHSEED,HTA
#10.	((care or nursing) adj2 (home or homes)) IN NHSEED, HTA
#11.	MeSH DESCRIPTOR Respite Care IN NHSEED,HTA
#12.	((respite or day) adj2 (care or caring)) IN NHSEED, HTA
#13.	MeSH DESCRIPTOR Hospices IN NHSEED,HTA
#14.	(hospice*) IN NHSEED, HTA
#15.	MeSH DESCRIPTOR Advance Care Planning EXPLODE ALL TREES IN NHSEED,HTA
#16.	((advance* adj2 (plan* or decision* or directive*)) IN NHSEED, HTA
#17.	(living will*) IN NHSEED, HTA
#18.	MeSH DESCRIPTOR Patient Care Planning IN NHSEED,HTA
#19.	MeSH DESCRIPTOR Continuity of Patient Care IN NHSEED,HTA
#20.	((advance* or patient*) adj3 (care or caring) adj3 (continu* or plan*)) IN NHSEED, HTA
#21.	MeSH DESCRIPTOR Attitude to Death IN NHSEED,HTA
#22.	((attitude* adj3 (death* or dying*)) IN NHSEED, HTA
#23.	MeSH DESCRIPTOR Physician-Patient Relations IN NHSEED,HTA
#24.	MeSH DESCRIPTOR Long-Term Care IN NHSEED,HTA
#25.	MeSH DESCRIPTOR Delivery of Health Care IN NHSEED,HTA
#26.	((end adj2 life)) IN NHSEED, HTA
#27.	(EOLC) IN NHSEED, HTA
#28.	((last or final) adj2 (year or month*) adj2 life)) IN NHSEED, HTA
#29.	((dying or death) adj2 (patient* or person* or people or care or caring)) IN NHSEED, HTA
#30.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 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
#31.	(#30) IN NHSEED
#32.	(#30) IN HTA

Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of barriers and facilitators to the involvement of carers in planning and decision making.

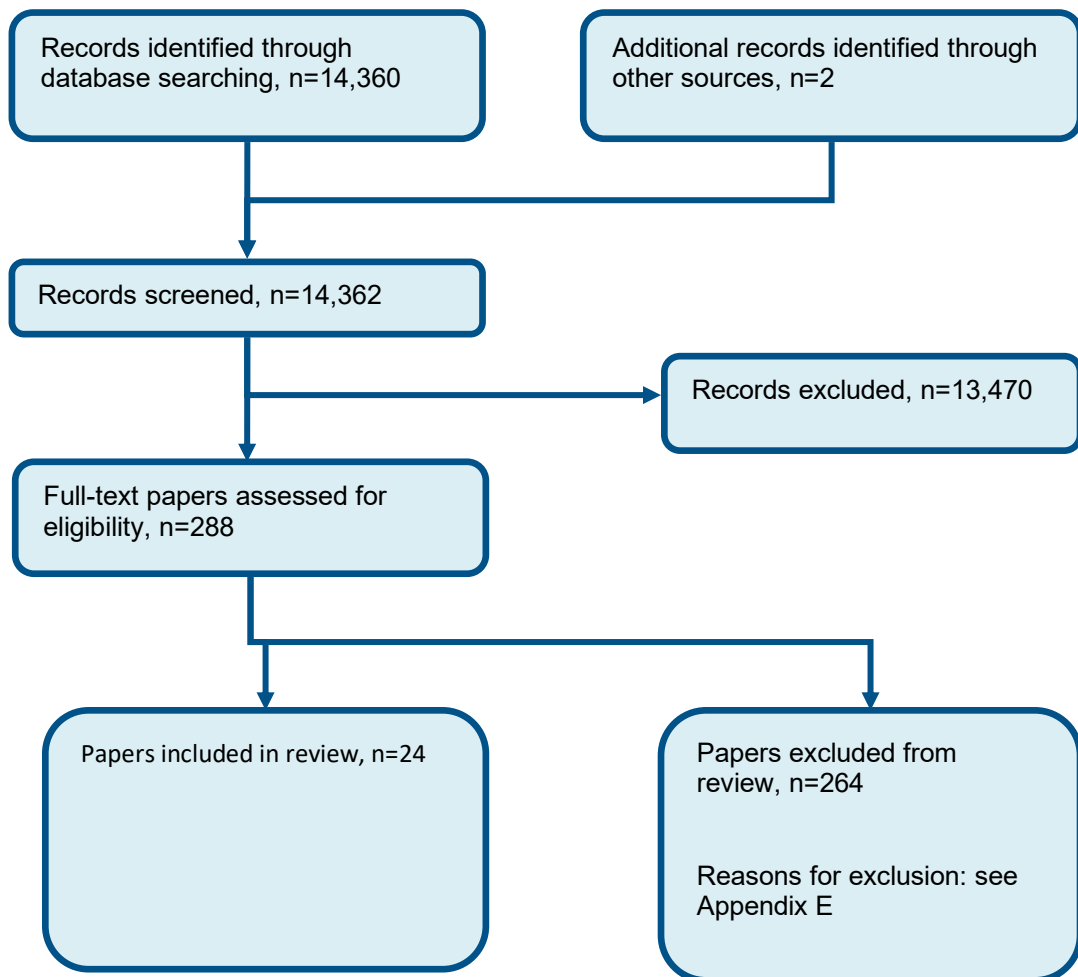
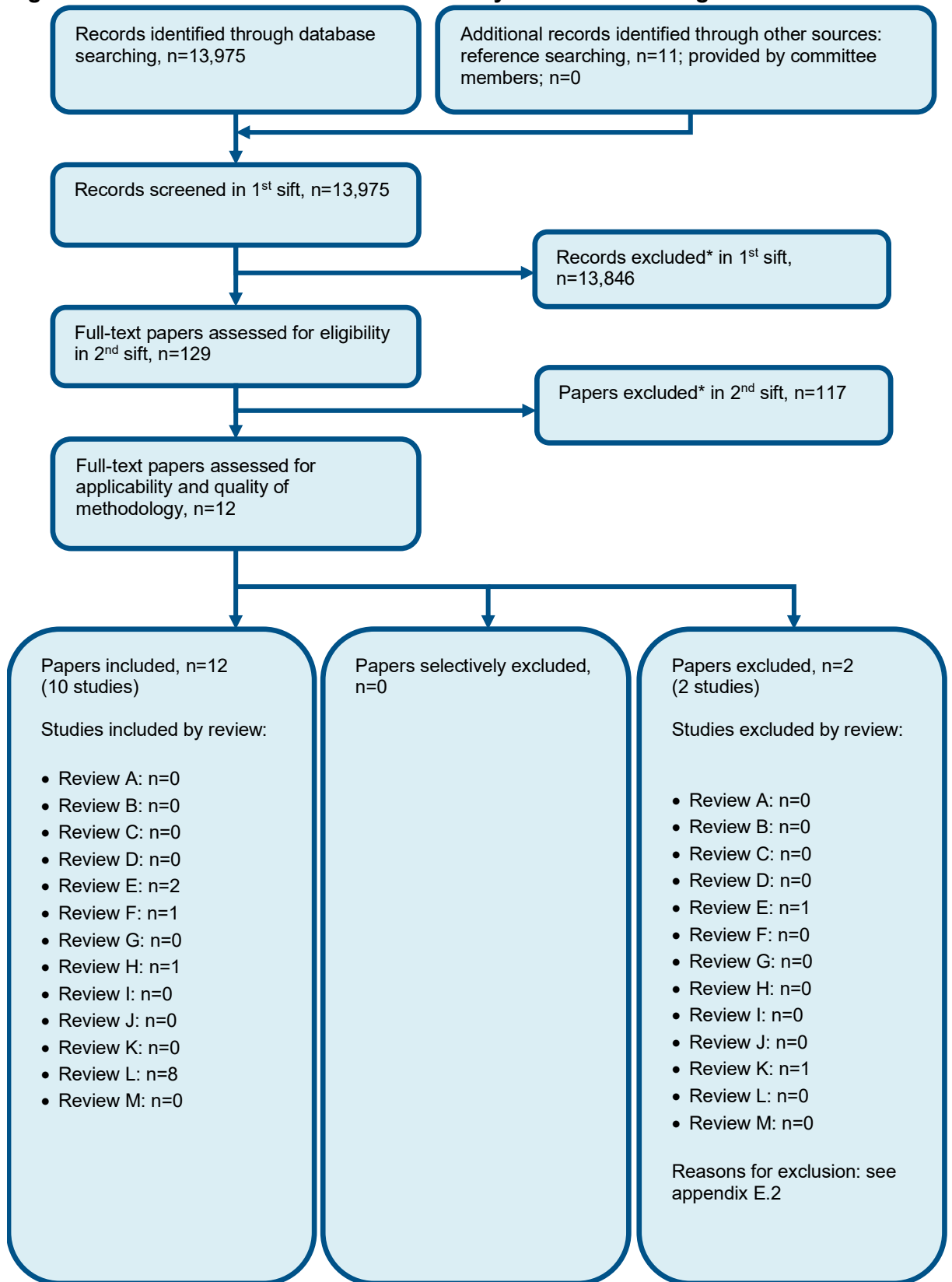


Figure 2: Flow chart of health economic study selection for the guideline



* Non-relevant population, intervention, comparison, design or setting; non-English language

Appendix D: Qualitative evidence tables

Study	Ates 2018 ⁸
Aim	To examine the burdens and rewards associated with family caregiving and the effects of the Integrated Palliative Care initiative Networks on caregivers support systems.
Population	Family caregivers looking after people with cancer, chronic obstructive pulmonary disease or chronic heart failure.
Setting	Integrated Palliative Care initiative Networks in Belgium, Germany, Hungary, The Netherlands, UK N=156
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	Face-to-face in-depth interview to gain narrative data, with thematic qualitative analysis. Interview guide developed, 2 interviews 3 months apart each lasting an average of 1 hour. Interviews were audio-recorded and transcribed verbatim. Thematic analysis
Findings	<p>Lack of knowledge: access to knowledgeable practitioners: Access to skilled practitioners increased satisfaction and improved feelings of helplessness and uncertainty.</p> <p>Emotional Burden :Care giving was seen by some people as a heavy burden and acknowledged it was tough.</p> <p>Access to healthcare providers: This was seen as positive and increased feelings of confidence.</p> <p>Trust in health-care providers: Where there was trust in health providers the experience of caring and services was more positive.</p>
Limitations and applicability of evidence	Analysis could have been more in depth. Applicable

Study	Caron 2005 ²⁴
Aim	To examine the experience and preoccupations of family caregivers about end-of-life issues, and more specifically, about treatment decision-making processes in the context of advanced dementia.
Population	Family caregivers involved in the care decisions for an older family member with late-stage dementia, as documented in the patient's medical record (n=24).
Setting	Canada, interview
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	<p>Face-to-face in-depth interview to gain narrative data, with thematic qualitative analysis.</p> <p>Grounded theory method was used. Each caregiver or caregiving dyad participated in one in-depth interview, recorded on audiotape in order to collect data in narrative form. The audiotapes were transcribed for analysis purposes. The questions posed in the early interviews were open ended. As the research progressed through an iterative process whereby the analysis of each interview prompted questions for subsequent interviews in order to capture experience of the caregivers, interview questions focused on specific dimensions of the model under development.</p> <p>The constant comparative method and line-by-line/dimensional analysis were used to code each interview. To ensure that personal beliefs of research team members were not imposed on the subject matter and to allow cross-validation in the interpretation of the interviews, at least two members of the research team participated in the data analysis sessions.</p>
Findings	<p>Frequency of contact: Nearly all caregivers expressed a desire to meet with health care professionals more, on an informal basis. Few caregivers were fully aware of their role as decision makers. Lack of knowledge from the family caregiver was a key barrier to decision making.</p> <p>Trust: Trust with physician an important facilitator in the decision making process. To be informed of the care needs allows caregivers to establish trust and, as a result, to delegate certain decisions. Interactions between the family caregivers and the professional in the care setting are an important dimension of effective and harmonious decision making for both caregivers and healthcare providers.</p> <p>Values and beliefs: A factor that influenced decision making, in terms of considering a medical treatment, is the concordance of values and beliefs between the caregiver and the professional. In nearly all of the situations described by caregivers who requested a specific intervention, their values and beliefs were matched by those of the care team. When values were shared, end of life moments were easier for the caregiver, and negative sentiments such as guilt about terminating treatment and grief were reduced.</p>
Limitations and applicability of evidence	<p>Role of researcher unclear. Analysis could have been more in depth. Unclear if themes reached saturation.</p> <p>Applicable</p>

Study	Denig 2012 ³⁹
Aim	To identify barriers to people dying with dementia and their carers receiving good end-of-life care, and to identify good practice that might inform improvements in care.
Population	Carers – relatives or friends who had provided care on a regular, unpaid basis to people who had died with dementia. (n=7). Gender (male): 2; Employment: Working 4, Retired 3; Ethnicity: White British 6, Other 1; Carers role: Full-time 4, Lived with person with dementia 4; Relationship: Wife 2, Daughter 3, Son 1, Other 1
Setting	UK. Set in the health and social care system of a London borough (Haringey).
Study design	Qualitative: nominal group technique.
Methods and analysis	<p>Each focus group comprised of staff from one professional group, was led by a researcher with clinical experience in this field and lasted approximately 1 h. A second researcher co-facilitated and took field notes. Sessions were also recorded. When a professional was unable to attend a focus group, an hour-long one-to-one interview was offered. A structured topic guide was developed with the steering group and from a toolkit that has been used for other palliative care populations. This provided headings to prompt the focus group moderator or the individual interviewer.</p> <p>A topic guide similar to that for the focus groups was used to lead semi-structured interviews, allowing a natural flow of conversation while ensuring comprehensive data collection. Interviews were conducted in a place of the carer's choice, usually their own home, lasting approximately 1 h. Interviews were recorded and field notes were taken by a second interviewer. If participants became upset, they could end the interview and they were offered support through the Admiral Nurse Service.</p> <p>The tapes and field notes of focus groups and one-to-one interviews were transcribed verbatim, preserving participant anonymity. The data were then pooled and coded manually using content thematic analysis. This involved detailed reading of each transcript by two researchers (WG and KHD) who independently identified distinct units of meaning and then collected similar units together. Initial themes describing the barriers to providing good quality end-of-life care were generated by both researchers who then combined units and relabelled categories, as necessary through an iterative process. The final emerging themes were then independently triangulated by ELS who checked and verified the themes by re-examining the original data.</p>
Findings	Advance care planning: There was variable awareness of advance care planning among families. There was little evidence that people at any stage of dementia were asked about their wishes. Carers therefore often have to make complex decisions for their relative, with little support or information: "We had to make important decisions... we found this hard and needed help...they thought he might need a tube to feed or another treatment that I cannot remember. Three different doctors said three different things... they said 'you have to decide'".
Limitations and applicability of evidence	<p>Mixed population so only evidence from carers was included. There were a limited number of participants, with even fewer when limited to just carers. The sample was restricted to one locality but 'represented a range of ethnicities, types of carers, living situations and levels of education'.</p> <p>Lack of detail of context of focus groups; the background of the researcher and selection of the methods used. However the study met its aims, gave adequate details of how focus groups were conducted and data analysis. The resulting data was sufficiently presented.</p>

Study	Denig 2013 ⁴⁰
Aim	To explore whether people with dementia and their Carers were able to generate and prioritise preferences for end-of-life care. Examining whether carers influenced the choices made by the persons with dementia.
Population	Number in study: carers n=5; people with dementia n=6; dyads of people with dementia and carers n=6; male/female (carers): 3/5; mean age (SD)(carers): 66.8 years; (dyad) 73.3 years; Diagnosis of people with dementia: Alzheimer's late onset n=4; atypical or mixed type Alzheimer's n=4; Alzheimer's of unspecified type n=1; relationship to person with dementia: spouse n=5; son/daughter n=2; sibling n=1.
Setting	Purposive sample from the Memory Service in Barnet, Enfield and Haringey Mental Health National Health Service Trust was recruited.
Study design	Qualitative: nominal group technique.
Methods and analysis	<p>Modified nominal group technique was used which involved three focus groups, using a predetermined schedule, which included an introductory text and a basic introduction to ACP: generation of ideas (10 minutes); discussion (15 minutes); further generation of ideas (10 minutes); discussion and generation of themes (10 minutes) and individual ranking (100 minutes).</p> <p>Qualitative data were collected from three nominal groups on different days from October 2009 to January 2010. The researcher was assisted by a specialist dementia (Admiral) nurse to support individual who required help during or after the group.</p> <p>Data analysis: Collation of themes and scoring of the individual ranked items and qualitative content analysis of discussion transcripts. Emerging patterns were identified, coded and categorised from the data, and were divided and organised within NVIVO8, supported by manual coding and theming independently and then collectively by the researcher and supervisor to ensure reliability and validity. The data tree and themes were then agreed upon.</p>
Findings	<p>Good quality care: all participants wished good quality care at the end of life, with carers hoping for control over this. Carers talked extensively about their perceptions of poor quality care, based upon recent media coverage and reflections of personal experiences of caring for a person with dementia, and framed this as care they would not want for themselves. Several spoke of care that was 'desirable'.</p> <p>Independence and control: the carers considered a future time when they themselves might lack decisional capacity. There was a general fear and uncertainty with a lack of trust in medical decision-making.</p> <p>The dyad group carers tended to speak on behalf of the person with dementia, thus influencing the collective view.</p> <p>The carers felt it was difficult to plan ahead and anticipate what may or may not happen.</p> <p>The carers felt that medical decision-making and the use of end-of-life care pathways could invalidate their ACPs.</p> <p>The carers expressed scepticism about whether an ACP would allow them to retain control. They thought that ACP may be a process with no firm outcomes open to (mis)interpretation by professionals.</p> <p>Several carers felt the only way to ensure that control was retained was to take matters into their own hands through assisted dying and euthanasia. The carer group grew in confidence to admitting that many felt similarly, to the extent that one member used the term</p>

Study	Dening 2013 ⁴⁰
	<p>'suicide'. While acknowledging that euthanasia is not legal in the United Kingdom they reached a consensus that you cannot discuss ACP without it.</p> <p>It was highlighted that if end-of-life care was better, individuals would not need to contemplate euthanasia.</p> <p>Summarising their views on ACP, the carer group felt that carers' needs should also be taken into account.</p> <p>Perceptions of burden and caring: the carers in the dyad often spoke over the person with dementia to point out they did not want their children to find themselves in a similar position [to themselves e.g making decisions and providing intimate care].</p> <p>Spousal carers appeared more accepting of their caring role, whereas siblings or children talked of the overwhelming difficulties of caring. One carer experienced such stress that should she also be affected by dementia, she had told her children that she wanted to go into a care home. She did not want her relationship with her children to be damaged by burden or responsibility.</p> <p>The carers challenged 'the system' arguing that if health and social care were effective in supporting people with dementia and their Carers, 'burden' would not be an issue.</p>
Limitations and applicability of evidence	<p>Mixed population so only evidence from carers was included. There were a limited number of participants, with even fewer when limited to just carers. The sample was restricted to one locality but 'represented a range of ethnicities, types of carers, living situations and levels of education'.</p> <p>Lack of detail of context of focus groups; the background of the researcher and selection of the methods used. However the study met its aims, gave adequate details of how focus groups were conducted and data analysis. The resulting data was sufficiently presented.</p>

Study	Forbes 2000 ⁵² (Gessert 2001) ⁵⁵
Aim	To examine families end of life decision making and their interactions with health professionals.
Population	Family members of residents at four purposefully selected nursing homes in Kansas City (n=28); 10 daughters 4 wives, 4 husbands, 3 daughter-in-law, 2 sons, 2 sisters, 1 nephew, 1 sister-in-law, 1 grandson. Median family member age (range): 66 (41-85). Median nursing home resident age (range): 84 (75-95). Investigators selected residents with moderately-severe dementia. Participants described their institutionalized relatives as having moderate to advanced cognitive impairment.
Setting	USA. Four nursing homes in the Kansas City area, including racial and economic diversity.
Study design	Qualitative: nominal group technique.
Methods and analysis	<p>Structured focus group (nominal group technique) with thematic qualitative analysis. Data were collected at focus groups, one at each of the four facilities. Each focus group had between 5 and 8 participants. Common, broad, open-ended questions were used in all four groups. Focus groups lasted approximately two hours and were tape recorded.</p> <p>Data analysis: Qualitative content analysis, the process of identifying, coding, and categorising patterns as they emerge from the data was used to analyse the data. Data analysis occurred in three phases. Following transcription, each focus group interview was read to obtain a 'sense of the whole'. Codes, words, or phrases to organise data were derived as they were identified from the data. Definitions</p>

Study	Forbes 2000 ⁵² (Gessert 2001) ⁵⁵
	were written for each code. Categories were developed to organise codes into meaningful clusters, and detailed descriptions were written for each category. Patterns and themes were then visualised within HUD*IST.
Findings	<p>Emotional effect: Significant emotional burdens experienced by family members in their roles as decision makers. Family members described their current burdens, guilt, and losses, but found it difficult to discuss dying or end-of-life discussions.</p> <p>Unrecognised dying trajectory: Most family members were unable to conceptualise the trajectory of disease and dying process. Family members made decisions with limited knowledge, unaware of what they did not know. They were unable to synthesise information into a larger conceptual framework to guide end-of-life decision. Many participants were comfortable with making decisions “when the need arose” but were unable to identify “the need to have arisen”. Participants tended to envision death as a “big event” and did not see their day-to-day decisions as having a direct bearing on their relative’s death. Decisions were being made “piece by piece” or “in the moment” without considering the “big picture”. Family members indicated that they lacked consistent communication with a specific healthcare provider. This lack of communication appeared to be a major factor in participants’ inability to envision the dying trajectory.</p>
Limitations and applicability of evidence	Little information on care home or population. Role of researcher unclear. Applicable.

Study	Holley 2009 ⁷¹
Aim	To assess caregivers expectations and satisfaction with a home-based geriatric palliative care program (Palliative Access Through Care at Home (PATCH)).
Population	<p>N=22 Carers (telephone interviews): male/female 3/19; age 62.2 +/-14.4; primary diagnosis of person caring for: dementia (n=12); cancer (n=7); failure to thrive (n=3) heart disease (n=13); falls and fractures (n=1); other (n=1); relation to patient: daughter n=12; son n=1; wife n=2; husband n=1; grandchild n=2; other n=4. Carers who went on to face-to-face interviews: n=13: no details of characteristics.</p> <p>People eligible for PATCH are: aged 65 and older; enrolled in Medicare Part B and have an existing University of Chicago affiliation; are homebound (as defined by Medicare) and have a limited life expectancy defined by the patient’s primary care provider as “not being surprised if the patient died in the next year.”</p>
Setting	PATCH is a home-care program developed through the University of Chicago’s Section of Geriatrics and Palliative Medicine in 2006. Carers either gave telephone interviews or face-to-face interviews.
Study design	Qualitative, mixed methods.
Methods and analysis	Structured telephone interviews and in-depth face-to-face semi-structured interviews with thematic qualitative analysis.

Study	Holley 2009 ⁷¹
	<p>Telephone interviews were asked for their own demographic information, time spent providing care, time spent working outside the home, and the extent of involvement of other caregivers. Also to identify the primary site of the patient's care (home, hospital, inpatient hospice, nursing home, or other), site of patient's death, and enrolment in hospice (yes/no) and to rate satisfaction (on a 5-point scale) with site of death and care provided by PATCH. At end they were asked if they would be willing to participate in a face-to-face interview.</p> <p>Face-to-face interviews lasted 25 to 60 minutes with the 13 participants that agreed to complete. Two of the authors developed an interview guide comprising lead and secondary questions that was used in conducting individual interviews. The interviewer followed respondents' cues to guide the questioning sequence, simultaneously ensuring that all domains in the guide were covered. The major domains included experiences with being a primary caregiver for a patient at the end of life, the healthcare system, and the PATCH program.</p> <p>Face-to-face interviews were audiotaped and transcribed. Three of the authors reviewed and independently coded the first seven transcripts using content analysis. Authors recorded themes and supporting quotes from transcripts and were discussed until consensus established. Reaching saturation after coding of seven transcripts, but further transcripts were extracted.</p>
Findings	<p>Preferences about the location of care: Two subthemes: - physical and psychological difficulty that frail older patients confront when trying to attend outpatient clinic appointments - attachment patients had to their homes after living in the same place for decades</p> <p>Ease of access to a Geriatrics and Palliative Care expert: several caregivers reported difficulties reaching their primary care provider before enrolment in PATCH. Messages often went through an answering service or voicemail and were not properly relayed, whereas PATCH provided 24-hour access to a practitioner. Calls were always returned in a timely manner.</p> <p>A parallel concern was having access to a practitioner trained in geriatrics, palliation, and end-of-life care. This access resulted in relief for lay caregivers, who often felt uncertain about the care they were providing for patients, and for patients, who felt comforted by the presence of a physician in their home.</p> <p>They appreciated the easy access to a knowledgeable practitioner that PATCH provided.</p> <p>Transitions of care: Caregivers described multiple problems regarding transitions of care before enrolment in PATCH. They recounted stories of transfers in and out of hospitals, sub-acute nursing facilities, and LTC facilities without sufficient communication between institutions, often in the face of mounting medical problems. Carers spoke of difficulties understanding different levels of care and recognising when the transition to end-of-life care should begin. This contrasted with PATCH where providers were "in tune with" patients' conditions and "helped us into that next level of" care'. By providing caregivers with a consistent place to turn despite multiple sites of healthcare delivery, PATCH was able to provide anticipatory guidance to patients and caregivers and help transitions toward the end of life occur more smoothly. Some criticisms on transitions of care were also voiced. One caregiver of one patient who was</p>

Study	Holley 2009⁷¹
	transferred to an LTC facility expressed disappointment when PATCH care was transferred to the LTC physician. Two other caregivers suggested that the program could be improved by enrolling patients earlier in the course of their illness, possibly helping them avoid the multiple transitions they had initially faced.
Limitations and applicability of evidence	Specifically looking at one program of care (PATCH) but also discusses the care they had before. No details of researchers potential bias or where conducted. The study was described well for how it was conducted, and analysed. Appropriate opposing positions considered. Only relevant in parts as some parts not about decision-making or planning. Also the topics may be system-related and it is based in USA, where system they are describing differs.

Study	Jackson 2012⁸¹
Aim	The objective of this study was to explore family perspectives of end-of-life care in long-term-care settings from interviews of family members who have had a loved one die in a long-term-care facility.
Population	Family members who had lost a loved one in a long-term-care facility during the prior 3 to 18 months. (n=19)
Setting	USA. Four long-term facilities.
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	19 interviews exploring family members' perspectives after death of a loved one. Face-to-face interviews allowed family members to share what the family experiences were like. Investigators used qualitative content analysis to examine the interview data. Then, the investigators conducted a meta-synthesis to explore the 19 interviews as one data set, identifying categories and uncovering important factors in end-of-life experiences.
Findings	Decision making in the presence of AD: Families reported that having ADs made decision making a lot easier, knowing that they could always say it was their loved ones wish. However, even with the presence of ADs, there were still grey areas about healthcare proxies making the decision to sign a DNR, and decisions about feeding tubes, fluids and other interventions. Advice to families: Families believed that early discussions were important in advocating for their loved ones wishes at the end of life. Families advised others to find good a good facility and have good healthcare staff to guide them through the process. Having ADs written down and in place prior to decline was noted by most as essential.
Limitations and applicability of evidence	Little information on analysis so rigour and reliability unclear. Unclear if themes reached saturation. Applicable

Study	Kryworuchko 2012 ⁹²
Aim	To explore family involvement in decisions about life support interventions in the intensive care.
Population	Family members of critically ill patients in the ICU. 6 family members of 3 patients participated.
Setting	Canada. Ottawa Hospital ICU
Study design	Qualitative: Face to face interviews.
Methods and analysis	<p>Family members were asked to describe at least 1 critical incident based on their current experience deciding about life support interventions for the patient in ICU. Participants were prompted to describe the decision making process, and the roles of others involved, As well, participants were asked about factors which promoted or detracted from their ability to effectively involved family members in shared decision making (SDM).</p> <p>Data were collected during face to face interviews with participants. Interviews were audio-recorded and field notes were taken by the interviewer. Analysis occurred after each interview to inform subsequent interviews. Interviews were transcribed verbatim and the NVivo 8 software program was used to facilitate data management. Directed content analysis of interview transcripts was done by the interviewer to identify critical incidents which were then grouped into categories that described the decision making process. The content was coded inductively into themes. Discrepancies were resolved with another team member.</p>
Findings	<p>Decisions to be made: HCP not offering alternative options - “There was no choice. But it was a very fast decision”. HCP desire to avoid burdening family - “One of the things that’s so stressful about being here is that you don’t know if people are telling you the truth. So your family member is dying and you don’t want people to placate you”</p> <p>Information exchange: Some family members experienced not knowing what questions to ask HCP.</p>
Limitations and applicability of evidence	<p>Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation.</p> <p>Applicable</p>

Study	Lamahewa 2017 ⁹⁶
Aim	To explore difficulties in decision making for practitioners and family carers at the end of life for people with dementia.
Population	Former (n=4) and current (n=6) family carers of people with experience of end of life care for a person with dementia
Setting	UK
Study design	Qualitative: Face to face interviews.
Methods and analysis	One focus group (n=3) and three individual semi-structured interviews were conducted with current carers; one focus group (n=4) was conducted with former carers. Individual semi-structured interviews were offered to family carers who preferred not to participate in a focus group.

Study	Lamahewa 2017 ⁹⁶
	<p>Interviews were conducted by an experienced qualitative researcher, and focus groups were facilitated by a researcher experienced in conducting focus groups, observed by an additional researcher who took field notes.</p> <p>Focus group and individual interviews were audio-recorded and transcribed verbatim by an external transcriber and checked by. An inductive approach was taken using thematic analysis methods. Each transcript was read independently by two researchers to familiarize themselves with the data. Following this, line-by-line coding was carried out by, who has a background in social sciences and, who is a general practitioner on both family and practitioner transcripts. Coding was discussed between; and as similar and complementary codes were identified in both family carer and practitioner transcripts, a single coding strategy was agreed for both groups. The remainder of the interviews and focus groups were coded using the agreed coding strategy by. After coding of all transcripts and clustering the codes into categories, provisional themes were agreed upon with others in the research team. Themes were revised iteratively, searching for negative and deviant cases to ensure the themes were supported by the data, increasing the rigour of the findings. Family carer and professional data were analysed together as following initial reading of the transcripts and discussions within the research team, and it was clear there was a high level of overlap between professional and carer views.</p>
Findings	<p>Uncertainty: Often decisions were based on the family member's insight about/or knowledge of the values or preferences of the person with dementia. However, they expressed feelings of uncertainty in how to best meet the needs of their relative.</p> <p>Advance care planning: Preparing early for a progressive decline in health and the inevitable end of life phase, when the person with dementia may be unable to convey or express their wishes, was thought to be vital by some participants. Advance care planning was thought to ease the burden of decision making for family who may otherwise struggle to make best interest decisions.</p>
Limitations and applicability of evidence	<p>Role of researcher unclear. Unclear if themes reached saturation.</p> <p>Applicable</p>

Study	Lind 2013 ¹⁰³
Aim	To explore how relatives of terminally ill, alert and competent intensive care patients perceive their involvement in the EOLC decision making process.
Population	Family members of deceased patients from four Norwegian ICUs (n=11). Patients were terminally ill, alert and competent intensive care patients (n=6). Inclusion criteria: >18 years for both patient and relative, daily visits by the relative and a decision to withdraw treatment document in the patient record.
Setting	Norway. Most interviews took place at the participants' home.
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	<p>Face-to-face single narrative-inducing question interviews, followed semi-structured interviews with thematic qualitative analysis.</p> <p>All interviews were conducted by the first author, an experienced ICU nurse and a trained researcher. Interviews lasted 60-90 minutes, were recorded digitally, and transcribed by the lead author and an assistant. Using a single initial narrative-inducing question 'Can you</p>

Study	Lind 2013 ¹⁰³
	<p>tell me what happened?’ an extensive narrative was elicited in all interviews. Next using a semi-structured interview guide, the interviewer followed up topics from the narrative.</p> <p>The interview texts were analysed in several steps using thematic narrative analysis. Each of the six narratives was studied separately and interpreted as a whole in an attempt to capture its meaning. Certain relevant themes emerged from each interview. The hermeneutic approach used involved a continual movement between the parts and the whole of the narrative being analysed. The emergent themes were compared across the six narratives, revealing both commonalities and variation. This process led to iterations, alternative explanations for the findings were discussed and agreed upon.</p>
Findings	<p>Transparency in communication: Family-clinician communication varied in quality. The information given by the assigned nurse was often considered vague. Those families strongly involved in the dialogue between doctors, nurses and patient or who acted as surrogates for the patient reported greater satisfaction with the communication. They saw their role as supportive by being physically present at the bedside and able to repeat the information to the patient. The families that did not participate in the doctor-patient dialogue also had limited communication with nurses and were allowed less time with the patient than desired. Hence, they were unsure how much and what kind of information the patient had received, especially regarding EOL decisions and treatment termination. This was a difficult matter for these families. They felt that important issues between the patient and themselves remained unresolved.</p> <p>Participation in the end of life decision making process: Since some families were uncertain how much information the patient had received, they could not easily judge whether they were informed.</p> <p>Family members described experiencing uninformed participation in decision making, specifically being shocked. This unpreparedness resulted in no patient-family communication and the specific basis for the patient’s alertness remained undiscussed.</p> <p>Two families were just informed of the doctors’ decision to terminate treatment. Both situations were perceived as offensive, and these families had struggled with the memory of the way this was done. Nurses did not participate in these talks. The relatives were unsure whether the patient’s consent was obtained or whether he was told of the decision.</p>
Limitations and applicability of evidence	<p>Subgroup from a parent study; little information on ICU population.</p> <p>Applicable</p>

Study	MacDonald 2011 ¹⁰⁹
Aim	To provide insight into how the clinical ethicist can effectively support family caregivers when making end-of-life healthcare decisions.
Population	20 family caregivers previously involved in end-of-life decision-making
Setting	Canada.
Study design	Qualitative: Face to face interviews.

Study	MacDonald 2011 ¹⁰⁹
Methods and analysis	<p>Using a grounded theory approach, a theoretical sampling of 20 family caregivers previously involved in end-of-life decision-making were interviewed. Semi-structured in-depth interviews were conducted by the lead author, audiotaped, and transcribed.</p> <p>Constant comparative analysis was used to guide analysis of the data. Constant comparative analysis is described as the process of taking information from data collection and comparing it to emerging categories. Three stages of coding, open, axial, and selective coding were used.</p>
Findings	<p>Knowing the family members wishes and considering their best interests: Throughout the course of the interviews, every family member emphasised the importance of knowing the patient's wishes in making decisions about care and treatment. Some respondents knew specifically what types of treatment their family member would want, and they realised the usefulness of this information in decision making. Many mentioned the aspect of considering their family members best interest, whether or not they knew their wishes.</p> <p>Effectiveness of healthcare professionals in supporting families: Family members discussed a desire to receive complete and accurate information, not wishing to have the opinion of healthcare professionals forced on them, and a wish for the HCP to view their patients in a more holistic way. They wanted to know the seriousness of their relatives' illness and consequently this information helped them in making decisions about care and treatment. The families desired congruence between words and actions, which helped them come to terms with the seriousness of their relatives situation.</p>
Limitations and applicability of evidence	<p>Role of researcher unclear. Unclear if themes reached saturation.</p> <p>Applicable</p>

Study	Michael 2014 ¹¹⁸
Aim	To examine how cancer caregivers view advance care planning (ACP) to inform an ACP program in an Australian cancer centre.
Population	Patients from the lung and gastrointestinal tumour streams. Patients with a prognosis of four or less weeks (as determined by the Palliative Prognostic Score or where unavailable, formulated prognoses by the treating clinician), Eastern Cooperative Oncology Group score of 0–3, and cognitively intact (≥ 22 on the Mini-Mental State Examination). Patients and caregivers were more than 25 years of age (A specific department exists within the cancer centre aimed at adolescents and young adults between the age of 18 and 25 years. 41 patients permitted 42 caregivers to be approached. 18 carers of 17 patients consented to participate.
Setting	Australia. Tertiary cancer centre, Melbourne.
Study design	Qualitative: Focus groups and face-to-face interviews.
Methods and analysis	The research used a qualitative descriptive design with grounded theory overtones. The study sought to provide a comprehensive summary of participants' views through theoretical sampling; multiple data sources (focus groups and interviews); inductive, cyclic, and constant comparative analysis; and condensation of data into thematic representations. The vignette technique was incorporated and involved short stories about people in defined circumstances, on which the interviewee was invited to comment. The vignettes can help participants to explore potentially sensitive topics, with participants determining whether to introduce personal experiences. The

Study	Michael 2014 ¹¹⁸
	<p>vignettes and interview guide used to explore cancer patients' ACP views were modified to describe situations of a family member/loved one at different cancer stages, with varying degrees of ill health, symptoms, and cognitive involvement.</p> <p>Before attending the FGs or interviews, caregivers were asked to explain their initial understanding of ACP. They were then given written explanatory information on ACP. On meeting the researcher(s), caregivers were asked to read the four vignettes, reflect on the situations in relation to the patient whose care they were involved with, and respond to semi-structured questions asking about their experiences and thoughts on ACP. FGs were led by N. M. and C. O., and interviews were conducted by C. O. The mean individual interview times were 67 minutes (standard deviation, 14.2); the mean FG times were 84 minutes (standard deviation, 19.6). On-going sampling occurred until data were repetitive and findings were considered to provide varied and valuable insights into caregivers' views.</p> <p>The cyclic and comparative analysis included inductive coding, comparable codes condensed into researcher-created categories, and comparable categories condensed into researcher-created themes. The second author conducted the initial analysis, and three other authors provided qualitative inter-rater reliability by reading transcripts and either agreeing with the analysis or discussing further ideas until reaching agreement.</p>
Findings	<p>Confronting ACP: Although some caregivers' families and friends may support and share ACP discussions, others find them difficult, possibly increasing caregivers' isolation. One caregiver described how the family usually "collectively try and work something out" when facing important decisions such as selling houses, but she was now taking leadership on ACP because her brother "says it's an awful topic" and her sister was "kind of detached." According to the caregivers, there is often a mismatch between primary and secondary caregivers' and patients' desires to discuss various ACP components. Caregivers sometimes found that patients could be confronted by the caregivers' information needs, Some felt that it important for patients to have private conversations with health professionals in which patients could share information that they protectively did not want caregivers to know.</p>
Limitations and applicability of evidence	<p>Little information on analysis so rigour and reliability unclear. Role of researcher unclear.</p> <p>Applicable</p>

Study	Muders 2015 ¹²⁷
Aim	To explore and document the needs of family caregivers of patients dying with dementia and to identify how healthcare professionals can adequately support them
Population	N=310 for the full study N=85 answered the two open-ended questions. Family members of dementia patients who had died.
Setting	Survey carried out in the Federal state of Rhineland-Palatinate, Germany between September 2008 and January 2009.
Study design	Qualitative study: cross-sectional study with open-ended questions, the study focuses on the responses to the open-ended questions only.

Study	Muders 2015 ¹²⁷
Methods and analysis	<p>Cross-sectional survey containing 2 open-ended questions from the Establishment of Hospice and Palliative Care Services (EPACS) survey that were analysed using qualitative methods. The questionnaire was sent to randomly drawn family members of deceased citizens. The two questions were “As far as I am concerned, I would have appreciated if the healthcare professionals” and “do you have suggestions on how to improve the care of terminally ill patients?” Only answers related to personal support for family caregivers of persons with dementia at the end of life were considered.</p> <p>Philipp Mayring’s approach to qualitative content analysis was used. Four main categories were constructed, only one is reported here that relates to the review question.</p>
Findings	<p>Communication and information: the respondents would have liked to be informed earlier and more comprehensively about general and specific issues. They would have appreciated easier contact with professionals, as well as more information about the diagnosis, about changes in the state of the health of their loved ones, and about outpatient support services.</p> <p>An important concern of respondents was obtaining information about the hospital staff.</p> <p>In some cases, relatives were not sufficiently informed about the disease pattern of dementia nor about the treatment. They requested an open and comprehensible communication with HCPs.</p> <p>Another suggestion was timely notification of families in case of a patient’s worsening state of health.</p>
Limitations and applicability of evidence	<p>The study was conducted after the patients had died so there may be recall bias. No details given about ethical considerations. No details given about researcher bias.</p> <p>Partially applicable: only one category met the PICO of the review.</p>

Study	O’Hare 2017 ¹³⁴
Aim	To learn about the experiences of family members and friends of patients with advanced kidney disease.
Population	Family members and friends of patients with advanced kidney disease.
Setting	USA
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	All participants completed a 45–60-minute semi-structured one-on-one interview conducted in person or by phone, digitally recorded with their consent, and transcribed verbatim. The interview questions were open-ended and participants were prompted to provide details and examples. Atlas.ti software was used to organize and code the data (Atlas.ti, Scientific Software Development GmbH, Berlin, Germany) and data analyses were based on grounded theory. To guard against bias, the analysis began with open coding using an emergent rather than a priori approach. Interviews with family members and friends were randomly assigned to and coded by two of the research team members. Five members of the research team iteratively reviewed the ongoing data organization to clarify meanings of refined codes and reach consensus on code families. The research team continued to conduct interviews and analyse data until reaching saturation, the point at which no new codes were identified.

Study	O'Hare 2017 ¹³⁴
Findings	Tension and conflict: Family members and friends described multiple sources of tension in their interactions with patients and the health care system. Interactions with patients and the health care system sometimes required that family and friends tread a fine line between upholding the patient's wishes and doing what they felt was in the patient's best interest. Interactions with the health care system on the patient's behalf could also be a source of embarrassment or discomfort for family members and friends.
Limitations and applicability of evidence	Applicable.

Study	Preston 2012 ¹⁴¹
Aim	To examine MND patients' bereaved relatives experiences of using the Preferred Priorities for Care (PPC) document, a patient-held record promoted by the End of Life Care Strategy as an ACP tool to promote discussion and communication amongst patients, family and health care professionals.
Population	Primary carers or bereaved relatives of patients with MND who had died > 3 months previously, as identified from a MND Care and Research Centre (N = 11). All patients must have completed a PPC document (Priorities for care). Participants were 'mostly' >65 years, male, British white and had been living with the patient. Any carers who were non-English, lacking ability to consent, or experiencing significant health problems were excluded.
Setting	UK, interviews at participants homes.
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	All patients completed a PPC. Most patients completed the PPC document in the presence of a relative or carer and a health care professional. Patients discussed the importance of completing the document with a person they had an established relationship with. Semi-structured face to face interviews, recorded and transcribed. Thematic analysis was used to analyse the data (no detail). Field diaries kept (no detail).
Findings	Timing: Document completion ranged from 2 to 17 months prior to death. Several participants suggested that the PPC document should be completed whilst patients were still able to talk or sign the document themselves. Document availability to others: Family and friends. The majority of participants showed the PPC document to their family and friends. Healthcare professionals. Participants were less likely to share the PPC document with healthcare staff. HCP awareness: A lack of awareness of the PPC document from HCP was identified as a major limitation of its use. Staff either seemed to not understand the document or ignore a patient's stated preferences and wishes.
Limitations and applicability of evidence	Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation. Applicable

Study	Ray 2014 ¹⁴²
Aim	To examine the ways, family caregivers of people living with motor neurone disease (MND) experienced the dying of their relative and to identify how health practitioners can better prepare families for end-of-life care.
Population	Family care-givers volunteered to participate in response to invitations issued through the MND Associations. Potential participants, whose family member had a confirmed diagnosis of MND, were contacted. Despite loss of potential participants through sudden health decline, 18 family caregivers from Australia and 11 from England participated in the original studies conducted between 2003 and 2006.
Setting	UK and Australia, interviews at participant's homes.
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	<p>Supplementary analysis is one of five types of secondary analysis described by Heaton. Supplementary analysis involves a more in-depth focus on an emergent issue that was not addressed by the primary research. Neither of the primary studies had analysed data concerning family caregiver's experiences of death; yet, 13 family caregivers from the combined studies discussed the dying process and/or the death of their relative. Applying supplementary analysis to the data sets enabled the investigation of caregiver's construction of the dying process and the death event for people with MND.</p> <p>The symbols E or A were assigned to each caregivers data to identify the country of origin and to enable comparisons to be made. NVivo software was used to manage the data and to generate themes. A process of description and conceptual ordering allowed data to be categorized and the constructions of the dying process and death event to be identified as they emerged from each caregiver's story. Data analysis including concept generation was achieved through face-to-face meetings at MND Symposia and on-going email correspondence. Sadly, Janice Brown died suddenly while we were in the final stages of analysis. Our combined work to date enabled the generation of this paper. However, some specific details such as demographics were no longer available.</p>
Findings	Phenomenon of silence: Some MND caregivers suggested that discussions about the dying process or the death event were associated with loss of hope, negative attitudes or seen as unnecessary. In two cases, caregivers described a covert understanding that MND was life limiting, but that dying and death were not subjects for discussion until the last hours of life. "We knew yes, but we never discussed it". "I think we were in denial for quite some while you know, we knew it was coming, but we didn't plan anything about it".
Limitations and applicability of evidence	Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation. Applicable

Study	Robinson 2000 ¹⁴⁷
Aim	To describe what it was like for surrogate decision makers to live through implementation of the treatment decisions that they made for their loved ones who suffered from advanced Alzheimer's disease.
Population	Wives of Patients with advanced Alzheimer's who had undergone a medical crisis. (n=12)
Setting	USA. Department of Veterans Affairs hospital
Study design	Qualitative: Face to face interviews.
Methods and analysis	<p>The researcher employed phenomenological techniques. Throughout each interview the researcher was conscious of bracketing her presuppositions and guiding the participant to remain focused on what it was like to live through the medical crisis her husband endured. Employing a selective and highlighting approach entailed listening to and reading a text several times to determine which statements or phrases seemed particularly essential or revealing. Commonalities were noted, supporting the emergence of certain themes.</p> <p>Once themes were identified with supporting quotes from the women, the meaning of each woman's quote as an individual and then as a collective was translated into a meaning statement. Next and overall linguistic transformation was made, defined as a phenomenologically sensitive written expression that attempt to capture the experience. It is the linguistic transformation that is reported.</p>
Findings	<p>Advance directives: Some participants had difficulties, despite their husbands clear directives and affirmation of health care providers that they would merely be carrying out his wishes, to implement a palliative care treatment plan. One lady rescinded her husband's wish to have in place a DNR order, however later after reflection reinstated the DNR.</p> <p>Four of the women did not have any advance directives to guide their decision making. These women struggled in living through their best interests decisions for their husbands. Participants expressed potential guilt at the thought of carrying through a treatment decision that would end their husband's life.</p> <p>Value statements: Some women were guided in their treatment decisions by extrapolating their husband's values from various statements or situations throughout their married lives. Even in such cases where these women clearly articulated their husband's values, a sense of struggle was present.</p>
Limitations and applicability of evidence	Unclear if themes reached saturation. Role of researcher unclear. Applicable
Study	Rosemond 2017 ¹⁴⁸
Aim	To understand how family decision makers experienced goal-based decision-making in advance of the death of the relative

Study	Rosemond 2017 ¹⁴⁸
Population	Family decision makers whose relative with advanced dementia died after participating in the goals of care intervention. N=16. The nursing home residents had to have a diagnosis of dementia, be older than 65 years of age, score 5-7 on the Global Deterioration Scale (moderate to severe impairment) and have an English-speaking family decision-maker. 27 residents in the intervention group of the trial died, making their family decision-makers eligible for the interview on end-of-life decisions, n=16 agreed.
Setting	22 North Carolina nursing homes, USA.
Study design	Qualitative study conducted as part of a cluster RCT.
Methods and analysis	Face-to-face semi-structured interviews with inductive, descriptive qualitative approach. ATLAS.ti (v. 7.5.10) was used to code the data. Part of a cluster RCT of a goals of care decision-aid intervention.
Findings	<p>Experiences of goals of care decision making differed based on whether or not family decision makers expressed trust in nursing home staff.</p> <p>Deciding on goals of care in the presence of trust: 3 themes were evident when the family member felt their relationships with the staff were based on trust:</p> <p>The end of life experience was positive: all caregivers who discussed having trusting relationships with NH staff also said that the end-of-life experience was positive for the resident and themselves.</p> <p>Goals of care discussions were dynamic: when relationships were based on trust, family decision makers experienced goals of care discussions as a process that was responsive to the resident's condition and nuances of treatment decisions.</p> <p>Formal goals of care discussions were not always necessary: family members reported less need for formal goals of care discussions. Instead, on-going interactions based on trust allowed for shifts in goals of care to occur gradually over time.</p> <p>Deciding on goals of care in the absence of trust:</p> <p>The end of life experience was negative: nearly all family members who did not have trusting relationships with staff reported that the end-of-life experience was negative for the resident and themselves.</p> <p>Goals of care discussions were perceived to be ignored: family members who reported a lack of trust in the staff noted the goals of care discussions seemed to have little impact, in essence, they perceived all residents were treated the same, based on institutionalised care practices.</p> <p>Goals of care discussions created confusion: in the absence of trust, family members were confused as to the intention of goals for care and their own role as decision makers.</p>
Limitations and applicability of evidence	Role of researcher unclear. The study evolved to categorise people under whether they had a trusting relationship with staff or not and how positive or negative this was, which was not the initial aim of the study. Applicable.

Study	Royak-Schaler 2006 ¹⁴⁹
Aim	To assess healthcare provider communication about end-of-life (EOL) and hospice care with patients with terminal cancer and their families, from the perspective of the family members.
Population	24 spouses and first-degree relatives of deceased patients with cancer who had been treated at the cancer centre from 2000-2002
Setting	USA, interviews conducted via telephone.
Study design	Qualitative: Face-to-face/telephone interviews.
Methods and analysis	Family members participated in one of two focus group discussions and completed a short questionnaire regarding their sociodemographic characteristics and the type of EOL care their deceased relatives had received. Quantitative data were analysed using descriptive statistics. Qualitative data were audiotaped and analysed by comparing, contrasting, and summarizing content themes from the focus groups using NUD*IST 5(N5) software. Main Research Variables: Family perceptions of communication with the healthcare team in EOL cancer care.
Findings	<p>Access to healthcare providers: Participants believed that having better access to the healthcare professionals involved in their loved ones care contributed to positive experiences, whereas participants who perceived the healthcare team to be less accessible had negative comments. Some participants believed that the staff were too busy to explain their loved ones health status or too busy to provide adequate care.</p> <p>Quality of communication: Participants commented on the need for more information from the healthcare team regarding the stage of disease and treatment decisions. When available, sufficient and accurate information helped them make informed decisions and feel comfortable with their loved ones care, even when the final outcome was death. Participants who were unhappy with the quality of communication expressed frustration with the healthcare professionals who failed to explain disease progression. They also felt the professionals failed to provide information about care options, including hospice care.</p>
Limitations and applicability of evidence	Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation. Applicable

Study	Waldrop 2011 ¹⁸⁰
Aim	To explore family members' experiences with a dying nursing home resident.
Population	31 caregivers of 27 nursing home residents who had died 2 months previously.
Setting	USA, interviews took place at the nursing home.
Study design	Qualitative: Face-to-face interviews.
Methods and analysis	Interested family caregivers mailed a response form to the first author. Interviews took place at the nursing home. They ranged from 60 to 90 minutes in length. Interviews were conducted by the author who is a licensed social worker with 20 years of social work practice experience. Interviews were guided by the use of an interview instrument that included 18 open ended questions and probes.

Study	Waldrop 2011 ¹⁸⁰
	<p>Participants were encouraged to share their responses to the progression of the illness through additional open-ended questions about their experience.</p> <p>All data were identified using a number-letter code. Interviews were audiotaped with permission and transcribed by a professional transcriptionist. Transcripts were entered into Atlas ti software for data management and coding. Qualitative data analysis was utilised to reduce large amount of text data to emergent themes that describe and illustrate the experience of family caregivers. Coding was iterative and involved both open and systematic coding. Finally the data were segmented according to the concepts of the living-dying interval.</p>
Findings	<p>Advance care planning: During the living-dying interval, caregivers were charged with identifying, addressing, and upholding their loved ones wishes when they are unable to express themselves. Some family caregivers had prior knowledge of a loved ones wishes; others did not. Some caregivers expressed having to uphold wishes that they did not agree with.</p> <p>Some caregivers expressed exquisite discomfort in being charged with making decisions. In other cases caregivers actions on the behalf of an incapacitated resident caused conflict with the nursing home staff. One family member did not want his father to have a DNR order. When a residents condition was rapidly deteriorating, family caregivers were often asked whether or not they wanted a resident to return to the hospital. In some cases there was a conflict between carer and provider.</p>
Limitations and applicability of evidence	<p>Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation.</p> <p>Applicable</p>

Study	Washington 2012 ¹⁸¹
Aim	To assess which specific intervention processes impacted informal hospital
Population	<p>N=76 included in the study. N=126 were enrolled in the study. N=89 participants completed the full study protocol and participated in an exit interview but researchers excluded data from first 10% of sample (n=8) to ensure caregivers' comments reflected feedback on the intervention after fidelity among the interventionists had been firmly established. N=5 interviews were unusable due to technical difficulties related to audio-recording.</p> <p>Participants had to be providing unpaid care to a patient receiving home hospice services, be age 18 or older, have completed at least a sixth-grade education, have no or only mild cognitive impairment, be able to speak and read English, and be without functional hearing loss or have a hearing aid allowing them to participate in the intervention.</p> <p>Participant characteristics were given for all 126 of those enrolled in the study. Mean age: 49; relationship to patient: adult child (n=59); spouse/partner (n=38); sibling (n=4); adult grandchild (n=4); parent of adult patient (n=5); friend or other (n=16).</p>

Study	Washington 2012 ¹⁸¹
Setting	Carers provided unpaid care for a home hospice patient receiving services from one of two hospice agencies located in the Pacific Northwest region of the United States.
Study design	Qualitative study. This study was part of a larger, mixed methods evaluation of a problem-solving intervention for informal hospice caregivers.
Methods and analysis	<p>Semi-structured interviews with thematic analysis.</p> <p>Participants part of bigger study and participated in an exit interview. Qualitative data generated during these interviews formed the basis of the present study.</p> <p>Participants took part in a psycho-educational intervention, where they learned Nezu et al's ADAPT problem-solving method and implemented it to address a specific challenge they encountered when caring for a dying family member or friend. The intervention was delivered face-to-face or by videophone during three individual sessions. Two additional visits were required to administer measures and conduct exit interviews.</p> <p>Interventionists were masters-prepared health professionals (two nurses, two social workers) who had received additional training in preparation for working with informal hospice caregivers and teaching the ADAPT method.</p> <p>Qualitative data were collected during the semi-structured interviews of participants during their fifth and final visit with the interventionist. Broad, open-ended questions and prompts were used to encourage them to reflect on all stages of the intervention and to provide insight into the benefits and challenges associated with their involvement in the project.</p> <p>They conducted thematic analysis of the data, using techniques outline by Braun and Clarke. An inductive approach was used to guide this process, resulting in the development of themes that were closely linked to the data. Transcribed data were imported into NVivo8 then two researches generated a list of codes based on the inductive analysis of approximately 10% of the interviews in the sample. Peer debriefing allowed them to develop and refine a coding framework that was modified through an on-going discussion of the differences.</p>
Findings	<p>Reflecting on caregiving: participating in the problem-solving intervention forced caregivers to make space in their lives to reflect on challenges they were facing. Caregivers appreciated the opportunity to think through things, due to a variety of reasons. This reflection set the stage for engaging in structured problem-solving efforts.</p> <p>Structuring problem-solving efforts: Caregivers repeatedly cited the structured format of the problem-solving intervention as helpful. This theme was particularly apparent among caregivers who found themselves overwhelmed by the realities of caring for a dying loved one. For them, walking through a logical, rational problem-solving process brought focus to their efforts. Participants reported that the intervention workbook was particularly useful in helping them focus their problem-solving efforts.</p>

Study	Washington 2012 ¹⁸¹
	Partnering with an interventionist: Many caregivers indicated they liked 'having [someone] listen' or 'having the opportunity to talk to somebody.' Others commented on specific attributes or behaviours of the interventionists, such as being 'really supportive', 'easy to talk to', 'a really good listener', providing 'undivided attention,' and creating an environment in which caregivers felt 'comfortable'.
	<p>Resolving problems: Many commented on the benefits associated with making progress toward solving a problem. For numerous participants 'charging ahead' and 'getting things done' was cited as helpful. Seeing results of the significant time and energy invested in caregiving was important. For these caregivers, working through the problem-solving steps was a important as learning them. This led to gaining a sense of confidence and control.</p> <p>Gaining confidence and control: Caregivers commonly reported feeling an enhanced sense of confidence and control over problems they encountered. While some caregivers implemented novel solutions to caregiving problems as a result of the intervention, others discussed feeling more confident that the approach they were using was most effective. They described feeling 'reassured' after working through the steps of the ADAPT model.</p> <p>A number of participants observed that the problem-solving process was applicable to non-caregiving challenges as well, resulting in feelings of empowerment in multiple areas of their lives.</p>
Limitations and applicability of evidence	<p>No details of researcher bias. All other methodology was clearly described.</p> <p>Specifically related to one problem-solving intervention, so this is not specifically relevant to decision-making, but is indirectly related.</p>

Study	Wilson 2011 ¹⁸⁶
Aim	To identify the factors that are important to families who must decide to either prolong or end treatment for patients who are seriously ill.
Population	Family members who had made end-of-life treatment decisions for a person close to them (n=10)
Setting	USA. Setting of interview was decided by interviewer and participant.
Study design	Qualitative: Face to face interviews.
Methods and analysis	<p>Semi-structured interviews were used to answer the research questions. The semi-structured format encouraged the participants to freely discuss their experiences, while also ensuring that the interviewer did not miss any important information. The interviews were audiotapes and then transcribed verbatim by the primary investigator.</p> <p>Data analysis began with verbatim line-by-line transcription of each interview; the principal investigator reviews each transcript while listening to the audiotape to ensure the accuracy of the transcription. Once the content of the transcript was verified the interview was read many times using the methods suggested by Cohen and associates and looking for the essential characteristics in the data. Once an overall understanding of the content was obtained, thematic analysis begun. Data were examined line by line, underlying phrases</p>

Study	Wilson 2011¹⁸⁶
	and naming themes. Twenty one thematic categories were initially identified in this process, once these themes were identified, the principle investigator reviewed each theme to validate its content, revising as appropriate.
Findings	<p>Knowing EOL wishes: knowing the wishes of the family member aided in the surrogates decision making. This communication involved more than just the existence of advance directives. Those who had not had such discussions struggled with decision making.</p> <p>Communication with healthcare providers: Participants expressed a great deal of frustration related to trying to get information about their family members' condition. Some healthcare providers were able to facilitate decision making by providing information and support to the family members. In contrast there were other healthcare providers who acted as barriers to the decision-making process. One participant recalled how she was not informed that her mother had been taken off the list for an organ transplant.</p> <p>Acceptance: All participants discussed the need to accept the impending death of their loved one, which included an acknowledgment of futility of the family members' condition. Until this acceptance was achieved, there could be no decision to terminate curative treatment.</p>
Limitations and applicability of evidence	<p>Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation. Role of researcher unclear.</p> <p>Applicable</p>

Study	Wittich 2013¹⁹⁰
Aim	To examine the ways that next of kin knew veterans' end-of-life preferences, and their ways of knowing whether those preferences were honoured in Veteran Affairs Medical Centre (VAMC) inpatient settings.
Population	Next of kin of deceased patients of the VAMC. (n=78)
Setting	USA, at the VAMC
Study design	Qualitative: Face to face interviews.
Methods and analysis	<p>Face to face in depth interviews were conducted with 78 next of kin by an interviewer. Interviews were conducted at the VAMC where the patient died. Each interview was tape recorded and transcribed. A semi-structured open ended interview guide was utilised. To ensure relevance, clarity, and readability, the guide was reviewed by an interdisciplinary research team.</p> <p>Data coding was an interactive, iterative process. Two coder-analysts simultaneously listened to the taped interviews and each made notations and wrote memos on the transcriptions. The transcriptions of the interviews were reviewed continuously to confirm, compare, and contrast emerging themes, patterns and interrelationships. The code book initially was comprised of items specific to the interview guide. As themes emerged new codes were discussed, negotiated and added to the code book. Upon thematic saturation, 25 codes with relevance to the analysis were employed.</p>

Study	Wittich 2013 ¹⁹⁰
Findings	<p>The process of knowing: The process of know a loved one's preferences regarding end of life care appeared to unfold over time and to be facilitated by hearing about the patients preferences, seeing their care, and interacting with the patient and the clinical staff. Often, at the point of hospitalisation, knowing their loved ones preferences for care was not the forthcoming concern.</p> <p>Ways of knowing: Hearing is knowing; listening to loved ones as he or she expresses preferences or listening to EOLC conversations with clinicians. Seeing is knowing; acquiring knowledge via observations of medical staff performing comfort care. Interacting is knowing; knowledge acquired through interactions with clinical staff.</p>
Limitations and applicability of evidence	<p>Little information on analysis so rigour and reliability unclear. Analysis could have been more in depth. Unclear if themes reached saturation.</p> <p>Applicable</p>

Appendix E: Excluded studies

E.1 Excluded clinical studies

Table 9: Studies excluded from the qualitative review

Reference	Reason for exclusion
Adam 2000 ¹	No relevant outcomes
Ammari 2015 ²	Inappropriate study design
Anderson 2008 ³	No relevant outcomes:
Anonymous 2014 ¹⁷⁰	Inappropriate study design
Aoun 2010 ⁴	Inappropriate study design
Aoun 2012 ⁶	No relevant outcome
Aoun 2015 ⁵	No relevant outcomes
Ashley 2016 ⁷	Inappropriate study design
Azami-Aghdash 2015 ⁹	Not review population
Bachner 2009 ¹⁰	Inappropriate study design
Bainbridge 2017 ¹¹	No relevant outcomes
Bakitas 2017 ¹²	No relevant outcomes
Beckstrand 2017 ¹³	Inappropriate study design
Boucher 2010 ¹⁴	No relevant outcomes
Bray 2007 ¹⁵	No relevant outcomes
Brazil 2005 ¹⁸	No relevant outcomes
Brazil 2010 ¹⁹	No relevant outcomes
Brazil 2010 ¹⁷	No relevant outcomes
Brazil 2012 ¹⁶	Inappropriate study design
Bristowe 2015 ²⁰	Not review population
Browne 2014 ²¹	Not review population
Cagle 2016 ²²	Inappropriate study design
Carduff 2014 ²³	No relevant outcomes
Carrillo 2018 ²⁵	Different healthcare system
Casarett 2008 ²⁶	Inappropriate study design
Cauley 2003 ²⁷	Inappropriate study design
Chiao 2015 ²⁸	Not review population
Ciemins 2015 ²⁹	No relevant outcomes
Clayton 2005 ³⁰	Not review population
Collier 2016 ³¹	No relevant outcomes
Conner 2015 ³²	Not review population
Corden 2011 ³³	No relevant outcomes
Crooks 2012 ³⁴	No relevant outcomes
Currow 2011 ³⁵	Inappropriate study design
Curtis 2005 ³⁶	No relevant outcomes
Daveson 2014 ³⁷	No relevant outcomes
Davies 2016 ³⁸	No relevant outcome
Dev 2013 ⁴¹	Inappropriate study design

Reference	Reason for exclusion
Dickinson 2013 ⁴²	Not review population
Docherty 2008 ⁴³	No relevant outcomes
Dumont 2010 ⁴⁴	Inappropriate study design
Dyregrov 2014 ⁴⁵	Not review population
Edwards 2012 ⁴⁶	No relevant outcomes
Evans 2006 ⁴⁸	No relevant outcomes
Evans 2016 ⁴⁷	No relevant outcomes
Evert 1996 ⁴⁹	Inappropriate study design
Ewing 2016 ⁵⁰	Not review population
Ewing 2018 ⁵¹	No relevant outcomes
Funk 2009 ⁵⁴	No relevant outcomes
Funk 2010 ⁵³	No relevant outcomes
Gott 2015 ⁵⁶	No relevant outcomes
Grbich 2001 ⁵⁷	No relevant outcomes
Guerriere 2016 ⁵⁸	Inappropriate study design
Guo 2010 ⁵⁹	No relevant outcomes
Hales 2014 ⁶⁰	Inappropriate study design
Haley 2002 ⁶¹	Inappropriate study design
Hall 2014 ⁶²	No relevant outcome
Han 2008 ⁶³	Not review population
Hanratty 2014 ⁶⁴	No relevant outcomes
Harding 2002 ⁶⁶	No relevant outcomes
Harding 2012 ⁶⁵	No relevant outcomes
Hasson 2009 ⁶⁷	No relevant outcomes
Hatcher 2014 ⁶⁸	No relevant outcomes
Henriksson 2011 ⁶⁹	No relevant outcomes
Holland 2014 ⁷⁰	No relevant outcomes
Holtslander 2010 ⁷²	No relevant outcomes
Hong 2011 ⁷³	Not review population
Hopeck 2017 ⁷⁴	Not review population
Horsfall 2013 ⁷⁵	No relevant outcomes
Hoskins 2005 ⁷⁶	Inappropriate study design
Hudson 2012 ⁷⁷	Inappropriate study design
Hynes 2012 ⁷⁸	No relevant outcomes
Ingleton 2010 ⁷⁹	Not relevant outcome
Jackson 2010 ⁸⁰	No relevant outcome
Jeyasingam 2008 ⁸²	Inappropriate study design
Jo 2007 ⁸³	No relevant outcomes
Joad 2011 ⁸⁴	No relevant outcomes
Kang'ethe 2011 ⁸⁵	No relevant outcomes
Kayser 2014 ⁸⁶	Not review population
Kehl 2009 ⁸⁷	No relevant outcomes
Kelly 2009 ⁸⁸	No relevant outcomes
King 2004 ⁸⁹	No relevant outcomes
Kobayakawa 2016 ⁹⁰	Inappropriate study design

Reference	Reason for exclusion
Kristjanson ⁹¹	Not review population
Kutner 2009 ⁹³	No relevant outcomes
Kutney-Lee 2015 ⁹⁴	Inappropriate study design
Lageman 2015 ⁹⁵	Not review population
Lamont 2000 ⁹⁷	Inappropriate study design
Larson 2002 ⁹⁸	Inappropriate study design
Leemans 2015 ⁹⁹	Inappropriate study design
Leichtentritt 2001 ¹⁰⁰	No relevant outcomes
Lendon 2015 ¹⁰¹	Inappropriate study design
Lhussier 2007 ¹⁰²	Not review population
Linderholm 2010 ¹⁰⁴	No relevant outcomes
Livingston 2010 ¹⁰⁵	Not review population
Lohfeld 2000 ¹⁰⁶	Not review population
Long 2014 ¹⁰⁷	Inappropriate study design
Low 2005 ¹⁰⁸	No relevant outcomes
Mangan 2003 ¹¹⁰	No relevant outcomes
Martín 2016 ¹¹¹	No relevant outcomes
McCarthy 2016 ¹¹²	Not review population
McLaughlin 2007 ¹¹³	No relevant outcomes
McNamara 2010 ¹¹⁴	Inappropriate study design
McSkimming 1999 ¹¹⁵	Not review population
McSwiggan 2017 ¹¹⁶	Not review population
Meeker 2005 ¹¹⁷	Inappropriate study design
Miyashita 2015 ¹¹⁹	Inappropriate study design
Mohammed 2018 ¹²⁰	No relevant outcomes
Montgomery 1985 ¹²¹	No relevant outcome
Moore 2013 ¹²²	Not review population
Moorman 2013 ¹²³	Inappropriate study design
Mori 2012 ¹²⁴	No relevant outcome
Morita 2004 ¹²⁵	Inappropriate study design
Mousing 2017 ¹²⁶	Not review population
Munck 2008 ¹²⁸	Not review population
Natan 2010 ¹²⁹	Inappropriate study design
Navaie-Waliser 2001 ¹³¹	Not review population
Neundorfer 1991 ¹³²	Inappropriate study design
Noome 2016 ¹³³	No relevant outcomes
Oliver 2009 ¹³⁵	No relevant outcomes
Osse 2006 ¹³⁶	Inappropriate study design
Pardon 2012 ¹³⁷	Inappropriate study design
Penrod 2012 ¹³⁸	No relevant outcomes
Peters 2006 ¹³⁹	No relevant outcomes
Piamjariyakul 2013 ¹⁴⁰	No relevant outcomes
Rhodes 1999 ¹⁴³	No relevant outcomes
Riggs 2014 ¹⁴⁴	No relevant outcomes
Roberts 2008 ¹⁴⁵	No relevant outcomes

Reference	Reason for exclusion
Robinson 2016 ¹⁴⁶	No relevant outcomes
Running 2009 ¹⁵⁰	Inappropriate study design
Sahlberg-Blom 2000 ¹⁵¹	No relevant outcomes
Salin 2007 ¹⁵²	Not review population
Salin 2009 ¹⁵³	Not review population
Schmall 1989 ¹⁵⁴	Inappropriate study design
Selman 2007 ¹⁵⁵	Not review population
Shi 1997 ¹⁵⁶	No relevant outcomes
Shih 2013 ¹⁵⁷	No relevant outcomes
Shyu 2000 ¹⁵⁸	Not review population
Simon 2002 ¹⁵⁹	Not review population
Sims-Gould 2010 ¹⁶⁰	No relevant outcomes
Singleton 2000 ¹⁶¹	Not review population
Sittisombut 2009 ¹⁶²	Inappropriate study design
Song 2011 ¹⁶⁴	Inappropriate study design
Song 2012 ¹⁶³	Inappropriate study design
Stajduhar 1998 ¹⁶⁵	No relevant outcomes
Stajduhar 2008 ¹⁶⁶	No relevant outcomes
Steele 2002 ¹⁶⁷	No relevant outcomes
Stephenson-Cino 1992 ¹⁶⁸	Not review population
Stephenson-Cino 1992 ¹⁶⁸	Not review population
Stockwell-Smith 2010 ¹⁶⁹	Not review population
Thompson 2014 ¹⁷¹	Inappropriate study design
Thoresen 2016 ¹⁷²	Not review population
Tilden 2004 ¹⁷³	Inappropriate study design
Turner 2016 ¹⁷⁴	No relevant outcomes
Vaddadi 1996 ¹⁷⁵	Inappropriate study design
van Eechoud 2014 ¹⁷⁶	Not review population
van Wijmen 2014 ¹⁷⁷	Not review population; no relevant outcomes
Vandrevalla 2017 ¹⁷⁸	Not review population
Walczak 2015 ¹⁷⁹	No relevant outcome
Waters 2001 ¹⁸²	Not review population
Weeks 2011 ¹⁸³	Not review population
Weibull 2008 ¹⁸⁴	No relevant outcomes
Wiles 2003 ¹⁸⁵	Not review population
Winter 2012 ¹⁸⁷	Inappropriate study design
Wittenberg-Lyles 2010 ¹⁸⁸	No relevant outcomes
Wittenberg-Lyles 2013 ¹⁸⁹	Inappropriate study design
Worth 2006 ¹⁹¹	No relevant outcomes
Yamamoto 1998 ¹⁹²	No relevant outcomes
Young 2008 ¹⁹³	Inappropriate study design
Zapart 2007 ¹⁹⁴	No relevant outcomes
Zhang 2003 ¹⁹⁵	No relevant outcomes

E.2 Excluded economic studies

There were no excluded economic studies for this review.