National Institute for Health and Care Excellence

Draft for consultation

End of life care for adults: service delivery

[G] Evidence review: Involving carers

NICE guideline

Evidence review

April 2019

Draft for consultation

This evidence review was developed by
the National Guideline Centre

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian.

Local commissioners and providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

ISBN
[add for final publication version only, delete this text for consultation version]

Contents

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 l. 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.

Population and setting	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)
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). For example: • 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 review[24, 39, 40, 52, 55, 71, 81, 92, 96, 103, 109, 118, 127, 134, 141, 142, 147-149, 180, 181, 186, 190], [8] 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 dementia is facilitated or inhibited	Study also collated themes and scored the individual ranked items.

Study	Design	Population	Research aim	Comments
		UK	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. N=6	To explore family involvement in decisions about life support interventions in the intensive care.	

Study	Design	Population	Research aim	Comments
		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	
O'Hare 2017[134]	Face-to-face semi-structured interviews with thematic	Family members and friends of patients with advanced kidney	To learn about the experiences of family members and friends of patients with advanced kidney	

Study	Design	Population	Research aim	Comments
	qualitative analysis.	disease. N=17 USA	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.
Royak-Schaler	Face-to-face/telephone semi-structured interviews with	Spouses and first-degree relatives of deceased patients	To assess healthcare provider communication about end-of-life	

Study	Design	Population	Research aim	Comments
2006[149]	thematic qualitative analysis.	with cancer who had been treated at the cancer centre from 2000-2002. N=24 USA	(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 • 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. tEasier 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 • 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 study[24] 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 condition[109] 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 intervention[181] 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 study[71] 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 experiences [8], 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. Dening (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 time[190] 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 patient[180]. Dening (2012)[39] found carers had scepticism about the ACP process, as it may be open to misinterpretation by professionals. One study[141] 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 carers [40] chaving 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			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**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			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**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	Many caregivers had difficulty reaching their primary care	Limitations	Minor concerns about	LOW

	and telephone interviews	providers. The more access they had the more positive their experience was.		methodological limitations	
			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	Caregivers involved in the dialogue had higher satisfaction than	Limitations	Minor concerns about	MODERATE

	groups (n=1) and face-to-face interviews (n=3)	those who had less involvement. Communication was important to caregivers but was variable in quality and lack of consistent communication.		methodological limitations	
			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 1.8) 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 Recommendations

G1. For advice on communication, information and shared decision making, see the NICE guidelines on patient experience in adult NHS services and people's experience in adult social care services. Apply the same principles for communication and information giving to carers of all ages.

G2. Support adults approaching the end of their life to actively participate in decision making by having in place:

- processes to establish the amount and type of information they would prefer
- systems to provide information in a way that meets their communication needs and preferences, for example, how it is given (verbally, on paper, by text, email, or other assistive technologies) and provision of professional interpreters
- arrangements to review and anticipate their information needs and preferences as circumstances change.

G3. When carers' needs are assessed, take into account that the support needs of a young carer are likely to be different to those of an older carer.

Coordinating care

Reviewing needs

G4. Develop systems enabling adults approaching the end of their life, to have:

- regular discussions with a member of their care team about changes in their health and social care needs and preferences
- repeat assessments of their holistic needs and reviews of their advance care plan when needed, for example at key transition points, such as at discharge from hospital or when the goals of treatment have changed.

<u>Advance care planning</u>

F2. Service providers should develop processes to:

- support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life consents
- take into account the views of carers and other people important to the person if the person approaching the end of their life lacks capacity to make decisions in line with the Mental Capacity Act 2005.

F3. For advice on supporting decision making, assessing mental capacity and advance care planning, see the NICE guideline on decision-making and mental capacity.

<u>Coordinating Care:</u>

G5. For specific advice on coordinating end of life support in residential settings, see the NICE guideline on people's experience in adult social care services.

J3. The lead healthcare professional for the person's care in each care setting should discuss all existing treatment plans with the person approaching the end of their life and, with the person's consent, their carers and other people important to them. This should include discussing:

- any changes that could optimise care and improve their quality of life (for example, reducing the number of unnecessary routine appointments, organising appointments close to the person's home, starting new treatments or stopping unhelpful treatments)
- community support available to help with their treatment.

1.9 Rationale and impact

1.9.1 Why the committee made the recommendations

Providing information

The evidence showed that a lack of knowledge about end of life care and the support and services available, and poor communication between adults approaching the end of their life and health and social care practitioners are barriers to understanding treatment options and confidently making decisions about care.

Based on this evidence and the committee's experience, the recommendations reflect the importance of systematically seeking and acting on the information needs and preferences of people approaching the end of their life, their carers and other people important to them. The committee also acknowledged that peoples' information needs will vary and change over time so regular reviews are needed.

Supporting carers

The information and support needs of carers will vary and the evidence did not identify one particular way of supporting carers. However, it did show that carers have better outcomes, such as maintaining quality of life and reduced carer burden, when supported. The committee agreed that health and social care practitioners should go beyond the strict statutory requirement for carers' assessments to ensure that they consider the needs of carers and to take into account how needs will vary for different carer groups. **Advance care planning**

The evidence for advance care planning was unclear, although it did show some benefit in supporting people to stay in their preferred place of care. There was not enough evidence for the committee to recommend a specific service model for advance care planning. However, the committee agreed that advance care planning helps people to achieve the personalised care and support they want.and that processes should be in place to provide it to adults approaching the end of their life. The committee also felt that this advance care planning should not only be restricted to planning for future loss of mental capacity.

The evidence on barriers to care described how carers felt a lack of control and a lack of trust in health and social care practitioners, resulting in scepticism about the benefits of advance care planning. The committee agreed that better communication and processes to involve carers in advance care planning would help to address this.

Reviewing needs

There was no evidence to indicate the best time to undertake reviews of service provision for people approaching the end of their life. Every person’s journey is individual, reflecting how their health can unpredictably fluctuate, with periods of deterioration, stabilisation and sometimes improvement. In addition, their psychological, social, financial and other support needs will vary, not always in step with the physical illness. The committee therefore agreed that regular reviews of care are important to identify when changes in care or other forms of support are needed when people are approaching the end of their life, for example when the goals of disease-modifying treatment change.

The committee recognised that regular discussions with the care team would help to identify changes in the person's needs and preferences. They also agreed that repeating holistic needs assessments and reviews of advance care plans would ensure that people continue to receive the right care and support.

Coordinating care

The evidence on identifying barriers to accessing services showed that continuity and coordination of care are often identified as being unsatisfactory for adults approaching the end of their life and their carers. The evidence also highlighted a lack of information and poor communication with carers, which could be improved with better coordination of care.

The committee agreed that good coordination of care and effective communication systems are especially important when people have contact with multiple services and organisation.

The committee also agreed good coordination of care should include systems to review appointments and home visits, both to support efficiency of care and also to avoid overwhelming the person with multiple visits from different services.

Reviewing current treatment:

There was no evidence identified on how and when to carry out an initial review of service provision for people approaching the end of their life. However, the committee agreed that it was important for all lead healthcare professionals responsible for the person's care to review and discuss the person's current care needs with them. In particular, they discussed identifying services that may be needed or could be stopped, and acknowledged that the involvement of too many services can be as problematic as too few. The committee also agreed that adapting care for treating conditions in adults needing end of life care would help ensure that the right care is provided at the right time.

To encourage more research in this area, research recommendations were also developed (see research recommendations 1 and 2).

1.9.2 Impact of the recommendations on practice

Together, these recommendations reflect good current practice available in some services, but there is variation nationally. Specifically, in advance care planning there is variation in the timing and availability of this service in different areas and for different patient groups.

Advance care planning should support adults in the last year of life to be cared for in their preferred place, which is often in the community. This may reduce the need for hospital services but increase demand for services in the community. The advance care plan documents the person's needs, improving coordination of care across the multipractitioner team and should help avoid unnecessary hospital admissions.

Improving understanding and communication will benefit services, ensuring that people make informed decisions and receive the appropriate care.

Increased investment may be needed for increased numbers of assessments and increased support accessed. The approach described in recommendations on supporting carers should result in better support for adults in the last year of life to stay in their preferred place of care longer, and may reduce the number of hospital admissions. Supporting carers should reduce the physical and emotional strains that are often experienced by carers. This may help reduce the need for, and therefore costs of, interventions for physical and health mental problems common in carers.

Reviewing the ongoing care of people in the last year of life means that appropriate care will be given and may reduce some resource use when unnecessary interventions are stopped.

In areas where good coordination of care is lacking, the recommendations should result in more efficient service provision and help to minimise crises and support people to stay in their preferred place of care. Good care coordination should also reduce the use of unnecessary services and avoid duplication of care.

Further details of the evidence and the committee’s discussion on involving carers please see the details provided in evidence review C: barriers to accessing end of life care services, evidence review D: coordinator and lead health professional, evidence review F: advance care planning, evidence review H: carer support services and evidence review I: information sharing.

1.10 The committee’s discussion of the evidence

1.10.1 Interpreting the evidence

1.10.1.1 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.

1.10.1.2 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.

1.10.2 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.

1.10.3 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.

References

1. Adam J. Discharge planning of terminally ill patients home from an acute hospital. International Journal of Palliative Nursing. 2000; 6(7):338-45

2. Ammari ABH, Hendriksen C, Rydahl-Hansen S. Recruitment and reasons for non-participation in a family-coping-orientated palliative home care trial (FamCope). Journal of Psychosocial Oncology. 2015; 33(6):655-674

3. Anderson BA, Kralik D. Palliative care at home: Carers and medication management. Palliative and Supportive Care. 2008; 6(4):349-356

4. Aoun S, Bird S, Kristjanson LJ, Currow D. Reliability testing of the FAMCARE-2 scale: Measuring family carer satisfaction with palliative care. Palliative Medicine. 2010; 24(7):674-681

5. Aoun S, Toye C, Deas K, Howting D, Ewing G, Grande G et al. Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice. Palliative Medicine. 2015; 29(10):929-38

6. Aoun SM, Connors SL, Priddis L, Breen LJ, Colyer S. Motor Neurone Disease family carers’ experiences of caring, palliative care and bereavement: An exploratory qualitative study. Palliative Medicine. 2012; 26(6):842-850

7. Ashley JL, Fasolino TK. Palliative and hospice care: Educational needs of inpatient registered nurses. Creative Nursing. 2016; 22(2):114-120

8. Ates G, Ebenau AF, Busa C, Csikos A, Hasselaar J, Jaspers B et al. "Never at ease" - family carers within integrated palliative care: a multinational, mixed method study. BMC Palliative Care. 2018; 17(1):39

9. Azami‐Aghdash S, Ghojazadeh M, Hossein Aghaei M, Naghavi‐Behzad M, Asgarlo Z. Perspective of patients, patients' families, and healthcare providers towards designing and delivering hospice care services in a middle income country. Indian Journal of Palliative Care. 2015; 21(3):341-348

10. Bachner YG, Carmel S. Open communication between caregivers and terminally ill cancer patients: The role of caregivers' characteristics and situational variables. Health Communication. 2009; 24(6):524-531

11. Bainbridge D, Bryant D, Seow H. Capturing the palliative home care experience from bereaved caregivers through qualitative survey data: Toward informing quality improvement. Journal of Pain and Symptom Management. 2017; 53(2):188-197

12. Bakitas M, Dionne-Odom JN, Jackson L, Frost J, Bishop MF, Li Z. "There were more decisions and more options than just yes or no": Evaluating a decision aid for advanced cancer patients and their family caregivers. Palliative and Supportive Care. 2017; 15(1):44-56

13. Beckstrand RL, Rohwer J, Luthy KE, Macintosh JLB, Rasmussen RJ. Rural emergency nurses' end-of-life care obstacle experiences: Stories from the last frontier. Journal of Emergency Nursing. 2017; 43(1):40-48

14. Boucher J, Bova C, Sullivan-Bolyai S, Theroux R, Klar R, Terrien J et al. Next-of-kin's perspectives of end-of-life care. Journal of Hospice and Palliative Nursing. 2010; 12(1):41-50

15. Bray YM, Goodyear-Smith FA. A migrant family's experience of palliative care. Journal of Hospice and Palliative Nursing. 2007; 9(2):92-99

16. Brazil K, Bainbridge D, Ploeg J, Krueger P, Taniguchi A, Marshall D. Family caregiver views on patient-centred care at the end of life. Scandinavian Journal of Caring Sciences. 2012; 26(3):513-518

17. Brazil K, Bainbridge D, Rodriguez C. The stress process in palliative cancer care: A qualitative study on informal caregiving and its implication for the delivery of care. American Journal of Hospice and Palliative Medicine. 2010; 27(2):111-116

18. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliative Medicine. 2005; 19(6):492-499

19. Brazil K, Kassalainen S, Ploeg J, Marshall D. Moral distress experienced by health care professionals who provide home-based palliative care. Social Science and Medicine. 2010; 71(9):1687-1691

20. Bristowe K, Horsley HL, Shepherd K, Brown H, Carey I, Matthews B et al. Thinking ahead--the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. Palliative Medicine. 2015; 29(5):443-50

21. Browne S, Macdonald S, May CR, Macleod U, Mair FS. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. PloS One. 2014; 9(3):e93288

22. Cagle JG, Carr DC, Hong S, Zimmerman S. Financial burden among US households affected by cancer at the end of life. Psycho-Oncology. 2016; 25(8):919-926

23. Carduff E, Finucane A, Kendall M. Understanding the barriers to identifying carers of people with advanced illness in primary care: Triangulating three data sources. BMC Family Practice. 2014; 14:48

24. Caron CD, Griffith J, Arcand M. Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings. Journal of Applied Gerontology. 2005; 24(3):231-247

25. Carrillo GM, Arias-Rojas M, Carreño SP, Gómez OJ, López R, Cárdenas DC. Looking for Control at the End of Life Through the Bond: A Grounded Theory on the Hospital Discharge Process in Palliative Care. Journal of Hospice and Palliative Nursing. 2018; 20(3):296-303

26. Casarett D, Pickard A, Bailey FA, Ritchie CS, Furman CD, Rosenfeld K et al. A nationwide VA palliative care quality measure: The family assessment of treatment at the end-of-life. Journal of Palliative Medicine. 2008; 11(1):68-75

27. Cauley JA, de Rekeneire N, Harris TB, Kaufman SR, Micco GP, Nevitt MC et al. Family involvement in end-of-life hospital care. Journal of the American Geriatrics Society. 2003; 51(6):835-840

28. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: A systematic review. International Nursing Review. 2015; 62(3):340-50

29. Ciemins EL, Brant J, Kersten D, Mullette E, Dickerson D. A qualitative analysis of patient and family perspectives of palliative care. Journal of Palliative Medicine. 2015; 18(3):282-285

30. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Discussing end-of-life issues with terminally ill cancer patients and their carers: A qualitative study. Supportive Care in Cancer. 2005; 13(8):589-99

31. Collier A, Sorensen R, Iedema R. Patients' and families' perspectives of patient safety at the end of life: A video-reflexive ethnography study. International Journal for Quality in Health Care. 2016; 28(1):66-73

32. Conner NE, Chase SK. Decisions and caregiving: end of life among blacks from the perspective of informal caregivers and decision makers. American Journal of Hospice & Palliative Medicine. 2015; 32(4):454-63

33. Corden A, Hirst M. Partner care at the end-of-life: Identity, language and characteristics. Ageing & Society. 2011; 31(2):217-242

34. Crooks VA, Williams A, Stajduhar KI, Cohen SR, Allan D, Brazil K. Family caregivers' ideal expectations of Canada's compassionate care benefit. Health & Social Care in the Community. 2012; 20(2):172-180

35. Currow DC, Burns C, Agar M, Phillips J, McCaffrey N, Abernethy AP. Palliative caregivers who would not take on the caring role again. Journal of Pain and Symptom Management. 2011; 41(4):661-672

36. Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed opportunities during family conferences about end-of-life care in the intensive care unit. American Journal of Respiratory and Critical Care Medicine. 2005; 171(8):844-9

37. Daveson BA, Alonso JP, Calanzani N, Ramsenthaler C, Gysels M, Antunes B et al. Learning from the public: citizens describe the need to improve end-of-life care access, provision and recognition across Europe. European Journal of Public Health. 2014; 24(3):521-7

38. Davies N, Rait G, Maio L, Iliffe S. Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study. Palliative Medicine. 2016; 31(8):726-733

39. Dening KH, Greenish W, Jones L, Mandal U, Sampson EL. Barriers to providing end-of-life care for people with dementia: A whole-system qualitative study. BMJ Supportive & Palliative Care. 2012; 2(2):103-7

40. Dening KH, Jones L, Sampson EL. Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. Palliative Medicine. 2013; 27(5):409-417

41. Dev R, Coulson L, Del Fabbro E, Palla SL, Yennurajalingam S, Rhondali W et al. A prospective study of family conferences: Effects of patient presence on emotional expression and end-of-life discussions. Journal of Pain and Symptom Management. 2013; 46(4):536-545

42. Dickinson C, Bamford C, Exley C, Emmett C, Hughes J, Robinson L. Planning for tomorrow whilst living for today: The views of people with dementia and their families on advance care planning. International Psychogeriatrics. 2013; 25(12):2011-2021

43. Docherty A, Owens A, Asadi-Lari M, Petchey R, Williams J, Carter YH. Knowledge and information needs of informal caregivers in palliative care: A qualitative systematic review. Palliative Medicine. 2008; 22(2):153-71

44. Dumont S, Jacobs P, Turcotte V, Anderson D, Harel F. Measurement challenges of informal caregiving: A novel measurement method applied to a cohort of palliative care patients. Social Science and Medicine. 2010; 71(10):1890-5

45. Dyregrov K, Berntsen G, Silviken A. The need for and barriers to professional help - a qualitative study of the bereaved in Sámi areas. Suicidology Online. 2014; 5(1):47-58

46. Edwards SB, Olson K, Koop PM, Northcott HC. Patient and family caregiver decision making in the context of advanced cancer. Cancer Nursing. 2012; 35(3):178-86

47. Evans BC, Coon DW. The "reckoning point" as a marker for formal palliative and end-of-life care in Mexican American families. Journal of Family Nursing. 2016; 22(4):606-630

48. Evans WG, Cutson TM, Steinhauser KE, Tulsky JA. Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. Journal of Palliative Medicine. 2006; 9(1):100-10

49. Evert H, Kukulska E. Polish carers, their dependents and respite care services. Australasian Journal on Ageing. 1996; 15(4):182-186

50. Ewing G, Austin L, Gibson D, Grande G. Hospital discharge in advanced disease: can we better support family carers? Palliative Medicine. 2016; 30(6):NP316-NP317

51. Ewing G, Austin L, Jones D, Grande G. Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. Palliative Medicine. 2018; 32(5):939-949

52. Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. Journal of Nursing Scholarship. 2000; 32(3):251-8

53. Funk L, Stajduhar KI, Toye C, Aoun S, Grande GE, Todd CJ. Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). Palliative Medicine. 2010; 24(6):594-607

54. Funk LM, Allan DE, Stajduhar KI. Palliative family caregivers' accounts of health care experiences: The importance of "security". Palliative and Supportive Care. 2009; 7(4):435-47

55. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. Omega: Journal of Death and Dying. 2001; 42(4):273-291

56. Gott M, Allen R, Moeke-Maxwell T, Gardiner C, Robinson J. 'No matter what the cost': A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context. Palliative Medicine. 2015; 29(6):518-528

57. Grbich CF, Maddocks I, Parker D. Family caregivers, their needs, and home-based palliative cancer services. Journal of Family Studies. 2001; 7(2):171-188

58. Guerriere D, Husain A, Zagorski B, Marshall D, Seow H, Brazil K et al. Predictors of caregiver burden across the home-based palliative care trajectory in Ontario, Canada. Health & Social Care in the Community. 2016; 24(4):428-438

59. Guo G, Phillips LR, Reed PG. End-of-life caregiver interactions with health care providers: learning from the bad. Journal of Nursing Care Quality. 2010; 25(4):334-43

60. Hales S, Chiu A, Husain A, Braun M, Rydall A, Gagliese L et al. The quality of dying and death in cancer and its relationship to palliative care and place of death. Journal of Pain and Symptom Management. 2014; 48(5):839-851

61. Haley WE, Allen RS, Reynolds S, Chen H, Burton A, Gallagher-Thompson D. Family issues in end-of-life decision making and end-of-life care. American Behavioral Scientist. 2002; 46(2):284-298

62. Hall J, Kenny P, Hossain I, Street DJ, Knox SA. Providing informal care in terminal illness: An analysis of preferences for support using a discrete choice experiment. Medical Decision Making. 2014; 34(6):731-45

63. Han H-R, Choi YJ, Kim MT, Lee JE, Kim KB. Experiences and challenges of informal caregiving for Korean immigrants. Journal of Advanced Nursing. 2008; 63(5):517-526

64. Hanratty B, Lowson E, Grande G, Payne S, Addington-Hall J, Valtorta N et al. Transitions at the end of life for older adults - patient, carer and professional perspectives: a mixed-methods study Health Services and Delivery Research. 2014; 2(17)

65. Harding R, Epiphaniou E, Hamilton D, Bridger S, Robinson V, George R et al. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. Supportive Care in Cancer. 2012; 20(9):1975-82

66. Harding R, Leam C, Pearce A, Taylor E, Higginson IJ. A multi-professional short-term group intervention for informal caregivers of patients using a home palliative care service. Journal of Palliative Care. 2002; 18(4):275-81

67. Hasson F, Spence A, Waldron M, Kernohan G, McLaughlin D, Watson B et al. Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease. Journal of Palliative Care. 2009; 25(3):157-63

68. Hatcher I, Harms L, Walker B, Stokes S, Lowe A, Foran K et al. Rural palliative care transitions from home to hospital: Carers' experiences. Australian Journal of Rural Health. 2014; 22(4):160-164

69. Henriksson A, Benzein E, Ternestedt BM, Andershed B. Meeting needs of family members of persons with life-threatening illness: A support group program during ongoing palliative care. Palliative and Supportive Care. 2011; 9(3):263-71

70. Holland JM, Currier JM, Kirkendall A, Keene JR, Luna N. Sadness, anxiety, and experiences with emotional support among veteran and nonveteran patients and their families at the end of life. Journal of Palliative Medicine. 2014; 17(6):708-11

71. Holley APH, Gorawara-Bhat R, Dale W, Hemmerich J, Cox-Hayley D. Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. Journal of the American Geriatrics Society. 2009; 57(10):1925-1931

72. Holtslander L, Duggleby W. The psychosocial context of bereavement for older women who were caregivers for a spouse with advanced cancer. Journal of Women and Aging. 2010; 22(2):109-24

73. Hong S-I, Hasche L, Lee MJ. Service use barriers differentiating care-givers' service use patterns. Ageing & Society. 2011; 31(8):1307-1329

74. Hopeck P, Harrison TR. Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations. Health Communication. 2017; 32(2):240-246

75. Horsfall D, Leonard R, Noonan K, Rosenberg J. Working together-apart: Exploring the relationships between formal and informal care networks for people dying at home. Progress in Palliative Care. 2013; 21(6):331-336

76. Hoskins S, Coleman M, McNeely D. Stress in carers of individuals with dementia and community mental health teams: An uncontrolled evaluation study. Journal of Advanced Nursing. 2005; 50(3):325-333

77. Hudson PL, Lobb EA, Thomas K, Zordan RD, Trauer T, Quinn K et al. Psycho-educational group intervention for family caregivers of hospitalized palliative care patients: Pilot study. Journal of Palliative Medicine. 2012; 15(3):277-81

78. Hynes G, Stokes A, McCarron M. Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. Journal of Clinical Nursing. 2012; 21(7-8):1068-77

79. Ingleton C, Chatwin J, Seymour J, Payne S. The role of health care assistants in supporting district nurses and family carers to deliver palliative care at home: Findings from an evaluation project. Journal of Clinical Nursing. 2011; 20(13-14):2043-2052

80. Jackson A, Purkis J, Burnham E, Hundt GL, Blaxter L. Views of relatives, carers and staff on end of life care pathways. Emergency Nurse. 2010; 17(10):22-6

81. Jackson J, White P, Fiorini J, Shay JT, Derderian L, Ayotte J et al. Family perspectives on end-of-life care: A metasynthesis. Journal of Hospice and Palliative Nursing. 2012; 14(4):303-311

82. Jeyasingam L, Agar M, Soares M, Plummer J, Currow D. A prospective study of unmet activity of daily living needs in palliative care inpatients. Australian Occupational Therapy Journal. 2008; 55(4):266-272

83. Jo S, Brazil K, Lohfeld L, Willison K. Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. Palliative and Supportive Care. 2007; 5(1):11-7

84. Joad AS, Mayamol T, Chaturvedi M. What does the informal caregiver of a terminally ill cancer patient need? A study from a cancer centre. Indian Journal of Palliative Care. 2011; 17(3):191-6

85. Kang'ethe S. Evaluating the role of support group structures as vehicles of palliative care: Giving productivity in the Kanye care program in Botswana. Indian Journal of Palliative Care. 2011; 17(1):11-19

86. Kayser K, DeMarco RF, Stokes C, DeSanto-Madeya S, Higgins PC. Delivering palliative care to patients and caregivers in inner-city communities: Challenges and opportunities. Palliative and Supportive Care. 2014; 12(5):369-78

87. Kehl KA, Kirchhoff KT, Kramer BJ, Hovland-Scafe C. Challenges facing families at the end of life in three settings. Journal Of Social Work In End-Of-Life & Palliative Care. 2009; 5(3-4):144-168

88. Kelly L, Linkewich B, Cromarty H, Pierre-Hansen NS, Antone I, Gilles C. Palliative care of first nations people a qualitative study of bereaved family members. Canadian Family Physician. 2009; 55(4):394-395.e7

89. King N, Bell D, Thomas K. Family carers' experiences of out-of-hours community palliative care: A qualitative study. International Journal of Palliative Nursing. 2004; 10(2):76-83

90. Kobayakawa M, Okamura H, Yamagishi A, Morita T, Kawagoe S, Shimizu M et al. Family caregivers require mental health specialists for end-of-life psychosocial problems at home: A nationwide survey in Japan. Psycho-Oncology. 2016; 25(6):641-647

91. Kristjanson LJ, Aoun SM, Yates P. Are supportive services meeting the needs of Australians with neurodegenerative conditions and their families? Journal of Palliative Care. 2006; 22(3):151-157

92. Kryworuchko J, Stacey D, Peterson WE, Heyland DK, Graham ID. A qualitative study of family involvement in decisions about life support in the intensive care unit. American Journal of Hospice & Palliative Medicine. 2012; 29(1):36-46

93. Kutner J, Kilbourn KM, Costenaro A, Lee CA, Nowels C, Vancura JL et al. Support needs of informal hospice caregivers: A qualitative study. Journal of Palliative Medicine. 2009; 12(12):1101-4

94. Kutney-Lee A, Brennan CW, Meterko M, Ersek M. Organization of nursing and quality of care for veterans at the end-of-life. Journal of Pain and Symptom Management. 2015; 49(3):570-577

95. Lageman SK, Mickens MN, Cash TV. Caregiver-identified needs and barriers to care in Parkinson's disease. Geriatric Nursing. 2015; 36(3):197

96. Lamahewa K, Mathew R, Iliffe S, Wilcock J, Manthorpe J, Sampson EL et al. A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia. Health Expectations. 2017; Epublication

97. Lamont EB, Siegler M. Paradoxes in cancer patients' advance care planning. Journal of Palliative Medicine. 2000; 3(1):27-35

98. Larson JS, Larson KK. Evaluating end-of-life care from the perspective of the patient's family. Evaluation and the Health Professions. 2002; 25(2):143-151

99. Leemans K, Deliens L, Francke AL, Vander Stichele R, Van den Block L, Cohen J. Quality indicators for palliative care services: Mixed-method study testing for face validity, feasibility, discriminative power and usefulness. Palliative Medicine. 2015; 29(1):71-82

100. Leichtentritt RD, Rettig KD. Values underlying end-of-life decisions: A qualitative approach. Health and Social Work. 2001; 26(3):150-159

101. Lendon JP, Ahluwalia SC, Walling AM, Lorenz KA, Oluwatola OA, Price RA et al. Measuring experience with end-of-life care: A systematic literature review. Journal of Pain and Symptom Management. 2015; 49(5):904-915.e3

102. Lhussier M, Carr SM, Wilcockson J. The evaluation of an end-of-life integrated care pathway. International Journal of Palliative Nursing. 2007; 13(2):74-81

103. Lind R, Nortvedt P, Lorem G, Hevroy O. Family involvement in the end-of-life decisions of competent intensive care patients. Nursing Ethics. 2013; 20(1):61-71

104. Linderholm M, Friedrichsen M. A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. Cancer Nursing. 2010; 33(1):28-36

105. Livingston G, Leavey G, Manela M, Livingston D, Rait G, Sampson E et al. Making decisions for people with dementia who lack capacity: Qualitative study of family carers in UK. BMJ. 2010; 341:c4184

106. Lohfeld LH, Tschopp AS, Trevor AW, Brazil K, Krueger P. Assessing the need for and potential role of a day hospice: A qualitative study. Journal of Palliative Care. 2000; 16(4):5-12

107. Long AC, Engelberg RA, Downey L, Kross EK, Reinke LF, Feemster LC et al. Race, income, and education: Associations with patient and family ratings of end-of-life care

and communication provided by physicians-in-training. Journal of Palliative Medicine. 2014; 17(4):435-447

108. Low J, Perry R, Wilkinson S. A qualitative evaluation of the impact of palliative care day services: The experiences of patients, informal carers, day unit managers and volunteer staff. Palliative Medicine. 2005; 19(1):65-70

109. MacDonald RC, Weeks LE, McInnis-Perry G. End-of-life healthcare decision-making: The intermediary role of the ethicist in supporting family caregivers and health professionals. Work. 2011; 40(1):63-73

110. Mangan PA, Taylor KL, Yabroff KR, Fleming DA, Ingham JM. Caregiving near the end of life: unmet needs and potential solutions. Palliative and Supportive Care. 2003; 1(3):247-59

111. Martín JM, Olano-Lizarraga M, Saracíbar-Razquin M. The experience of family caregivers caring for a terminal patient at home: A research review. International Journal of Nursing Studies. 2016; 64:1-12

112. McCarthy SA, Jenn NC, Leng CCK, Hamzah E. What are the experiences and needs of patients and carers receiving community palliative care in Malaysia? A qualitative study. Progress in Palliative Care. 2016; 24(2):73-83

113. McLaughlin D, Sullivan K, Hasson F. Hospice at home service: the carer's perspective. Supportive Care in Cancer. 2007; 15(2):163-70

114. McNamara B, Rosenwax L. Which carers of family members at the end of life need more support from health services and why? Social Science and Medicine. 2010; 70(7):1035-1041

115. McSkimming S, Hodges M, Super A, Driever M, Schoessler M, Franey SG et al. The experience of life-threatening illness: patients' and their loved ones' perspectives. Journal of Palliative Medicine. 1999; 2(2):173-84

116. McSwiggan LC, Marston J, Campbell M, Kelly TB, Kroll T. Information-sharing with respite care services for older adults: A qualitative exploration of carers' experiences. Health & Social Care in the Community. 2017; 25(4):1404-1415

117. Meeker MA, Jezewski MA. Family decision making at end of life. Palliative and Supportive Care. 2005; 3(2):131-42

118. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. Journal of Pain and Symptom Management. 2014; 47(6):1064-77

119. Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y. A nationwide survey of quality of end-of-life cancer care in designated cancer centers, inpatient palliative care units, and home hospices in Japan: The J-hope study. Journal of Pain and Symptom Management. 2015; 50(1):38-47.e3

120. Mohammed S, Swami N, Pope A, Rodin G, Hannon B, Nissim R et al. "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. Psycho-Oncology. 2018; 27(4):1229-1236

121. Montgomery RJ, Gonyea JG, Hooyman NR. Caregiving and the experience of subjective and objective burden. Family Relations. 1985; 34(1):19-26

122. Moore G, Collins A, Brand C, Gold M, Lethborg C, Murphy M et al. Palliative and supportive care needs of patients with high-grade glioma and their carers: A

systematic review of qualitative literature. Patient Education and Counseling. 2013; 91(2):141-153

123. Moorman SM, Inoue M. Persistent problems in end-of-life planning among young- and middle-aged American couples. Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2013; 68B(1):97-106

124. Mori H, Fukuda R, Hayashi A, Yamamoto K, Misago C, Nakayama T. Characteristics of caregiver perceptions of end-of-life caregiving experiences in cancer survivorship: In-depth interview study. Psycho-Oncology. 2012; 21(6):666-674

125. Morita T, Hirai K, Sakaguchi Y, Maeyama E, Tsuneto S, Shima Y. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. Journal of Pain and Symptom Management. 2004; 27(6):492-501

126. Mousing CA, Timm H, Lomborg K, Kirkevold M. Barriers to palliative care in people with chronic obstructive pulmonary disease in home care: A qualitative study of the perspective of professional caregivers. Journal of Clinical Nursing. 2017; Epublication

127. Muders P, Zahrt-Omar CA, Bussmann S, Haberstroh J, Weber M. Support for families of patients dying with dementia: a qualitative analysis of bereaved family members' experiences and suggestions. Palliative & Supportive Care. 2015; 13(3):435-442

128. Munck B, Fridlund B, Martensson J. Next-of-kin caregivers in palliative home care - From control to loss of control. Journal of Advanced Nursing. 2008; 64(6):578-586

129. Natan MB, Garfinkel D, Shachar I. End-of-life needs as perceived by terminally ill older adult patients, family and staff. European Journal of Oncology Nursing. 2010; 14(4):299-303

130. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual. London. National Institute for Health and Care Excellence, 2014. Available from: http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview

131. Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan K. The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. Gerontologist. 2001; 41(6):733-741

132. Neundorfer MM. Family caregivers of the frail elderly: Impact of caregiving on their health and implications for interventions. Family and Community Health. 1991; 14(2):48-58

133. Noome M, Dijkstra BM, van Leeuwen E, Vloet LCM. Exploring family experiences of nursing aspects of end-of-life care in the ICU: A qualitative study. Intensive and Critical Care Nursing. 2016; 33:56-64

134. O'Hare AM, Szarka J, McFarland LV, Vig EK, Sudore RL, Crowley S et al. "Maybe they don't even know that I exist": challenges faced by family members and friends of patients with advanced kidney disease. Clinical Journal of the American Society of Nephrology. 2017; 12(6):930-938

135. Oliver DP, Washington KT, Wittenberg-Lyles E, Demiris G, Porock D. 'They're part of the team': Participant evaluation of the ACTIVE intervention. Palliative Medicine. 2009; 23(6):549-555

136. Osse BHP, Vernooij-Dassen MJFJ, Schadé E, Grol RPTM. Problems experienced by the informal caregivers of cancer patients and their needs for support. Cancer Nursing. 2006; 29(5):378-388

137. Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D et al. Preferred and actual involvement of advanced lung cancer patients and their families in end-of-life decision making: A multicenter study in 13 hospitals in Flanders, Belgium. Journal of Pain and Symptom Management. 2012; 43(3):515-526

138. Penrod J, Hupcey JE, Shipley PZ, Loeb SJ, Baney B. A model of caregiving through the end of life: seeking normal. Western Journal of Nursing Research. 2012; 34(2):174-193

139. Peters L, Sellick K. Quality of life of cancer patients receiving inpatient and home-based palliative care. Journal of Advanced Nursing. 2006; 53(5):524-533

140. Piamjariyakul U, Smith CE, Russell C, Werkowitch M, Elyachar A. The feasibility of a telephone coaching program on heart failure home management for family caregivers. Heart and Lung. 2013; 42(1):32-39

141. Preston H, Fineberg IC, Callagher P, Mitchell DJ. The preferred priorities for care document in motor neurone disease: Views of bereaved relatives and carers. Palliative Medicine. 2012; 26(2):132-138

142. Ray RA, Brown J, Street AF. Dying with motor neurone disease, what can we learn from family caregivers? Health Expectations. 2014; 17(4):466-76

143. Rhodes P, Shaw S. Informal care and terminal illness. Health & Social Care in the Community. 1999; 7(1):39-50

144. Riggs JS, Woodby LL, Burgio KL, Bailey FA, Williams BR. "Don't get weak in your compassion": Bereaved next of kin's suggestions for improving end-of-life care in Veterans Affairs Medical Centers. Journal of the American Geriatrics Society. 2014; 62(4):642-8

145. Roberts A, McGilloway S. The nature and use of bereavement support services in a hospice setting. Palliative Medicine. 2008; 22(5):612-625

146. Robinson CA, Bottorff JL, McFee E, Bissell LJ, Fyles G. Caring at home until death: enabled determination. Supportive Care in Cancer. 2017; 25(4):1229-1236

147. Robinson EM. Wives' struggle in living through treatment decisions for husbands with advanced Alzheimer's disease. Journal of Nursing Law. 2000; 7(1):21-39

148. Rosemond C, Hanson LC, Zimmerman S. Goals of care or goals of trust? How family members perceive goals for dying nursing home residents. Journal of Palliative Medicine. 2017; 20(4):360-365

149. Royak-Schaler R, Gadalla S, Lemkau J, Ross D, Alexander C, Scott D. Family perspectives on communication with healthcare providers during end-of-life cancer care. Oncology Nursing Forum. 2006; 33(4):753-60

150. Running A, Shumaker N, Clark J, Dunaway L, Tolle LW. Veteran preferences for end-of-life care. International Journal of Older People Nursing. 2009; 4(1):41-7

151. Sahlberg-Blom E, Ternestedt BM, Johansson JE. Patient participation in decision making at the end of life as seen by a close relative. Nursing Ethics. 2000; 7(4):296-313

152. Salin S, Astedt-Kurki P. Women's views of caring for family members: use of respite care. Journal of Gerontological Nursing. 2007; 33(9):37-45

153. Salin S, Kaunonen M, Astedt-Kurki P. Informal carers of older family members: How they manage and what support they receive from respite care. Journal of Clinical Nursing. 2009; 18(4):492-501

154. Schmall VL, Pratt CC. Family caregiving and aging: Strategies for support. Journal of Psychotherapy & the Family. 1989; 5(1-2):71-87

155. Selman L, Harding R, Beynon T, Hodson F, Hazeldine C, Coady E et al. Modelling services to meet the palliative care needs of chronic heart failure patients and their families: Current practice in the UK. Palliative Medicine. 2007; 21(5):385-390

156. Shi L, Samuels ME, Richter DL, Stoskopf CH, Baker SL, Francisco SY. Primary care physicians and barriers to providing care to persons with HIV/AIDS. Evaluation and the Health Professions. 1997; 20(2):164-187

157. Shih WM, Hsiao PJ, Chen ML, Lin MH. Experiences of family of patient with newly diagnosed advanced terminal stage hepatocellular cancer. Asian Pacific Journal of Cancer Prevention. 2013; 14(8):4655-60

158. Shyu YI. Patterns of caregiving when family caregivers face competing needs. Journal of Advanced Nursing. 2000; 31(1):35-43

159. Simon C, Kumar S, Kendrick T. Who cares for the carers? The district nurse perspective. Family Practice. 2002; 19(1):29-35

160. Sims-Gould J, Martin-Matthews A. We share the care: Family caregivers experiences of their older relative receiving home support services. Health & Social Care in the Community. 2010; 18(4):415-423

161. Singleton J. Women caring for elderly family members: Shaping non-traditional work and family initiatives. Journal of Comparative Family Studies. 2000; 31(3):367-375, ii-iii, vii, xi

162. Sittisombut S, Maxwell C, Love EJ, Sitthi-Amorn C. Physicians' attitudes and practices regarding advanced end-of-life care planning for terminally ill patients at Chiang Mai University Hospital, Thailand. Nursing & Health Sciences. 2009; 11(1):23-28

163. Song JI, Shin DW, Choi JY, Kang J, Baek YJ, Mo HN et al. Quality of life and mental health in the bereaved family members of patients with terminal cancer. Psycho-Oncology. 2012; 21(11):1158-1166

164. Song JI, Shin DW, Choi JY, Kang J, Baik YJ, Mo H et al. Quality of life and mental health in family caregivers of patients with terminal cancer. Supportive Care in Cancer. 2011; 19(10):1519-26

165. Stajduhar KI, Davies B. Palliative care at home: reflections on HIV/AIDS family caregiving experiences. Journal of Palliative Care. 1998; 14(2):14-22

166. Stajduhar KI, Martin WL, Barwich D, Fyles G. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. Cancer Nursing. 2008; 31(1):77-85

167. Steele LL, Mills B, Long MR, Hagopian GA. Patient and caregiver satisfaction with end-of-life care: does high satisfaction mean high quality of care? American Journal of Hospice & Palliative Medicine. 2002; 19(1):19-27

168. Stephenson-Cino P, Steiner M, Krames L, Ryan EB, Huxley G. Depression in elderly persons and its correlates in family practice: A Canadian study. Psychological Reports. 1992; 70(2):359-368

169. Stockwell-Smith G, Kellett U, Moyle W. Why carers of frail older people are not using available respite services: An Australian study. Journal of Clinical Nursing. 2010; 19(13-14):2057-2064

170. Sudore RL. Family involvement at the end-of-life and receipt of quality care. Journal of Pain and Symptom Management. 2014; 48(6):1108-1116

171. Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. Palliative and Supportive Care. 2014; 12(3):223-31

172. Thoresen L, Lillemoen L. "I just think that we should be informed" a qualitative study of family involvement in advance care planning in nursing homes. BMC Medical Ethics. 2016; 17:72

173. Tilden VP, Tolle SW, Drach LL, Perrin NA. Out-of-hospital death: Advance care planning, decedent symptoms, and caregiver burden. Journal of the American Geriatrics Society. 2004; 52(4):532-539

174. Turner M, King C, Milligan C, Thomas C, Brearley SG, Seamark D et al. Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': A qualitative study of the oldest carers' experiences. Age and Ageing. 2016; 45(3):421-426

175. Vaddadi K. Stress of caregiving for the chronically mentally ill. Psychiatric Annals. 1996; 26(12):766-771

176. van Eechoud IJ, Piers RD, Van Camp S, Grypdonck M, Van Den Noortgate NJ, Deveugele M et al. Perspectives of family members on planning end-of-life care for terminally ill and frail older people. Journal of Pain and Symptom Management. 2014; 47(5):876-86

177. van Wijmen MPS, Pasman HRW, Widdershoven GAM, Onwuteaka-Philipsen BD. Motivations, aims and communication around advance directives: A mixed-methods study into the perspective of their owners and the influence of a current illness. Patient Education and Counseling. 2014; 95(3):393-399

178. Vandrevala T, Samsi K, Rose C, Adenrele C, Barnes C, Manthorpe J. Perceived needs for support among care home staff providing end of life care for people with dementia: A qualitative study. International Journal of Geriatric Psychiatry. 2017; 32(2):155-163

179. Walczak A, Henselmans I, Tattersall MHN, Clayton JM, Davidson PM, Young J et al. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. Psycho-Oncology. 2015; 24(3):287-293

180. Waldrop DP, Kusmaul N. The living-dying interval in nursing home-based end-of-life care: Family caregivers' experiences. Journal of Gerontological Social Work. 2011; 54(8):768-87

181. Washington KT, Demiris G, Parker Oliver D, Wittenberg-Lyles E, Crumb E. Qualitative evaluation of a problem-solving intervention for informal hospice caregivers. Palliative Medicine. 2012; 26(8):1018-24

182. Waters CM. Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. Qualitative Health Research. 2001; 11(3):385-398

183. Weeks LE, MacQuarrie C. Supporting the volunteer career of male hospice-palliative care volunteers. American Journal of Hospice and Palliative Medicine. 2011; 28(5):342-349

184. Weibull A, Olesen F, Neergaard MA. Caregivers' active role in palliative home care - to encourage or to dissuade? A qualitative descriptive study. BMC Palliative Care. 2008; 7:15

185. Wiles J. Informal caregivers' experiences of formal support in a changing context. Health & Social Care in the Community. 2003; 11(3):189-207

186. Wilson D. Quality care at the end of life: the lived experience of surrogate decision makers. Journal of Hospice and Palliative Nursing. 2011; 13(4):249-256

187. Winter L, Parks SM. The reluctance to burden others as a value in end-of-life decision making: A source of inaccuracy in substituted judgment. Journal of Health Psychology. 2012; 17(2):179-188

188. Wittenberg-Lyles E, Oliver DP, Demiris G, Washington KT, Regehr K, Wilder HM. Question asking by family caregivers in hospice interdisciplinary team meetings. Research in Gerontological Nursing. 2010; 3(2):82-88

189. Wittenberg-Lyles E, Oliver DP, Kruse RL, Demiris G, Gage LA, Wagner K. Family caregiver participation in hospice interdisciplinary team meetings: How does it affect the nature and content of communication? Health Communication. 2013; 28(2):110-8

190. Wittich AR, Williams BR, Bailey FA, Woodby LL, Burgio KL. "He got his last wishes": Ways of knowing a loved one's end-of-life preferences and whether those preferences were honored. Journal of Clinical Ethics. 2013; 24(2):113-24

191. Worth A, Boyd K, Kendall M, Heaney D, Macleod U, Cormie P et al. Out-of-hours palliative care: A qualitative study of cancer patients, carers and professionals. British Journal of General Practice. 2006; 56(522):6-13

192. Yamamoto N, Wallhagen MI. Service use by family caregivers in Japan. Social Science and Medicine. 1998; 47(5):677-691

193. Young AJ, Rogers A, Addington-Hall JM. The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: A retrospective survey of surviving family and friends using the Views of Informal Carers Evaluation of Services questionnaire. Health & Social Care in the Community. 2008; 16(4):419-428

194. Zapart S, Kenny P, Hall J, Servis B, Wiley S. Home-based palliative care in Sydney, Australia: The carer's perspective on the provision of informal care. Health & Social Care in the Community. 2007; 15(2):97-107

195. Zhang AY, Siminoff LA. The role of the family in treatment decision making by patients with cancer. Oncology Nursing Forum. 2003; 30(6):1022-1028

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.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	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]

Review question	All questions – health economic evidence
Review strategy	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. 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] Inclusion and exclusion criteria 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. 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. If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. Where there is discretion 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. The health economist will be guided by the following hierarchies. Setting: 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). Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. Health economic study type: Cost–utility analysis (most applicable). Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). Comparative cost analysis. Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. Year of analysis: The more recent the study, the more applicable it will be. 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'. Studies published before 2007 will be excluded before being assessed for applicability and methodological limitations. 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

Review question	All questions – health economic evidence
	the analysis will be for decision-making in the guideline.

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
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

Database	Dates searched	Search filter used
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 inappropiate 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 inappropiate 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 inappropiate 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 inappropiate 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

1 **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

2 **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)

ASSIA (ProQuest) search terms

1.	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")

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 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)

1 **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.

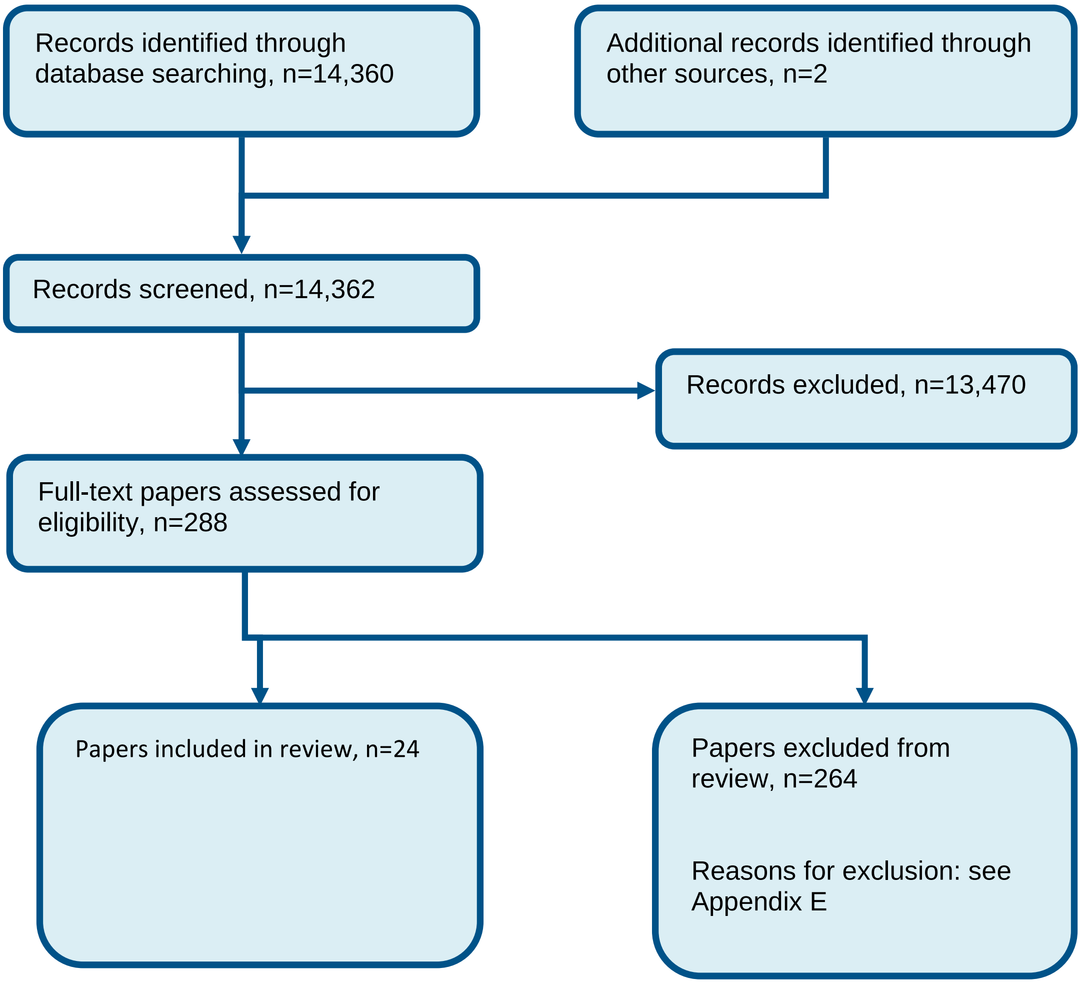
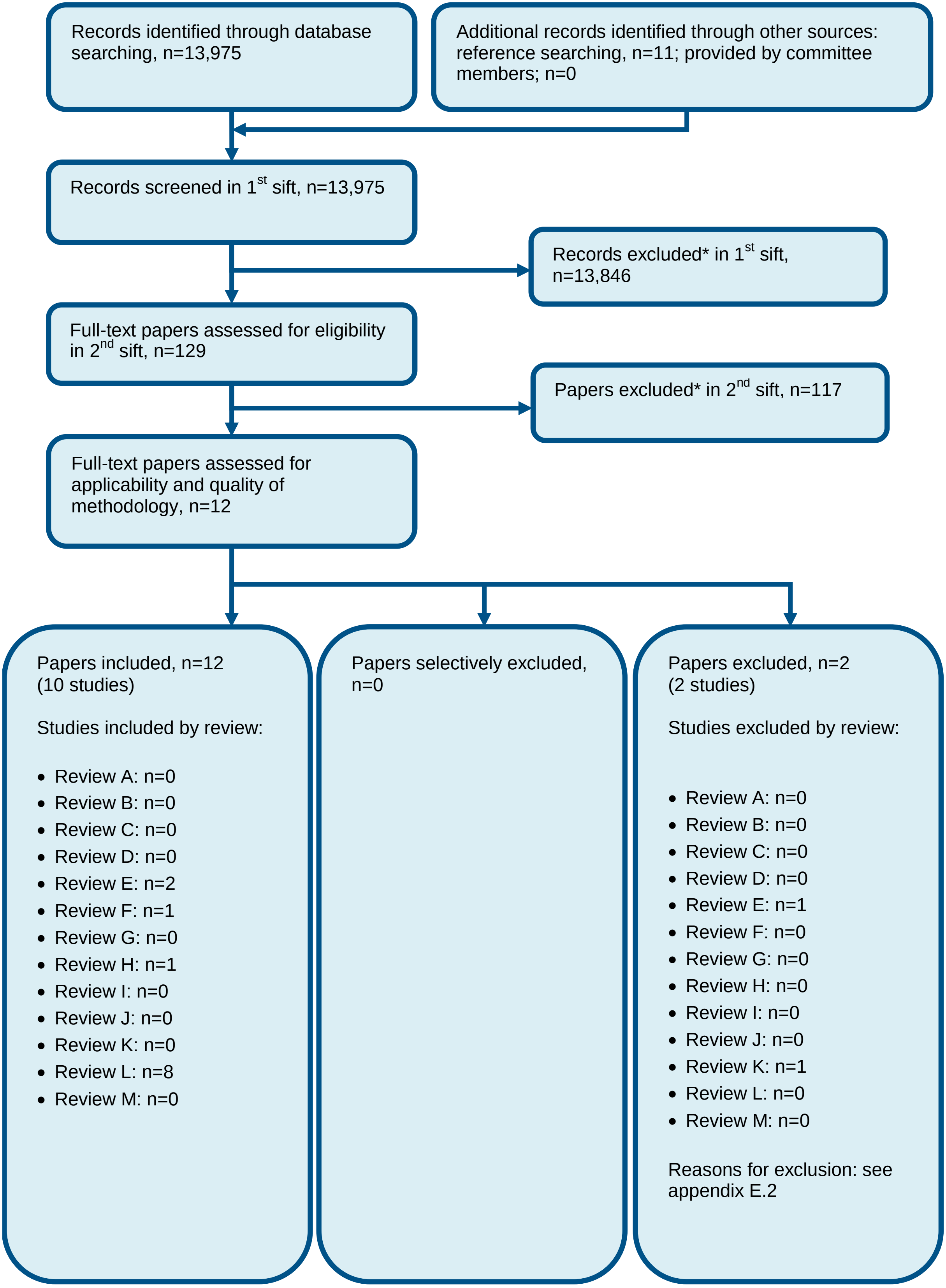


Figure 2: Flow chart of health economic study selection for the guideline



* 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	**Lack of knowledge: access to knowledgeable practitioners:** Access to skilled practitioners increased satisfaction and improved feelings of helplessness and uncertainty.
	Emotional Burden :Care giving was seen by some people as a heavy burden and acknowledged it was tough.
	Access to healthcare providers: This was seen as positive and increased feelings of confidence.
	Trust in health-care providers: Where there was trust in health **providers the experience of caring and services was more positive.**
Limitations and applicability of evidence	Analysis could have been more in depth. Applicable

Study	**Caron 2005**[24]

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	Face-to-face in-depth interview to gain narrative data, with thematic qualitative analysis. 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. 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.
Findings	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.
	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.
	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.
Limitations and applicability of evidence	Role of researcher unclear. Analysis could have been more in depth. Unclear if themes reached saturation. Applicable

Study	**Dening 2012**[39]

Study	**Dening 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	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. 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. 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.
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	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’. 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.

Study	**Dening 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	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). 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. 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.
Findings	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'.
	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. The dyad group carers tended to speak on behalf of the person with dementia, thus influencing the collective view. The carers felt it was difficult to plan ahead and anticipate what may or may not happen. The carers felt that medical decision-making and the use of end-of-life care pathways could invalidate their ACPs. 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. 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

Study	**Dening 2013**[40]
	‘suicide’. While acknowledging that euthanasia is not legal in the United Kingdom they reached a consensus that you cannot discuss ACP without it. It was highlighted that if end-of-life care was better, individuals would not need to contemplate euthanasia. Summarising their views on ACP, the carer group felt that carers’ needs should also be taken into account.
	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]. 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. 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.
Limitations and applicability of evidence	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’. 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.

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	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. 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

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	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.
	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.
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	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. 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.”
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]
	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. 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. 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.
Findings	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
	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. 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. They appreciated the easy access to a knowledgeable practitioner that PATCH provided.
	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

Study	**Holley 2009**[71]
	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 2012**[81]
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]

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	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). 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.
Findings	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”
	Information exchange: Some family members experienced not knowing what questions to ask HCP.
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	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. Interviews were conducted by an experienced qualitative researcher, and focus groups were facilitated by a researcher experienced in

Study	**Lamahewa 2017**[96]
	conducting focus groups, observed by an additional researcher who took field notes. 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.
Findings	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.
	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.
Limitations and applicability of evidence	Role of researcher unclear. Unclear if themes reached saturation. Applicable

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 withdrawn 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	Face-to-face single narrative-inducing question interviews, followed semi-structured interviews with thematic qualitative analysis. 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 tell me what happened?' an extensive narrative was elicited in all interviews. Next using a semi-structured interview guide, the

Study	Lind 2013 [103]
	interviewer followed up topics from the narrative. 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 lead to iterations, alternative explanations for the findings were discussed and agreed upon.
Findings	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.
	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. 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. 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.
Limitations and applicability of evidence	Subgroup from a parent study; little information on ICU population. Applicable

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.
Methods and	Using a grounded theory approach, a theoretical sampling of 20 family caregivers previously involved in end-of-life decision-making

Study	MacDonald 2011[109]
analysis	were interviewed. Semi-structured in-depth interviews were conducted by the lead author, audiotaped, and transcribed. 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.
Findings	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.
	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.
Limitations and applicability of evidence	Role of researcher unclear. Unclear if themes reached saturation. Applicable

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 vignettes and interview guide used to explore cancer patients' ACP views were modified to describe situations of a family

Study	Michael 2014[118]
	member/loved one at different cancer stages, with varying degrees of ill health, symptoms, and cognitive involvement. 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. 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.
Findings	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.
Limitations and applicability of evidence	Little information on analysis so rigour and reliability unclear. Role of researcher unclear. Applicable

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.
Methods and	Cross-sectional survey containing 2 open-ended questions from the Establishment of Hospice and Palliative Care Services (EPACS)

Study	Muders 2015[127]
analysis	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. 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.
Findings	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. An important concern of respondents was obtaining information about the hospital staff. 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. Another suggestion was timely notification of families in case of a patient’s worsening state of health.
Limitations and applicability of evidence	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. Partially applicable: only one category met the PICO of the review.

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.
Findings	Tension and conflict: Family members and friends described multiple sources of tension in their interactions with patients and the

Study	O'Hare 2017[134]
	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	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. 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.
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]

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	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. 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.
Findings	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. 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.
	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.
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
Population	Family decision makers whose relative with advanced dementia died after participating in the goals of care intervention. N=16. The

Study	Rosemond 2017[148]
	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	Experiences of goals of care decision making differed based on whether or not family decision makers expressed trust in nursing home staff. 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: 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. 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.
	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.
	Deciding on goals of care in the absence of trust: 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 ant themselves.
	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.
	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.
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	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.
	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.
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

1

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]
	Participants were encouraged to share their responses to the progression of the illness through additional open-ended questions about their experience. 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.
Findings	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. 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.
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	Washington 2012[181]
Aim	To assess which specific intervention processes impacted informal hospital
Population	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. 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. 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).

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	Semi-structured interviews with thematic analysis. Participants part of bigger study and participated in an exit interview. Qualitative data generated during these interviews formed the basis of the present study. 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. 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. 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 stage s of the intervention and to provide insight into the benefits and challenges associated with their involvement in the project. 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.
Findings	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.
	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.

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'.
	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.
	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. 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.
Limitations and applicability of evidence	No details of researcher bias. All other methodology was clearly described. Specifically related to one problem-solving intervention, so this is not specifically relevant to decision-making, but is indirectly related.

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	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. 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 and naming themes. Twenty one thematic categories were initially identified in this process, once these themes were identified, the

Study	**Wilson 2011**[186]
	principle investigator reviewed each theme to validate its content, revising as appropriate.
Findings	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.
	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.
	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.
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. Role of researcher unclear. Applicable

Study	**Wittich 2013**[190]
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	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. 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.
Findings	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.

Study	Wittich 2013[190]
	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.
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

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
Vandrevala 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.