Appendix D: Qualitative evidence tables

Study	Bamford 2018[51]
Aim	To explore the factors that facilitate good End of Life Care for people with advanced dementia from the perspective of stakeholders including family carers and people with dementia.
Population	People with dementia who had joined a Case Register for those willing to participate in research studies and those registered with Join Dementia Research. N=11 Bereaved and current carers N=18
Setting	Newcastle University. October 2013 to January 2016.
Study design	Qualitative interview study
Methods and analysis	Face-to-face interviews following a Q-Sort activity. One focus group with the carers The interviews and focus groups focused on accounts of End of Life Care in dementia and the perceived barriers and facilitators to the delivery of care. Topic guides where used to structure the discussions while allowing for the emergence of new ideas from participants. All interviews were audio-recorded, and transcribed in full and anonymised for analysis. This was part of a project that took a social constructivist perspective and explored multiple perspectives of people delivering and receiving care. The interviews and focus groups were thematically analysed and key issues where identified. Emergent themes were discussed in data workshops with the themes being modified when the final version of the codes were agreed.
Findings	**Timing of planning discussions:** Barriers identified to planning ahead included a preference to focus on living in the present; a lack of awareness that dementia is a terminal condition, assumptions that family members and healthcare professional would know their wishes and be able to make decisions on their behalf if necessary ,confidence in the quality of the current and future provision and difficulties in engaging in discussions about end of life care when they felt fit and healthy. Carers reported they were uncertain about the preferences of the person with dementia and could find the decision- making burdensome.

Study	Bamford 2018[51]
	Coordination and continuity of care: This requires close coordination between different agencies and co-ordination within services. Issues with poor communication were identified.
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Bajwah 2013[48]
Aim	To explore understanding of the disease, preferences regarding end-of-life planning, and views on communication and coordination of care in patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD).
Population	Patients with a diagnosis of non-specific interstitial pneumonia, IPF and idiopathic interstitial pneumonia, as classified by the American Thoracic Society/European Respiratory Society criteria with a percentage-predicted transfer factor <40%, and an ability to understand and speak English fluently. Carers and health professionals involved in the care of these patients were also identified. Eight patient participants (four from RBH and four from KCH), and four carers (from RBH).
Setting	UK. Royal Brompton (RBH) and Kings College Hospital (KCH) NHS Foundation Trusts between December 2010 and March 2011.
Study design	Qualitative interview study
Methods and analysis	Face-to-face semi-structured interviews. The interviews were informal in style, and loosely followed a topic guide that was initially guided by review of the literature. This topic guide was piloted prior to use. Interviews began with a general discussion about what patients understood by their disease and its prognosis, and then progressed to explore end-of-life preferences and communication-related issues. Prompts were used to elicit further information. All interviews were audio-recorded, transferred verbatim onto a secure transcription database, and then imported into NVIVO 9software to facilitate analysis using the constant comparative method. Each transcript was subject to line-by-line axial coding by SB. Codes were scrutinised for internal consistency through an iterative process. Codes and subcodes were tabulated during the charting process to allow abstraction and synthesis of themes. The complete coding frame and sample comparison were reviewed by SB, JK and IJH to confirm the analysis and interpretation. To maximise analytical rigour, a selection of the interviews was reviewed by a second researcher (JK), and consensus achieved. Excerpts from the interview transcripts are presented below, to illustrate themes. All participants' names have been changed to preserve anonymity.
Findings	**End-of-life information needs:** All participants shared a common sentiment about the lack of information to help plan for the future. Central to this was a wish to understand exactly how they would deteriorate at the end of life. "I haven't sort of um haven't really

Study	Bajwah 2013[48]
	discussed how it will develop with anybody, but you know that may be my own fault if I don't talk about it um to somebody, and you don't know them I've got nothing to worry about (laughs)". Patients wanted to have the option of gathering further information, and being able to discuss issues, if they wished, which they did not feel was currently the case.
	End-of-life planning, decision making and care: No patients, and no patients cared for by the carers, reported they had formulated end-of-life plans, or considered end-of-life preferences, such as preferred place of care or preferred place of death. A number of carers were aware of broad preferences, but in-depth conversations had not occurred. All patients, and all carers, realised the importance of such conversations, but did not know how to initiate conversations with their loved ones. No patients, or carers, reported palliative care involvement stating that they were not aware of any such services.
	Coordination of care: Patients and carers reported being very satisfied with the specialist respiratory care received. However, communication between health professionals and coordination of care was flagged as a problem by all participants. "I think they try to liaise between each other but it so often falls apart … there is really a short coming amongst um getting information from one aspect of the medical profession to the other."
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Benzar 2011 [67]
Aim	To identify the range of health care experiences of family caregivers and patients who received palliative care consultations after they left the hospital, and to understand how palliative care teams might best prepare patients and caregivers for the post-hospital experience.
Population	Patients who received palliative care consults at Oregon Health and Science University (OHSU) and who were: 1) discharged alive between two weeks and three months before identification of patient for interview; 2) discharged to either home without hospice, home with hospice, nursing home, or inpatient hospice and English-speaking. Purposely recruited to include subjects who were non-white, did not carry a diagnosis of cancer, and were discharged to nursing homes. N=19 patients and/or their caregivers. Patient characteristics: Age (mean (SD)): 66 years (16); male: 8; female: 11; ethnic minorities: 4; Alive for interview: 4; Patient location of care after hospital discharge: inpatient hospice: 4; home hospice: 6; home, no hospice: 7; nursing home: 2; Survival after hospital discharge: 5 days or under: 5; 6-12 days: 5; 13030 days: 5; 31-90 days: 0; over 90 days: 4.

Study	**Benzar 2011** [67]
	Caregiver characteristics: Age (mean (SD)): 50 years (13); male: 5; female: 14; ethnic minorities: 5; caregiver relationship to patient: daughter/stepdaughter: 8; wife: 2; son/stepson: 2; friend; other 5.
Setting	OHSU consults from September 1, 2006-August 31st 2007.
Study design	Retrospective qualitative study.
Methods and analysis	Semi-structured in-depth interviews for 1-2 hours. Interviews were analysed by 2 independent coders using NVivo v.8. They started with broad questions that allowed subjects to determine, in the context of semi-structured interviews, what was important about their experience with palliative care and the discharge process. The interviews were then analysed using qualitative description. A researcher coded all 19 interview transcripts line by line, identifying 84 discrete codes. These codes were then organised into 15 codes within 6 major themes, the interview transcripts were re-coded by the original researcher and independently by a second researcher. Inter-coder reliability was calculated as letter-by-letter agreement using NVivo. Of the 6 themes, 3 were concerns that could be addressed by a palliative care team before hospital discharge. They chose to focus further analysis on these. The other three themes were related to experiences after hospital discharge that were outside of the scope of an inpatient palliative care team and therefore outside the scope of their study.
Findings	**Prognosis:** lacking information about prognosis and disease progression was a recurrent theme. In the hospital, prognoses were sometimes vague or overoptimistic and lacked information about what caregivers should expect. In one consult the main documented goal was to discuss goals of care and prognosis, and the patient's chart confirmed that these had been discussed however the caregiver thought attempts to discuss prognosis were dancing around the topic, and that they had to really tell the person. Another participant felt he had to read into what the doctors were saying about his father's death. He was concerned that not everyone would have been able to draw the conclusion that his father was about to die. Another participant was surprised when her mother, who originally went home with hospice for cancer, died unexpectedly while later from a dialysis shunt infection, which she felt she had not been told to watch out for.
	Symptom management: families often lacked the education that they needed to recognise and manage symptoms. In some cases, teaching about medicine use for symptoms was sparse and not written down. If dosing instructions on the prescription bottle were inadequate, caregivers had no contingency plans. Inconsistencies were found in instructions and One participant said "the prescribed her [her mother] with over £1000 in medicines….the discharge paper was blank…they didn't give her what she needed. They changed what was working to other medicines. It seemed like we had never spoken to those people at all", the authors verified that the discharge medication summary was blank, and the dosing instructions provided by the pharmacy did not correspond with the doses the patient had been taking in hospital. Another caregiver of someone on home hospice for end-stage liver disease was not prepared to adjust medication doses when needed. Although symptom control was a major emphasis of this patient's palliative care consultation in the hospital, after hospital discharge, the caregiver was confused over the pain medication as it left the patient sleeping all day.
	Whom to call with questions: another area of concern was who to contact with questions and concerns. Some quotes also reflect difficulty with simply navigating the healthcare system. Both of the patients mentioned had only one documented encounter with palliative care during their stay. The daughter of an 85-year-old female who went home without hospice after a GI bleed had difficulty learning about options for home care. She said "several times we didn't know what was out there to help us…She wanted to come home and we wanted to provide care for her at home…But we didn't know what other type of care there was…We finally got some of

Study	Benzar 2011 [67]
	that information but…We had to struggle to search it out, and answers weren't readily available." One participant was grateful to find a receptionist at the doctor's office to help her through the process. "The medical system, if you are not part of it, is a pretty foreign thing…if you find a person that will work with you, whether it be a doctor, a nurse…the scheduler…They are there to help guide you through the system. But finding them and really cultivating that relationship makes a huge difference." **Hospice:** only one of the preceding quotations came from a patient cared for by a hospice program. Their data included multiple examples in which patients and families with hospice mentioned that hospice nurses answered all their questions, helped them adjust medications, and contacted the physicians for them. However only 53% of patients in this study were discharged to home or inpatient hospice. Additionally, even patients discharged with hospice experienced gaps in the discharge planning process before they left the hospital. **Palliative care teams:** another key finding was that, at the time of their interviews (up to three months after hospital discharge), several patients and their families did not remember their interactions with the palliative care team, despite being shown pictures of team members to help jog their memories. In other cases, interviewees remembered the palliative care team members but could not distinguish interactions with them from interactions with other types of care teams.
Limitations and applicability of evidence	Unclear on data saturation. Applicable.

Study	Briggs 2010[92]
Aim	Originated from a consultation in Borough on understanding the experiences and expectations of patients diagnosed with life-limiting diseases during the last year of life.
Population	Borough-registered patients (n=30) and carers (n=20) aged 16 year and over. Patients were being treated at various hospitals or hospices or were receiving treatment in their homes. N=50; males: 18; women: 32; Aged: 40 to 90 years old; Ethnicity: white: 35, black African: 5, Asian: 4, Irish: 2, mixed race: 2. Non-cancerous conditions (COPD, heart failure, Parkinson's disease, dementia, strokes, heart disease and HIV): 32, cancerous conditions 19.
Setting	End of life care services within Borough's PCT, England.
Study design	Qualitative interview study.
Methods and analysis	Open-ended qualitative interviews and observations. The interviews examined the patient's carer's knowledge of service, experiences of each service with which they had contact, the efficiency of those services and suggestions for improvements. Observations were also made of patient/carer/professional interactions in some patients' home settings.

Study	Briggs 2010[92]
	Interviews lasted between 30 minutes and 1.5 hours and were transcribed verbatim for inductive analysis, so data were categorised thematically, with the key areas of investigation providing the overall framework for coding.
Findings	**Context:** patients' and carers' views on Borough EOL care services: participants appreciated GPs for their ability to respond to emergencies and prioritise EOL patients, as well as advocate for patients in the absence of effective communication from other agencies and departments.
	Developing tense emotions in the course of care: diagnosis of a terminal condition and the subsequent period was a highly sensitive time. Large family and friend support networks helped where they could and often advocated on their behalf, but not all patients were blessed with this. In these instances, some patients tended not to be aware of services provision or were tired of reporting their social and practical circumstances because the persistence involved in 'speaking up', 'filling in forms', and 'making phone calls' made for heavy demands on these patients. This was why they tended to either 'get on as best they could' or gave up after a few phone calls or if no one 'followed up on them'.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. No details of the decision to stop data collection and more details required about coding and themes. Applicable

Study	Coombs 2017[157]
Aim	To describe decision-making processes that influence transitions in care when approaching the end of life.
Population	Patients with advanced and progressive illness, with high risk of dying in the next 12 months, and their carers. N=40
Setting	Residential care home, a medical assessment unit and a general medical unit in New Zealand.
Study design	Qualitative interview study.
Methods and analysis	Field observations and longitudinal semi-structured interviews with thematic qualitative analysis.
Findings	How patients managed risk in decision making about transitions in care: Patients expressed preference to stay at home, often even with increasing risks at home, rather than being admitted to hospital. All patients stated they had made the decision about their admission into hospital, and this was the view shared by the carers. In this they weighed the benefit of being at home with the risk. They used practical resources, mainly equipment and carer support and anticipating future needs to manage increasing risks. Equipment (e.g bed pans, commode, walking aids, wheelchairs, personal alarms) which helped them to undertake the activities of daily living. As their condition advanced/deteriorated, different pieces of equipment were sourced to manage the associated risks, enabling them to remain at home.

Study	Coombs 2017[157]
	Carers played a vital role in them staying at home. Anticipating future needs and making appropriate changes helped patients cope and remain at home. This often involved patients emotionally preparing themselves for change. If the deterioration was too sudden, they were unable to adjust quickly.
Limitations and applicability of evidence	Little information on potential bias of researcher. Applicable, but there were HCPs as well as patients and carers included within the study so only one theme (out of two) could be included.

Study	Csikai 2010 [168]
Aim	To explore the communication process between patients' caregivers and health care professionals, including social worker about serious illness and end of life.
Population	Bereaved hospice caregivers of patients over 60 receiving home hospice services. N=10; Age range: 45-88 years; care recipients' ages range: 67-99 years. The relationships to the care recipients were: husbands, wives, daughters, daughter-in-law, and sister. Primary diagnoses: various cancers, heart and lung diseases. Hospice stay range: 1 week – 2 years.
Setting	1 large and 2 small urban setting Hospices in USA.
Study design	Qualitative (phenomenological) study.
Methods and analysis	Semi-structured in-depth interviews conducted within 3-6 months from the time of the patient's death. Interviews lasted 1 1/2 – 2 hours. A semi-structured interview guide was used that contained broad and open-ended questions. The primary domains examined were communication with health care professionals about end-of-life care options and decisions/transitions to hospice. All data were transcribed with the aid of a professional transcriptionist. The data were then compiled and rigorously analysed by reading and re-reading transcripts several times and creating codes and noting the emerging themes. Atlas-ti was used for data management. Using content, context and comparative approaches, the researchers organised the participants' statements into categories/codes to identify underlying patterns and themes. All data were coded by considering the responses of all participants and by dividing them into categories that covered various responses. Codes and categories were compared, contrasted and sorted until no new categories and codes emerged.
Findings	**Involvement of health care professionals:** most of the participants talked about the central role of the physician in the discussion of the patients' serious illnesses and decision making about end-of-life care options. They reported that the physicians were the primary givers of information about diagnosis/prognosis and recommendations regarding treatment/care plans. The next most mentioned

Study	**Csikai 2010** [168]
	professional involved in decision making about care were social workers. They discussed the typical roles as liaison between families and health care professionals and as brokers who facilitated needed referrals for care. One participant said 'I guess they told the social worker and then the social worker passed it on, you know, through all the red tape that they have to go through to set it up." The participants that did remember involvement of a social worker in their situation generally did not have much to offer about their actions and one-half of participants did not mention social workers at all. Other health care professionals such as nurses and hospice personnel were also involved at times in the discussion and transition to hospice care. Nurses however seemed to be tangentially involved mentioned simply as people who were in the room by 6 participants. Two participants mentioned that hospice personnel provided some information about hospice services prior to enrolment.
	Relationship with Physician: the nature and quality of patients' relationships with their primary physicians were important in the communication process. Some reported that the physicians were seen as "god-like" entities. Also the participants spoke of the respect and trust they and the patients had in their physicians and its importance. It seems that with such trust and respect would come the expectation of truthfulness. Patients and caregivers expected that the physician would honestly discuss the situation and make a recommendation for plan of care and in some cases they did not have this.
	Involvement of patients in decisions: patients were reported by some caregivers to be involved in the decision-making process. One participant revealed that he wanted, as well as needed, his wife's (patient) participation. Even though the news was not anticipated to be good, some participants believed it was important that the patients were involved in conversations about their illness and future care plans. Caregivers sometimes also controlled the flow, withheld information and shielded patients from decision making because of the seriousness of the condition, or because of advanced age. A secondary theme regarding patient involvement in decisions was revealed in discussion about advance care planning. These caregivers' generally discussed a lack of written advance directives, but revealed knowledge of patients' wishes for care at the end of life as a way that allowed patient participation in decisions that were made.
	Content of discussion: the content of the discussions about serious illness and end-of-life care options was varied, but typically included disclosure of terminal prognosis and future care needs at least in a general way. In some cases, the diagnosis/prognosis was clearly given. In other cases, there was reluctance on the part of physicians to give complete disclosure of prognosis to the patients and caregivers. In one situation, after information was shared about the prognosis, a couple of options for end-of-life care, including hospice, were outlined, but not adequately descried.
	Understanding of hospice: Patient and caregiver understanding of hospice in the transition process varied. Some mentioned a lack of adequate understanding of hospice philosophy and services. The sentiment was similar to other studies' findings that patients and families only found out about the most beneficial aspect s of hospice after enrolment (Casarett et al 2004; Casarett et al 2003). Other caregivers had previous experience with hospice indirectly through family or friends or previous utilisation of hospice themselves with another family member, so they had a better idea of what to expect.
	Suggestions for improvement: one area for improvement in communication about end-of-life hospice care could be improved was that more information was needed sooner in the discussion/decision-making process. Some of the participants believed that information about the trajectory of the disease and the dying process should be given much earlier, even as soon as right after diagnosis. The information should include what to expect in terms of medical treatments as well as what services are available to assist

Study	**Csikai 2010 [168]**
	with care for the end stage of the disease. The perception of compassion by health professionals is another aspect that can facilitate communication. The caregivers in this study strongly suggested that professionals work together to provide information needed to make end-of-life care decisions.
Limitations and applicability of evidence	Small sample size. Note: study was the second phase of a larger study of bereaved hospice caregivers' perceptions of communication about end-of-life care and the transition to hospice care. The first phase was an exploratory cross-sectional mail survey. Little information on potential bias of researcher. Rigour of data collection unclear as more details needed on how recorded and transcribed. No details of data saturation. Applicable.

Study	**Davison 2006[183]**
Aim	To determine the perspectives of patients with ESRD of the salient elements of ACP discussions.
Population	24 patients with end stage renal disease from the Northern Alberta Renal Program. Participants were purposively selected on the basis of their willingness to discuss the issues and were stratified by age, gender, and dialysis modality. Fourteen patients were recruited from the Renal Insufficiency Clinic and were clinically expected to require dialysis within the next 12 mo.
Setting	Canada. Northern Alberta Renal Program at the University of Alberta between August 2004 and June 2005.
Study design	Qualitative interview study
Methods and analysis	Nominal group technique; face-to-face interviews. Two exploratory focus groups with eight (pre-dialysis and dialysis) patients. The issues raised during focus groups in conjunction with a critical review of the literature formed the basis for the study interviews. Personal audio-recorded interviews, typically lasting 60 to 90 min, subsequently were conducted in 24 study participants. All interviews were transcribed and validated against the recorded material by the interviewer. Data collection and analysis were continual and dialectic; constant comparative and iterative analyses were used. This analysis consisted of identifying and coding sections of transcribed text into thematic categories. Associations between the derived themes were sought by synthesizing, theorizing, and re-contextualizing to create a framework to understand patients' perceptions of the salient elements of facilitated ACP.
Findings	Patient's Perceived Benefit of ACP: Patients clearly identified ACP as an important part of medical care when they had a clear idea of how the process would benefit them. They were much less likely to engage actively in a process from which no benefit was perceived. "Talking about [ACP] lets you know what's going to happen. I need to know what the symptoms are and he wouldn't tell me … because I'm really worried about nausea, vomiting, and not being able to breath. Someone should be talking to you about what's coming."

Study	Davison 2006[183]
	Information Giving: Patients experienced fear and uncertainty about their future. Information giving was seen by these participants as a critical element of the ACP process in that it promoted self-reliance; alleviated fear and uncertainties; helped prepare them for the future, including death; and gave them the knowledge to make decisions that were compatible with their values and beliefs.
	Role of Physicians in Facilitated ACP: Participants clearly believed that physicians were responsible for initiating and guiding facilitated ACP, mainly because physicians were seen as the primary source of information that is central to this process. “I would hope that health care providers are sufficiently trained to inform the patients at the right time what to expect and not wait until the very last minute.”
Limitations and applicability of evidence	Subgroup from a parent study, little information on population details or role of researcher. No details of data saturation. Applicable.

Study	den Herder-van der Eerden 2017[196]
Aim	To examine how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers receiving care from several integrated palliative care initiatives in 5 European countries.
Population	Patients with advanced disease (62% cancer, 24% COPD, 13% heart failure), whose doctors answered ‘No’ to the surprise question. N=152
Setting	Belgium, Germany, Hungary, the Netherlands, and the United Kingdom.
Study design	Longitudinal qualitative study design
Methods and analysis	Interviews with a two-step qualitative content approach
Findings	**Relational continuity:** this was a prominent theme in all countries. There were positive and negative experiences related to having or not having close relationships with a small number of health care professionals (e.g hospital specialists, general practitioners (GPs), nurses, physiotherapists or hospice care professionals) and seeing them on a regular basis. The HCPs paid attention to them and talked about their personal lives, not just their illness. Being known to HCs provided trust and their needs and wishes could be taken into account to tailor their care. It also meant they could monitor the patients’ illness progress. However lack of relational continuity was often experienced and they had to build new relationships, repeat their histories and did not know what to expect from HCPs. Experiences of relational continuity with GPs varied widely across countries. Those with longstanding relationships with GPs valued this. GPS often had an important role in coordinating care, prescribing medication and making referrals. However many respondent experienced a lack of involvement of GPs. Often they took a backseat when patients were (still) treated by hospital specialist, or specialised palliative care teams, consequently not receiving the support they needed or expected from their GPs.

Study	den Herder-van der Eerden 2017[196]
	Informational continuity: they found it important for HCPs to be well informed, which stopped them repeating their histories and provided trust that the HCP had the right information to make correct treatment decisions. In all countries informational continuity seemed to be weak. This was revealed in situations where many different HCPs were involved, within the hospital, between the hospital specialists and GPs, between hospitals and acute (out-of-hour) situations. It was apparent they were often badly informed about the patient's history, did not have access to other health care professionals' patient records or did not have regular contact. This resulted in repeating medical histories several times, receiving contradictory information, worrying about the quality of care and become agent of information transfer between HCPs, while they did not want to have this responsibility. In all countries there were some respondents who had examples of closely working HCPs in teams or networks, who were well informed of their histories and personal circumstances. They found that these HCPS were often involved in collaborative integrated palliative care initiatives.
	Management continuity: they wanted to be seen as a person with multidimensional needs rather than a medical subject. This required that health care professionals viewed respondents with a holistic lens and provided multiprofessional care in order to support their multidimensional needs. Where this was absent HCPs worked in a fragmented fashion and only dealt with their own medical speciality. This was found mainly among individual hospital specialist and between hospital specialists and GPS. This meant problems were inadequately addressed, remained unaddressed or were discovered too late. Respondents saw a large difference when multiprofessional care was provided. They often did not know how exactly HCPs worked together or were not interested in this as long as they received multiprofessional care. Those that knew their HCPs came together in meetings, felt that their care was connected and coherent.
Limitations and applicability of evidence	No details on data saturation. Applicable.

Study	El-Jawahri 2017[223]
Aim	To assess perceptions about hospice.
Population	Patients with metastatic cancer, with a prognosis under 12 months, and their caregivers. N=16 patients; N=7 Caregivers (of the 16 patients)
Setting	Massachusetts General Hospital Cancer Centre, USA
Study design	Qualitative interview study.
Methods and analysis	Semi-structured interviews with the framework approach qualitative analysis.
Findings	Overarching ideas: there were variable gaps in understanding about hospice, widely perceiving a psychological transition to accepting certain imminent death.

Study	El-Jawahri 2017[223]
	Knowledge of hospice: they defined it as those facing the very EOL e.g last days. Most common perceived role was to provide symptom relief, with emphasis on making comfortable. Some perceived provision of psychosocial or spiritual support for patient and their families and patient medical care. Some inaccurately thought that it assisted with activities of daily living or practical issues. A few found it most relevant to those who lack family support.
	Attitudes about hospice: these reflected (positive and negative); concerns about suffering, loss of dignity, and death, as well as their perceived understanding of hospice services.
	Concerns about suffering, loss of dignity, and death: Those with positive attitudes viewed hospice as a key support in the face of feared outcomes. A safe place for patients with gaps in family support; a relief for family to know their loved ones are being cared for; a comfort for help to reduce suffering and maintain dignity. Those with negative attitudes focused on hospice as a key harbinger of feared outcomes.
	Perceived understanding of hospice services: those with positive attitudes reflected on good prior hospice experience; one with negative reflected on poor prior experience.
	Perceived barriers to hospice utilisation: the perceived barriers were related to knowledge and attitudes, and they highlighted three influencing factors: psychological barriers to projecting a need for hospice, perception of EOL care as a personal or family domain, and a lack of understanding about hospice.
	Psychological barriers to projecting a need for hospice: these barriers were common and referenced uncertainty, emotional cost of losing hope, and avoidance of feared outcomes. One caregiver noted that family members might avoid contacting hospice so they don't put fear into the patient.
	Perception of EOL care as a personal or family domain: several thought that patients may prefer to care for themselves or that family may provide support without the need for hospice. Some voiced specific concerns about hospice staff interfering on patient and family privacy.
	Lack of understanding about hospice: several noted that many may not utilise hospice because they do not understand enough about it or are not thinking deeply enough about it, or don't learn about it until the last minute.
	Preferences of learning about hospice: given perceived barriers to hospice utilisation, they largely showed interest in gaining clarity and/or reassurance about hospice. Almost all identified one aspect they wanted to learn more about.
	Areas of interest: they primarily wanted to know about hospice logistics, including the range of services, locations of care, members of the hospice team, and frequency/length of home hospice visits.
	Preferred methods of learning: responses reflected that hospice was a sensitive and somewhat mysterious topic to broach. Almost all respondents identified interest in reviewing information about hospice in brochure, video or internet format, for a gentle introduction, a broad picture or an in-depth look in to what hospice is actually like. They also expressed interest in discussing hospice with current providers whom they trusted, often as a follow-up to reviewing information. Some wished to learn from current hospice patients or staff or with other interested families, to gain reassurance, a real life view of hospice, or information that one might not have thought to request.

Study	**El-Jawahri 2017[223]**
	Preferred timing of learning: Perceived optimal timing of learning about hospice reflected attention to what would be the most effective and/or the least detrimental to patients. Most suggested learning early after their diagnosis. Some of these suggested waiting for time to process initial shock of diagnosis and adjust to the treatment plan, or delaying in-depth information until the patient's health worsens. Or some thought not until something imminent occurs or there are no other options, with a few specifying that early information would interfere with hope and quality of life.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. Applicable.

Study	**Epiphaniou 2014 [233]**
Aim	To explore patients' experience of care coordination in order to inform current debates on how best to coordinate care and deliver services in end-of-life patients with lung cancer and those with chronic obstructive pulmonary disease (COPD).
Population	Patients with advanced progressive conditions assumed to be in the last year of life. N=18 patients; 6 carers participated in some or all of the serial interviews. Age range: 46-90; males: 12; females: 6. Patients with lung cancer: 11; COPD: 7; Service usage: number of consultations between October 2011 and September 2012: GP at practice: 102; GP at home: 19; GP on phone: 103; district nurse: 3; palliative care nurse: 39; lung nurse: 6.
Setting	Three hospital outpatient clinics of the Respiratory Department at a London teaching hospital between October 2011 and September 2012.
Study design	Qualitative longitudinal study.
Methods and analysis	Patients were interviewed by a psychologist with extensive experience and training in conducting and analysing qualitative interviews. Interviews were audio-recorded and completed at home at three different time points using a semi-structured interview schedule. The topic guide for the first and subsequent interviews focused on 1) the condition (diagnosis, prognosis, current problems, support, and support needs); 2) experiences when interacting with the NHS (professionals' coordination, experiences when visiting the clinics, being discharged from the clinics, experiences following the visit and referrals if they were well coordinated); 3) perceptions of future care (i.e. the plans for the future); and 4) perceptions of current and future care (what coordination meant for them, how it can improve, perception on whether they felt their care was coordinated, care expectations). Interviews were transcribed verbatim and imported into NVIVO 9, where thematic analysis procedures were implemented. The psychologist read and re-read the transcripts and searched for meanings and patterns with regard to patients' experiences in care coordination. Notes and ideas which would be used in subsequent stages were coded. Initial codes from the data, with interview extracts as examples, were then recorded to be used later on. Codes were then organised and annotated into themes which at the end would adequately capture the contours of the coded data. As a final stage, the psychologist re-read the entire dataset and also

Study	**Epiphaniou 2014** [233]
	discussed the themes to reach a consensus with two researchers and following final agreement, the coding frame was applied to the entire dataset.
Findings	**Timeline:** was the main theme emerging from the analysis indicating participants' experiences across their illness trajectory, i.e. from diagnosis to the time of the interview. Across their illness trajectory, patients discussed their experiences with regard to the role of a key worker, a specialist nurse or a community palliative care nurse. The specialist nurse coordinated their care between and within hospitals and community services while the CPCN coordinated care in the community. Along with the role, monitoring and follow-up was a second emerging sub-theme. In order to aid transparency, the results are reported separately for lung cancer and COPD patients.
	Experiences of lung cancer patients: **- Role of key worker: coordination between and within hospital settings:** for some the key worker shared the diagnosis and referred them to hospital clinicians. The key worker was also the main point of contact and also liaised with other professionals to hasten treatment procedures for prompt treatment services. **- Role of key worker:** coordination with the services outside the hospitals: furthermore the key worker coordinated care with community services such as social services, the GP, or referred patients to community palliative care services. For some patients and carers the key worker requested financial support on their behalf. They also contacted the GP for emergencies. Seven patients who required palliative care were referred by the key worker to community palliative care services. **- Role of key worker: to provide support:** the majority of patients with lung cancer and their carers appreciated the key worker being caring and supportive. However, one carer commented on the key worker not responding to calls and thus not being supportive. **- Role of CPCN: coordination of care in the community:** when referred to community palliative care services, CPCNs acted as the patients' main coordinator within the community. The CPCN also prepared for the future and provided support. Consequently the involvement of a coordinator across their illness trajectory enabled access to hospital, community and social services. Patients and carers felt supported and appreciated the professional's role. **- Monitoring and follow-up:** patients with lung cancer reported regular follow-ups.
	Experiences of patients diagnosed with COPD: unlike lung cancer patients, COPD patients did not usually have access to a dedicated key worker for their illness. Patients reported access to services during acute exacerbations, which were followed by a discharge back to the community. Lengthy periods between these meant scarce monitoring and follow-up after discharge. However, a small number of patients (n=4) reported consistent check-ups from their GP or hospital every 6,9,12 months. Acute exacerbations: after an acute exacerbation some COPD patients are admitted as inpatients. Monitoring and follow up: contrary to their expectations, some patients reported vague follow-up from professionals in the community or from the hospital. However, some reported check-ups at the hospital or GP. Only one patient with COPD reported follow-up from community services following discharge from hospital. Most patients persevered to manage their illness on their own. Patients with COPD who had lung cancer (n=3) reported access to different services following the involvement of the key worker: access to financial services; psychological support and support form community palliative care.

Study	**Epiphaniou 2014** [233]
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable.

Study	**Epstein 2015** [234]
Aim	To aid in better understanding of, and provide potential solutions to, barriers to communication about end-of-life care.
Population	Patients with advanced liver, biliary or pancreas cancers and no prior advance directives. The majority was receiving chemotherapy and all were being followed at least monthly by their outpatient medical oncologist. N=26 (12 participants from the video arm and 14 participants from the video arm) who articulated questions, comments, or both. The total number in the RCT N=54. Approximately half of all 54 participants outlived the 6-moth pre-planned follow-up duration of the study period.
Setting	Memorial Sloan Kettering Cancer Centre, USA.
Study design	Qualitative interview study.
Methods and analysis	Qualitative thematic content analysis of participants' responses to a RCT of an educational video or narrative about CPR in patients with advanced gastrointestinal cancers. Articulated questions and/or comments were analysed by two reviewers into themes from each participant. After jointly reviewing individual thematic coding results the reviewers' reached consensus on seven distinct themes.
Findings	**Advance care planning should be started early:** comments included 'we have to discuss it', 'we have not discussed it' and 'it's better to deal with these things when you're reasonably healthy.'
	Information about the process of cardiopulmonary resuscitation (CPR) affirmed existing personal beliefs/knowledge/values
	Participants were apprehensive about ACP but wanted to discuss it: they were often apprehensive to discuss inherently difficult topics, but expressed the concomitant desire, nonetheless, to plan for the future through such discussions. This 'paradox' of ACP illustrated itself in different ways. Sometimes it arose within the family unit itself, or a patient expressed both components of the paradox (e.g that ACP is difficult yet important), it came through in analysis either directly or more subtly.
	Gaps in medical knowledge emerged: critical to education and ultimate decisions about medical treatment, gaps in knowledge emerged.
	CPR information was helpful or acceptable: while less common than the 'paradox'' theme, impressions also arose regarding the palatability of the educational material on CPR, including the notion that such information was helpful.
	Physicians should be involved in ACP: some responses spoke directly to this theme. Other responses more indirectly referenced the role of the physician, or at least the healthcare team. This theme relates to a slightly different paradox that others described: a minority of admitted cancer patients have discussed advance directives with their oncologist (or want to with their oncologist) although half would want their oncologist to be the doctor (as opposed to a previously unknown, admitting physician) with whom they discuss

Study	Epstein 2015 [234]
	such issues should these conversations be deemed as ‘necessary’ to have. Therefore, despite an understandable degree of apprehension to discuss topics as difficult as death and dying, if presented as imperative, advance care planning is generally recognised by the patient, and sometimes the family caregiver, as important to discuss with the oncologist in order to best plan practically, realise life goals, and fulfil relationship duties.
	Medical questions arose: not only did gaps in knowledge emerge, but so did medical questions about CPR and other treatments illustrating the utility of these educational media to act as a vehicle through which modifications can be made to medical treatment decisions, and shed light on common and often complex aspects about end-of-life care.
Limitations and applicability of evidence	Little information on potential bias of researcher. Applicable

Study	Gerlich 2012[273]
Aim	To explore the needs of older patients with advanced heart failure, and their experiences with health care delivery in Germany.
Population	The main inclusion criteria were participants of age 70 and above and with heart failure in an advance stage according to the New York Heart Association Functional Classification. Furthermore, to identify patients with poor prognosis, the recruiting senior physicians in the geriatric hospitals used the ‘surprise question’ (‘Would I be surprised if my patient were to die in the next 12 months?’). In the present study, patients were included if the physicians’ answer to the ‘surprise question’ was ‘No’.
Setting	Germany; two geriatric hospitals in Hannover and Heidelberg.
Study design	Qualitative interview study.
Methods and analysis	All interviews were carried out at the place of recruitment by the same interviewer (KK) who was externally supervised. The patient interviews were digitally recorded and verbally transcribed. All 25 transcripts of the baseline interviews were scrutinised for the initial incorporation into the data material. The transcripts were analysed by a qualitative descriptive approach. All meaningful text units were identified and open-coded separately by two researchers. The codes were then grouped into several relevant subcategories which were subsequently summarized into three main categories. No new categories emerged after the analysis of the 12th interview and consequently at this point we stopped the baseline analysis. The analytic process and the emerging categories were continuously discussed in the study group until a consensus was reached. The analysis was supported by the software program MAXQDA® for the analysis and organization of the material.
Findings	**Information needs:** Patients reported that they had been informed about their illness, but the patients’ understanding of their heart disease seemed rather unspecific. One patient explained only that ‘something was wrong with his heart’
	Prognosis: It seemed that the prognosis of heart failure was rarely discussed between patients and carers. Heart failure was not recognized as a potentially life-limiting disease, and issues of death and dying were not directly mentioned by any of the patients interviewed.

Study	**Gerlich 2012**[273]
Limitations and applicability of evidence	Small sample size. Unclear if themes reached saturation. Applicable

Study	**Hanratty 2012** [306]
Aim	To explore older adults' experiences as they move between places of care at the end of life
Population	People older than 75 years who had moved between at least two care settings in the previous three months who were aware that they had been diagnosed with heart failure, lung cancer, or stroke and were thought to be in their last year of life. N=30; age range 69-93 years; more than half were living in disadvantaged areas of northwest England. The interviewees had collectively moved 67 times between care settings in the three months before being interviewed.
Setting	Northern England in 2009-2010.
Study design	Qualitative study with semi-structured face-to-face interviews
Methods and analysis	Part of a larger project on transitions in health care settings at the end of life for people with stroke, heart failure and lung cancer. All interviews were conducted by one researcher. They were recorded and transcribed verbatim. The interview topic guide covered the participants' social context and relevant life history, their understanding of their illness, the nature of any transitions they had experienced, and how they understood and interpreted their experiences of transitions. There was a comprehensive list of prompts under each topic to ensure consistency. The participants were asked to talk about their experiences, good and bad, of health and social care as they moved between care settings in the last six months. They sought perceptions of the quality of care in each setting in addition to the experience of moving between places and the care received immediately after a transfer. Data analysis used the principles of Framework, a modified form of thematic analysis. The transcripts were read and reread by two researchers, then line-by-lie coding for initial categories which were then grouped into themes.
Findings	**Prioritisation of institutional processes:** many of the interviews conveyed a sense that the care system was imposing processes on patients with limited recognition of or flexibility to the individuals' needs or wishes. The problems ranged from administrative procedures, such as outpatient appointments, to the provision of aids and appliances. In some situations, the imposition of rules intruded directly into life at home. One interviewee descried how they had to ask for fewer social service carers to visit, as they, too, intruded on her day-to-day routine. The authors state that adherence to procedure is important for patient safety and the efficient running of a large organisation, but it also may leave staff unable to respond flexibly to an individual's needs or wishes. These issues emerged in discussion of the organisation of visits to the hospital after hospital discharge. Reliance on working family members for transport was common, and time spent waiting and time taken off work was a source of annoyance and guilt.

Study	Hanratty 2012 [306]
	Support across settings: some of the accounts suggested that the older adults felt that they were sent out of hospital without adequate time to prepare themselves, insufficient community support in place, and little knowledge of how to access the services they required. One account implied a lack of participation in the discharge planning process. 'They kept telling me I was going home and I was alright, I was going home. My legs hadn't been seen to, the infections hadn't gone, the swelling hadn't gone down, but they were quite willing to send me home, and then they decided to keep me in, and that happened to me four times in hospital and in the end, it came that…they sent me home I had no medication ot come home with, just I had just got my old insulin but they gave me no instructions, no knowledge, nothing and the sister was on the phone when I left, and she never bothered she just waved like that when I went out (Female, aged 80 years, lung cancer). Another participant was able to advocate successfully for his own care but noted an apparent failure in communication between hospital and community. Many of the problems appeared to be minor, but the consequences for the elderly and unwell could be considerable.
	Being heard: a good understanding of the purpose of any move into or out of an institution, and the associated practical arrangements, may help to minimise any distress associated with the transition. There were many examples of communication between health professionals and patients that was effective and well received by patients. The feeling that, at times, no one was listening to patients or families emerged as a theme from patients with all three conditions. This was particularly apparent when they had just moved into or out of hospital.
	Dignity: clear examples of mistakes associated with transitions were rare in the study. Possible errors with medications were described by only two of the participants when they were leaving the hospital. A third interviewee was concerned that medication dispensed from a hospital pharmacy may not have been for her, as they were dissimilar to medications that she had at home. But as older adults were placed into new and unfamiliar situations, they described care that may have lacked dignity. Loss of false
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable

Study	Horne 2012 [348]
Aim	To explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment.
Population	People with lung cancer and their family members who spoke English and had completed 'active' treatment were invited by their lung cancer nurse specialist to take part in the study. Together with an invitation letter, an information sheet outlined the topic and the types of questions they would be asked. Forty-two patients and twenty-seven family members were invited. A purposive sample of 25 patients of white British origin

Study	Horne 2012[348]
	(18 men and 7 women) aged between 47 and 85, and 19 family members were recruited. Fourteen family members were related to patient participants and five family members were related to two patients who declined to take part. Twenty-one patient participants had died within 30 months of the study starting.
Setting	UK. Participants were recruited via a specialist cancer centre in a city and a local cancer centre in a town in the north of England, UK. The settings were chosen because it was thought they would allow sufficient recruitment within the identified data collection period. Both settings employed lung cancer nurse specialists.
Study design	Qualitative interview study with semi-structured face-to-face interviews
Methods and analysis	After participants gave consent to participate they were invited by the principal researcher to be interviewed. Most chose to be interviewed in their home either alone or jointly with a family member. Family members of invited patient participants were invited to attend one of two group interviews. A semi-structured interview guide was developed with the support of the research advisory group which included doctors, nurses and a bereaved carer. Questions within the interview guide were developed to explore participants' views about discussing and planning for their future. Process consent was used periodically to check peoples' willingness to continue the interview. Data were collected between December 2006 and May 2008 and interviews lasted an average of 31 min. Interviews continued until no new categories emerged. All interviews were audio-taped with the patient and family members' consent and transcribed verbatim. Each transcript was given a unique code and pseudonyms were used to preserve anonymity. Field notes were written immediately following each interview and focus group. Transcripts were manually coded by the principal researcher and checked by the co-authors for consistency. The analysis was conducted using a constructivist grounded theory approach which meant that analysis began following the first interview using a constant comparative method, a continuous and iterative process throughout data collection. Conceptual categories were developed by taking data apart line by line into small units of meaning and then building it back together to develop the theoretical interpretation. Later interviews were used to theoretically sample emerging categories by refining the interview questions used to test out the emerging categories. Emerging categories were shared with the advisory group to check for 'fit' and further refine the interview guide to test emerging categories. Data were compared and contrasted across interviews looking for similarities and differences to draw out meanings and relationships. Negative examples and silences were considered in the process of analysis. Theoretical memos and conceptual diagrams were used to aid construction of the theoretical interpretation by considering relationships between categories. Data from family members and joint interview data were analysed separately. Following the development of substantive categories these findings were used to triangulate the emerging theoretical interpretation. Credibility and rigour were enhanced by checking with the research advisory group if the theoretical interpretation of the findings 'fitted' with their clinical practice and were understandable to them. A framework for evaluating qualitative research provided quality indicators to help the researchers establish the veracity of the study, its conduct and findings.
Findings	**Facing death when it comes:** Planning for one's own dying and death was not something that people with lung cancer reported having discussed, except in relation to the practical arrangements that would be necessary following their death. People instead preferred to focus on living in the present by 'carrying on as normal' whilst they still felt reasonably well, and seeking to postpone facing

Study	**Horne 2012**[348]
	death until the time came. They also sought to delay awareness of their forthcoming death for as long as possible, preferring not to know when they would die. ‘‘And I just think if I get to be poorly, I know myself if I’m poorly and I’m going to think to myself yeah things need to be, I’ll do it then. But at the present time I feel okay and I’m not going to be discussing what’s going to happen if I die or God knows I don’t want to go down that road, not yet anyway’’. Eighteen of the 25 patients talked about not feeling ill; they therefore took a stance of disbelief towards their diagnosis or death being imminent. They did not see the need to discuss the future. Some participants reported that whilst they felt well, they would continue to let their families think they were still well. Likewise family members reported that when patients appeared well, this impeded any discussion of preferences for the future.
	Clinical discussions about the future: Eight people talked about the doctor knowing what was best for them, trusting in the doctors’ knowledge of cancer with implicit acceptance of treatment or advice. Others reported that they did not trust their doctor or had no ‘faith in’ them, which they related to wrong predictions about the time left to live, lack of explanations about what treatments were available and wrong information or advice about treatments. Explanations when given were offered in steps and focussed on medical issues. Eleven people reported that their doctors had not presented different options for future treatment or care. Thirteen patients reported that health professionals did not have ‘deep discussions’ or initiate discussions about the future which they related to lack of clinic time, a focus on their condition or their own desire not to discuss the future.
	Previous experience: Seventeen people with lung cancer reported experiences of other peoples’ cancer or deaths. Fourteen talked about their experience of others dying and seven of these 14 related this to cancer. One person spoke about their experiences of someone with cancer who had not died. For some these experiences influenced them to make a will or make decisions. Some people talked about not wanting to be a burden on their family having witnessed the effect on family of someone’s death. Still others talked about foregoing treatment and linked this to the unfortunate experiences of others.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. Applicable.

Study	**Jack 2016**[371]
Aim	To explore patients' and family caregivers' experiences and perceptions of Hospice at Home care.
Population	Participants were in receipt of Hospice at Home service on at least three occasions and were deemed to have a life expectancy measured in weeks rather than days. Sixteen patients and 25 caregivers were interviewed (n = 41). The majority of patients had a cancer diagnosis and were, in the main, older people with 88% (14) aged over 71 years; additionally, 37% (6) lived alone (factors recognized as challenges in providing a home death).
Setting	UK. Service located in North West England covering two counties. The Hospice at Home service was developed to support people to remain at home and to die at home.
Study design	Qualitative interview study

Study	**Jack 2016**[371]
Methods and analysis	Face-to-face semi-structured interviews. A topic guide was developed from the previous elements of the evaluation of the service. A conversational style was adopted with semi-structured digitally recorded interviews to enable relevant issues to be covered, but which provided flexibility for pursuing appropriate elements of inquiry raised by the participants. Interviews mostly took place in the participant's home (one was undertaken at the hospice when the patient was attending day therapy and one family caregiver requested a telephone interview). Individual or joint interviews were offered to patients and family caregivers and only two had individual interviews. Some patients had more than one family caregiver participate, for example, where several family members shared the care. Data were collected from October 2014 - July 2015.
Findings	**Communication:** There was a clear consensus among participants that the Nurses were skilled communicators able to engage patients and caregivers in often difficult discussions about death and dying. “They [Nurses] approach you and talk about cancer… a lot of people hide their emotions, they can't cope with it. All of the staff have approached it … in the manner that I would have liked to have been approached … Because of the nature of their work, you have the confidence in speaking to them, speaking about what's going to happen to you, where you're going and what's the by-product, the future, without any of the silliness”
	Caring for caregivers: Caregivers find it difficult to hand over the patient's care to others, putting the needs of the patient above their own. Additionally, knowing that someone had their best interests in mind was reassuring to caregivers who felt that their needs and their health were clearly regarded as important.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. No examples of interview guide. Applicable.

Study	**Johnston 2016**[397]
Aim	To explore patients, and their partners, views and experiences of the EOLC-LTC service.
Population	Patient and family member/carer and key health professionals involved in their care included. Patients were: considered to be in the last year of their life due to chronic respiratory disease or heart failure; having the mental capacity to give informed consent; physically able to complete a 30 minute interview; established on the services caseload for at least 3 months; having palliative care needs (past/present and on-going). The second group consisted of approximately six key stakeholders. N=6 patients; age range 59-83; males: 4, females: 2.
Setting	End-of-life care Long term conditions service (EOLC-LTC), East Midlands from February 2014-February 2016.
Study design	Qualitative study.

Study	Johnston 2016[397]
Methods and analysis	Interview data from both groups of participants were combined and analysed thematically. All interviews were conducted, transcribed verbatim and checked by the interviewer. Data were entered onto NVivo and coded by the researcher, who revised initial coding following constant comparison of the scripts. Initial themes and subthemes were identified then reviewed, revised and agreed.
Findings	**Accessing routine care:** patients and carers reported being unable to make timely GP appointments (particularly their 'own' GP), and experiencing delays in obtaining prescriptions. Attending hospital or practice appointments could be a struggle, and unnecessary hospital admissions, particularly at weekends, were seen as distressing for, and by , patients. Patients and carers were reluctant to ask for help. Community services did not necessarily visit at a convenient time.
	Knowledge and understanding of the EOLC-TC service: knowledge and understanding of the service was variable. Although patients and their carers gave very positive feedback about their care, few reported knowing about the service in any depth, and generally referred to the name of their own nurse, or to the service, by the short four-letter acronym of the organisation funded to the service.
	Qualities of the Service: Particular elements of the manner in which the service was delivered, were highly valued by patients and clinicians alike. Patients expressed their confidence in the service and liked having the same individual nurse allocated to them, who they could get to know well. Although occasionally the nurses had to cover for each other, for example: annual leave, patients were accepting of this as the team were seen to work closely together and share the same approach to treatment. With other services several different individuals might visit the patient, and treatment approaches and management might be contradictory, which was a concern of carers as well as patients. Patients valued the reliability and dependability of the EOLC nurses, were confident that they would visit as requested/arranged and do what they had promised. The EOLC-LTC nurses were perceived as able to expedite prescriptions, facilitate more flexible hospital appointments and liaise with GPs and consultants on the patients' behalf. Having a regular pre-booked visit from the nurse, often on a weekly basis, meant that the onus was not always on the patient to ask for the nurse to call, and encouraged patients to feel empowered to request more contact if they feel it necessary. Patients and carers also appreciated having some control over when the nurse visited compared with other community nurse services. Patients described how they saw the EOLC-LTC nurses as delivering a comprehensive service that could and would help with anything and everything.
	Building a close/therapeutic relationship: Spending time with the patient: the frequency and consistency of the EOLC-LTC nurse visits helped a close relationship to develop between the nurse, the patient, their family and other support networks. The ability of clinicians to 'have time' and to share this with their patients was valued. It was common for patients and carers to describe how they felt able to talk about anything with their EOLC-LTC nurse. This communication was facilitated by the closeness of the relationship and knowledge of the individual and their family. This included discussions about advance care planning, which could be revisited, as appropriate to the individual. Some patients needed several opportunities to talk about their wishes and make plans.

Study	**Johnston 2016[397]**
	The process of decision-making in condition management was referred to by patients as being one made together with the EOLC-LTC nurse and their family; plans were perceived as being made jointly, rather than being imposed.
Limitations and applicability of evidence	Little information on potential bias of researcher. No examples of interview guide. Very small sample size. No details of strengths and limitations of study. Applicable.

Study	**Klindtworth 2015[430]**
Aim	To understand how old and very old patients with advanced HF perceive their disease and to identify their medical, psychosocial and information needs, focusing on the last phase of life.
Population	Old and very old patients (70 years or over) with severe HF (NYHA III-IV). N=25; males: 11; females: 14; age (mean): 85 years; living situation: home: 18 (72%), assisted living/nursing care home: 7 (28%).
Setting	3-monthly intervals over a period of up to 18 months.
Study design	Qualitative longitudinal interview study.
Methods and analysis	In-depth interviews. Interviews were all conducted with the first author and comprehensive field notes were taken during the interview to gather data on non-verbal reactions and the course of the interview in order to facilitate contextualisation of the data. An interview postscript was written shortly after the interviews to record the context, atmosphere and the interviewer's subjective impressions for each interview. The interview guide covered the patients' experiences with heart failure, their main concerns at present (physical, psychological, social or spiritual), views on their care and treatment, and information about their condition and treatment. The interview guide used for the sequential interviews included the same key topics as the one employed in the first interview, whilst focusing predominantly on perceived changes in the patient's illness trajectory and life, and deepening individual issues identified in previous interviews. Interviews were audio-recorded and transcribed verbatim. All transcripts were checked with the audio file and thoroughly anonymised. The iterative analysis started after the first interviews. Researchers' field notes and interview postscripts were sued to enhance the interpretation. The qualitative analysis was performed using an inductive approach according to the principles of Grounded Theory. Starting with a careful look at the transcripts they openly coded relevant passages in the interviews with respect to the research questions using the qualitative data analysis software MAXQDA 10. First coding steps were conducted by two researchers and subsequently synthesised. The field notes, interview postscripts and interview memos were used to enhance the joint interpretation. During the process codes were subsumed alongside main categories into sub-categories. Additionally they conducted in-depth analysis of relevant passages to identify latent structures of meanings. -analysed using qualitative methods in relation to Grounded theory. Frequent team meetings (with experts in public health, nursing care, sociology, general medicine and palliative care) intensified reflection on the data.
Findings	**Dealing with the end of life:**

Study	Klindtworth 2015[430]
	Value and worthlessness in old age: Although most patients expressed a strong preference to die at home, specialist palliative care and facilities (for example: hospices) were not discussed as an option to realise dying at home. At the same time, some of the interviewees did not reject hospitalisation if pain became unbearable.
	Preparation for death: given the limited lifetime remaining, the respondents thought it particularly relevant that arrangements be made before they passed away. In all cases, the patients' funeral was already planned and a will in place regarding their personal finances. Many patients said it was important to know that their family was provided for. However, arrangements for the time before death, i.e. the process of dying and concomitant medical concerns were often less definitely defined. While all interviewees did not want life-prolonging treatments, they had a range of strongly divergent ways to express their wishes: from written statements of intent (living wills and enduring powers of attorney) to oral delegation of decision-making power to family members or primary representatives. What is more, some made contradictory statements regarding the intention and implementation of advance directives. Some patients, however, reject the living will completely because they see no need for this document or mistrust possible actions by physicians; thus, they are confident that their family will handle things without any written directions. Renewed inquiry during the sequential interview sessions suggested that this attitude did not change over time.
	Delivery of health care: **Perceptions regarding care:** Appropriateness of (medical) care: the interviewed patients' assessment of the quality of medical and nursing care varied depending on whether they thought the treatment was appropriate, necessary and met their needs. If decisions about medical treatment, prescriptions and home visits made by the professionals do not meet a patients' expectations, they may be perceived as inadequate or 'wrong', particularly with treatment of pain.
	Continuity of care: transition situations, i.e. from hospital to home, often reveal gaps in the provision of care. Although all patients interviewed preferred to be cared for at home, joint discussions between doctor and patient regarding medical and therapeutic treatment options in ambulatory settings did not take place. One patient perceived recurrent visits to a day unit (in addition to visits by nursing and medical assistants) as stressful.
Limitations and applicability of evidence	No details on data saturation. Applicable.

Study	Low 2005 [475]
Aim	To explore the experiences of people involved in UK palliative care day services and identify the important outcomes of this service.
Population	Patients, informal carers and volunteers from four palliative care day units in the UK. All PCDS patients could participate if they were first time users of the service who had been attending for less than four months; needed to speak English and able to give consent.

Study	**Low 2005** [475]
	Carers were those providing the majority of emotional and physical support and not employed by a statutory body. Volunteers were all involved in the provision of PCDS, whether in a supportive role, or delivery of therapies or as volunteer drivers. N=18 patients; N=12 carers; N=22 day unit volunteers; N=11 PCDS managers. Median age: 60 years. Predominantly white British (16/18). Focus groups ranged from three to six participants.
Setting	Four purposively selected (to reflect the wide range of PCDS service delivery in the UK) palliative day units in the UK (Solihull, North Glasgow, East Surrey and Bradford).
Study design	Qualitative study with focus groups.
Methods and analysis	Focus group was conducted with each of these groups and a separate focus group with the 11 PCDS managers. Each focus group was facilitated by the research nurse and the Senior Research Fellow. The focus groups aimed to cover the following: perceptions of the benefits of PCDS and challenges facing PCDS; perceptions of the impact of PCDS on their quality of life; perceptions of the challenges in delivering PCDS. The focus groups were audiotaped and transcribed verbatim for thematic analysis. Themes were generated individual and the discussed by both reviewers.
Findings	Benefits of PCDS on service users: - Access to palliative care health professionals: patients indicated that the ease of accessing all the relevant palliative care professionals in one place through PCDS was invaluable. In particular, most patients highlighted that they felt more comfortable in discussing certain issues with these staff rather than their GP who they perceived as being too busy and not specialists in cancer care. Patients trusted these palliative care professionals and had confidence that they would manage any problems that arose quickly and effectively. They also highlighted that the PCDS staff were monitoring them regularly and would pre-empt any problems that might arise. In turn, the ability to access these professionals provided patients with the security and peace of mind that any health problems that arose could be dealt with. Input from other health professionals such as physiotherapists and occupational therapists were welcome by some patients and often their main reason for coming to PCDS. They saw treatment from these professionals as the opportunity to improve their physical functioning and mobility.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details on data saturation. More details required on development of themes. Applicable.

Study	**MacArtney 2015**[481]
Aim	To explore experiences shaped by resilience and acceptance to show how they both facilitate as well as restrict possibilities for people at the end of life.
Population	Characteristics: n=40; male: 46%, female: 54%; mean age (range): 68 (30 to 91) years; those known to have died post-interview the median days' survival was 23 (range 1 to 112) days.

Study	**MacArtney 2015**[481]
	Purposive sample of inpatients on specialist care unit in a hospital who were in last few weeks (or in some cases months of life); cognitively able to undertake an interview (a score of >23 on the Mini Mental State Examination); not in significant pain and capable of providing consent. Most had high palliative care needs requiring an inpatient stay.
Setting	Specialist palliative care unit, part of a sub-acute care hospital that also had an attached specialist community palliative care unit. Australia.
Study design	Qualitative interview study
Methods and analysis	In-depth semi-structured interviews with thematic qualitative analysis. The interviews south to cover, when appropriate, four key areas of the patient's experiences of inpatient specialist palliative care, including reflections on their illness and time before admission; how they came to be an palliative care inpatient; what location they preferred to be cared for in and where they had considered dying; and their personal and existential reflections on illness and dying. A dialogical interviewing approach was used to probe for detail and ask questions as the interview progressed. Interview techniques appropriate to the palliative care setting were used. Thematic qualitative analysis was used. Participants were treated as providing 'socially competent' understandings of their experiences. From this the accounts were then explored to draw out the underlying structures, practices and discourses that shaped participant's understandings. After each interview was completed and transcribed each interview was read systematically to identify themes, patterns and issues. These would then be developed or challenged through reading of other interviews and in discussion with colleagues. As the analysis developed, the authors would go back over transcripts and notes to compile similar, atypical, conflicting and contrasting examples.
Findings	'Palliative care equals dying': expectations of palliative care. There were a number of overlapping and competing expectations with the movement from life-prolonging to life-enhancing care. Palliative care held negative connotations for many patients in the study, one patient expressing that they were scared of palliative care as to them it equalled dying. As well as the negative connotations and expectations of what palliative care might mean, the impact of palliative care on carers was talked about as leading to resistance and pressure to not engage palliative care. With carers perhaps not understanding the meaning of palliative care. As well as questions about what palliative care is, approaching palliative care can involve relational dynamics including managing the emotional expectations of others, such as carers, family and healthcare professionals. Several participants explained how a 'dysfunctional' relational dynamic with their doctors affected their gradual shift in focus away from curative or life-prolonging options. The expectation that the palliative care of a patient is against the oncologist's 'business' reflects a tension between life-prolongin and life-enhancing strategies of care that was perceived to exist by some participants. It is possible that the resulting confusion and perceived exclusivity of these two pathways mirrors a difficult dynamic in the field whereby palliative care practices have increasingly been mainstreamed, at the same time as efforts have been made to demark a professional specialisation of palliative care. The resulting 'crisis of definitions' means that what is meant by palliative care and how it is delivered is therefore relationally dependent. One patient found palliative care became more associated with finding easier ways to die and less about quality of life issues. Another 'rebelled against this [palliative care], because he couldn't understand its meaning or purpose. For those with no experience of

Study	MacArtney 2015[481]
	palliative care the sudden transition to it tended to invoke fears long associated with palliative care, such as ideas of 'giving-up' and discursive framing of palliative care as a way for clinicians to (quasi-legally) help their dying patient have a quicker death. As a consequence, many described how the complexity they faced allowed them to re-engage their treatment under a discourse of resilience, while also being resistant to any move towards palliative care as an end of life strategy. This resulted in many participants initially perceiving palliative care to be sitting outside of the curative-hope framework, and, to a certain extent, found it to also be a challenge to that framework. Nonetheless, as we explore in the following section, for a number of participants, experiencing palliative care raised questions about their life-prolonging treatment pathway.
	'Being around a little longer': extending resilience with palliative care. The majority of participants were unfamiliar with palliative care when it was first topicalised by their doctor and thus their introduction to it was talked about as producing feelings of anxiety and fear about what it meant for their life expectancy. Other studies found that in part to help mitigate such reactions the preferred clinical strategy is to 'phase in' the patient's introduction to palliative care while continuing to receive technically life-prolonging treatment (Gardiner 2011; Meyers 2004; O'Leary 2009). For several participants in this study this phasing in of palliative care often helped to problematize experiences of the care and treatment the participant was receiving. The use of palliative care is experienced here as making life more comfortable, as the participant seeks to prolong life for as long as possible. Yet the relational dynamic of 'wanting to be around for a bit longer' is qualitatively focused on being around for family. The phasing in of palliative care not only brought into questions participants' expectations of the future, but it also helped to question the fears and anxieties of SPC. Some participants made the distinction that the aim of their current admission to specialist palliative care was to find a better form of pain management, rather than as part of an end of life process. The transition to palliative care was initially understood as finding ways to remain resilient within a life-prolonging framework, with palliative care providing the necessary pain and symptom relief to continue with life-prolonging options.
	'After a while you just can't keep going': toxic resilience: The move to palliative care can disrupt previous notions, expectations and experiences of care and treatment. What was of particular interest was how resilience within a potentially curative or life-prolonging focus became viewed as a problematic, even toxic, dynamic and counter-productive to maintaining or enhancing the participant's quality of life as they approached the end of life.
	'I just accepted it': knowing and feeling the right time to stop: faced with the implications of remaining resilient (or at times toxic resilience), several (but not all) participants engaged another (potentially) normative ethic in negotiating the transition to palliative care – that of acceptance.
Limitations and applicability of evidence	Little information on potential bias of researcher. Small sample size. No details of data saturation. Not a lot of details of transferability to other settings and limitations not discussed. Applicable

Study	MacPherson 2013[484]
Aim	To explore the views of people with severe COPD about advance care planning.
Population	Patients with severe COPD as defined by the Gold Standards Framework - have a diagnosis of COPD and one or more of: Disease assessed to be severe for example: (FEV1 <30% predicted – with caveats about quality of testing); recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations); fulfils long-term oxygen therapy criteria; MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house through breathlessness; signs and symptoms of right heart failure, combination of other factors, for example: anorexia, previous ITU/NIV/resistant organism, depression; >6 weeks of systemic steroids for COPD in the preceding 12 months. N=10
Setting	UK. The participants were interviewed in their own homes.
Study design	Qualitative interview study
Methods and analysis	A Breathe-Easy group (support group of patients with lung conditions, supported by the British Lung Foundation) was consulted before the study to inform the initial topic guide. The participants were interviewed in their own homes, with a relative present if they preferred, using a semi-structured approach with a broad topic guide that evolved during the study. Each interview was digitally audio recorded, with field notes added immediately afterwards. All interviews were completed on one visit between September 2010 and February 2011. The digital recordings of each interview were transcribed verbatim with the field notes added alongside. Each transcript was read and sections representing opinions, experiences or emotions were coded, and a rough coding tree formed. These codes were then examined and the coding framework adjusted. Two transcripts were also coded by another author (CW) to minimise bias and ensure all themes were identified and explored. The coding framework was iteratively developed from the data with both descriptive codes and analytical codes used. The software package Transana17 was used to assist with transcription and data management. A grounded theory approach was used to generate theories from the data collected, based entirely on the themes and subthemes identified.
Findings	Information provision: Most participants reported having had little discussion with healthcare professionals about COPD itself, causing anger in some participants, particularly about a perceived lack of communication around the time of diagnosis. “Nobody’s ever talked to me about anything really, seriously. I did...I said to you I didn’t even know I had COPD. That’s how much the doctors have talked to me.” Some had a fatalistic attitude to life in many participants, describing feeling that they would die whatever happened and there was little that they or anyone could do to affect what happened up to that point.
	Discussions about the future: Two participants reported having had some discussion about the future with healthcare professionals. The first had consisted of a district nurse mentioning that he [the participant] was very unwell, and had he thought about the future, which he took to mean had he planned his funeral. He had become very upset by this, and had complained about that nurse. All other participants described consultations with health professionals being very focused on the present, usually on their current problem. Their future or preferences for treatments were never discussed, and some participants were unable to imagine discussing these issues within the consultations they had. Most participants wanted more information about how their disease would progress, and more discussion about the future. They found it difficult to raise these discussions themselves, despite wanting to.

Study	MacPherson 2013[484]
	Decision making: Participants were keen to be involved in decisions about their treatment and to discuss treatment options. When treatments were decided without any discussion with the patient, this damaged their relationship and trust with their healthcare provider. A few patients preferred their doctors to generally make decisions, and they would be happy to go along with their advice, believing it to be the patient's responsibility to raise any concerns they had about the proposed treatment.
	Planning for the future: Despite being keen for more involvement in current decisions about their care, participants were wary about making advance decisions about future treatment. Similar to the concerns of the participant due to complete an advanced care planning document, participants had concerns about knowing their future treatment preferences and did not see why making decisions in advance would be helpful. Participants recognised that their symptoms varied significantly, and all had adapted to this by making routine decisions on a day-to-day basis. They generally had a reasonable idea of their preferences, but not enough to make a binding decision that would then be applicable in the future.
Limitations and applicability of evidence	Small sample size. More detail required about coding and theme development. Applicable.

Study	McVeigh 2018,[511]
Aim	To explore the specialist and generalist palliative care provision for people with non-malignant respiratory disease.
Population	Bereaved carers
Setting	Rural and urban Northern and Republic of Ireland between 2012 and 2013.
Study design	Qualitative interview study
Methods and analysis	Convenience sample of 17 bereaved carers Face-to-face or telephone semi-structured interviews. Interviews ranged from 22-8 minutes with an average of 50 minutes. All interviews were digitally-recorded, transferred verbatim. Data were analysed adopting a thematic analysis framework. NVivo was used to manage the data and support the categorisation and of the data. Stage 1: assignment of descriptive themes to sections of the data to describe their meaning. Stage 2:descriptive themes were used to generate interpretative themes and highlight emerging patterns. Stage 3. Identification of overarching themes. .
Findings	**Lack of preparedness for death.** Barriers identified included the unpredictable nature of non-malignant respiratory disease and lack of knowledge about prognosis.

Study	McVeigh 2018,[511]
	Availability of services. Barriers identified included lack of availability to services (Republic of Ireland not Northern Ireland) and late introduction of the services.
	Role Ambiguity:lack of clarity around the role of the caregiver and the input into conversations and decision making about care.
Limitations and applicability of evidence	Small sample size. Little information on potential bias of researcher. Applicable.

Study	Mason 2013[502]
Aim	To report the experiences and perceptions of people with advanced multi-morbidity to inform improvements in palliative and end-of-life care.
Population	Patients and their carers using established UK clinical guidelines for the identification of people anticipated to be in their last year of life. 42 interviews with patients alone, two with carers alone and 43 as joint interviews. Participants completed one (8), two (10) or three (19) interviews. Within 9 months 11 (30%) had died. N=37 patient and N=17 carers. Age (range): 76 (55-92); males: 23, females: 14; multiple conditions: heart, respiratory, liver and renal failure, lung cancer, neurological conditions and mild dementia.
Setting	An acute admissions unit in a Scottish regional hospital; a large English general practice and a London respiratory outpatient clinic.
Study design	Qualitative study.
Methods and analysis	Semi-structured serial interviews with patients and case-linked family carers at 8-12 weekly intervals, using a multi-perspective approach. Patients were interviewed in their own homes and invited to talk about their understanding of their health conditions and their experiences of receiving care from different care providers and settings. Each patient was followed for 5-9 months. The interviews were audio-recorded, transcribed and imported into NVivo software for analysis. Data from each setting was analysed separately. A constructivist approach was taken and thematic analysis chosen because of its utility in comparing data from divergent sources. Cross-case analysis was then conducted to produce an integrated understanding of themes across settings and in different contexts. Interpretive analysis of the subgroup with multi-morbidity explored themes pertaining to experiences and understanding of living with deteriorating health due to multiple conditions.
Findings	Experiences of care: multiple services: as might be expected, the patient and carer experiences reflected a continuing struggle to cope with multiple care systems, services and staff. At the same time, they tried to maintain a semblance of normality amidst growing feelings of dependency. Participants gave accounts of complicated, confusing and sometimes unresponsive services. Lack of care

Study	Mason 2013[502]
	coordination and continuity among the numerous service providers led to perceptions of inconsistent and impersonal care. No diagnostic label and little explanatory language to describe their health problems made requesting appointments or a GP visit difficult. Attending clinics was physically demanding and these often failed to address complex, on-going problems Many patients took more than 10 different medicines daily. Frequent medication changes, usually associated with hospital admissions, led to doubts about their purpose and efficacy. Carers had to deal with the increasing physical and emotional demands of caring, oversee multiple medications, and do all this with little indication of how long it might last. Patients without a family carer struggled to manage everything by themselves.
	Understanding of deteriorating health due to multiple conditions: patients and carers drew on their experiences of the healthcare system, their beliefs about illness and accounts from friends, family and the media to try to make sense of their health problems and treatments. The most common interpretation was that the various conditions suffered by the patient were inevitable effects of aging. This understanding of deteriorating health as 'old but not ill' was used to rationalise perceived failings of the healthcare system. Some suggested that their care was poorer because they were 'older,' leading to complaints about inequity. Beliefs about just being old meant that these people generally focused on living as well as possible in the present. They avoided planning ahead and only sought help if they were very ill or unable to cope. Not depending on services was seen as a way to preserve autonomy, and being a carer was a responsibility to be accepted and not questioned. There was little evidence of integrated care planning or any open discussions about the future between patients, family carers and health professionals. Talking about planning ahead or deteriorating was viewed negatively by some people who had no experiences of doing so. Patients and carers were often unaware of the patient's risk of dying. When a crisis or death did occur, it often felt unexpected, even if the GP had hinted that it could happen at any time. None of the participants showed any understanding of the potential benefits of planning ahead to optimise quality of life and death. Deteriorating health due to multiple illnesses was interpreted as 'getting old' so palliative care, which was largely associated with managing imminent death, had no role to play.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details about interview guide. No details of data saturation. More details needed on development of themes and opposing viewpoints. Applicable.

Study	Metzger 2013[554]
Aim	To describe patients with HF and their family members' experiences with, and perceptions of, inpatient PC consultations.
Population	Participants were English-speaking adults with a primary diagnosis of HF, who were referred to the inpatient palliative care consultation service for goals of care discussions. Family members were required to be English-speaking adults, and identified by the patient participant as being involved in either the planning or delivery of his/her care. N=40; N=24 patients with late-stage HF and/or N=16 designated family members. Age mean (range): 70 years (26-93 years); male: 62.5%, female: 37.5%); Race: Caucasian: 83%, African American: 17%. PC performance score (scale 0-100): median: 50-60, range

Study	Metzger 2013[554]
	20-70. All of the patient participants fit the criteria for NYHA Stage III or IV HF or ACC/AHA HF Class C or D. Most had multiple comorbidities and had been hospitalised more than once in the previous years.
Setting	Participants over a 9 month period from the inpatient palliative care consultation service of a 750 bed tertiary academic medical centre in upstate New York. The medical centre features inpatient and outpatient HF services, and is a designated hea3rt transplant centre.
Study design	Qualitative descriptive research design.
Methods and analysis	In-depth semi-structured interviews conducted by a single researcher using interview guides. Interviews were digitally recorded, transcribed verbatim by and entered into ATLAS-ti, along with field notes from interviews. Qualitative content analysis used to identify themes and patterns in the data. Interview transcripts were first read to get a sense of the whole, and then coded line-by-line, using a start list of codes inductively developed from the data. As the analysis proceeded patterns and relationships, both within and across cases, were sought. Themes were then derived from this analysis.
Findings	Participants had little previous knowledge of PC and formed impressions based on their interactions with the team: 1a) The surprise consult: the majority of participants were unprepared for the PC consult. They reported having no or little previous understanding of the term palliative care, and being unaware of the existence of the PC consultation service and/or that a referral had been made. Those participants, for whom the PC consult was unanticipated, generally reacted initially with suspicion, caution, and/or scepticism. For example, one participant reported that she initially suspected that her cardiologist had enlisted the PC team to convince her to consent to the placement of an LVAD, an intervention she had previously declined. Those participants, for whom the PC consult was expected, generally welcomed it. 1b) Forming impressions: after meeting with the PC team nearly all of the participants offered definitions of PC, with many, but not all equating PC with hospice or end-of-life care. They reported that their definitions were based on information from the referring team and/or their interactions, over time, with the PC team. 1c) “they come from a different world”: when asked to compare the PC team to other hospital-based teams, participants generally emphasised the differences between them. They attributed these differences primarily to the unique style and focus of the PC team. They described clinicians from the PC services as “listening”, being “more compassionate”, “sending more time”, and having a holistic focus. 1d) Outcomes of PC: “they made it better”. Nearly all reported that working with the PC team had a positive impact on their hospital experience, feeling informed, supported and reassured. Participants’ perceptions of their relationships with the referring team providers influenced whether they viewed the overall outcome of the PC team’s involvement as additive or corrective.
	Participants described the overall role of PC as one of support 2b) working the system: the majority of participants reported that the PC team was involved in activities such as: advocating for them with other agencies or providers, facilitating complicated discharges, coordinating care, arranging and conducting family meetings, and overcoming obstacles in order to assist them in reaching their goals. One family member talks about them navigating them through the available services and getting a plan in place, which is the biggest hurdle, one patient felt they are the people that can get things done for you, with every person being custom.

Study	Metzger 2013[554]
	2c) Providing information: the majority of participants reported that the PC team conveyed information during their hospital stay. Providing information did not make the PC team unique, however, as most clinicians offer information. Rather, differences in the nature and scope of the information distinguished the PC service from other services. PC clinicians took a broader approach, discussing all available options, including the option of PC, and what to expect (prognostic information) with respect to the individual patient's situation. One family member reported during the second interview, that before meeting with the PC team, she and her family felt ill-equipped to make decisions related to her mother's care, as they were unaware of available options. Other participants also commented on the benefits of having options. 2d) Transitioning to comfort care: Several participants reported that the PC team was instrumental in facilitating a "smooth" or "easy" transfer from aggressive, disease treatment-driven care to comfort care.
	Participants had a sense of prognosis which directed treatment goals: all of the participants reported having an understanding of patient prognosis. However, in only half of the cases were the participants' understanding of patient prognosis in agreement with their understanding of the clinician's prognosis. Where there was agreement participants discussed changes over time in their patient care goals based on a shared or agreed understanding of prognosis. With one exception, they all redirected to a comfort care approach. In the discordant cases, none of the participants demonstrated changes in goals over time, and all pursued a plan of care that reflected their own understanding of prognosis, which was always more optimistic than that of the clinicians.
	The conflation of PC and hospice was a barrier to PC in HF care: Although participants were not asked about hospice in HF care many announced that hospice would not work for them. When asked about the reasons that hospice was not an option for them the participants discussed their understanding of the "rules" of hospice. They explained that these rules were "deal-breakers" for HF patients primarily because they hindered aggressive management of their HF symptoms. For example not controlling symptoms the same as before. Many felt PC is synonymous with hospice care. In those cases the majority of participants predicted that PC would have no place in their current plan of care. Several suggested however, that PC might play a role "down the road" if the current treatment plan failed and/or their disease became "really fatal". For those show did not define PC as hospice or strictly end-of-life care, continued PC involvement was welcomed, even if participants predicted hospice would not be an option.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details of transferability to other settings and limitations of the study. Applicable.

Study	Murray 2002[582]
Aim	To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease.
Population	Outpatients with newly diagnosed advanced inoperable lung cancer or with cardiac failure (New York Heart Association grade IV). 59 patients consented in outline to participate. The average age of the 20 patients with lung cancer was 65 years, 15 lived with their spouse, 12 had non-small cell lung cancer, 17 were offered and 16 received chemotherapy or radiotherapy, and five were alive at the

Study	Murray 2002[582]
	end of the study. The average age of the 20 patients with cardiac failure was 74 years, the commonest cause was ischaemic heart disease, 11 lived with a carer, and seven were alive at the end of the study.
Setting	UK. Interviews conducted in patients' home.
Study design	Qualitative interview study
Methods and analysis	Nominal group technique; face-to-face interviews. In depth interviews at three monthly intervals for up to a year with patients and their main informal carer in the patient's home. Patients were asked to talk about the main issues they were facing and their views about the care and support they were receiving. At 8-12 weeks after any bereavement we interviewed carers, if appropriate, the general practitioner, and other key professionals. A focus group for each diagnostic group allowed key health and social care professionals, a chaplain, patients, informal carers, and voluntary sector representatives to discuss the issues raised by the interviews and consider alternative service options. Interviews and focus groups were tape recorded and transcribed (with field notes). Analysis was ongoing throughout the fieldwork to allow emergent themes to be fed back into the data collection. These themes and the research questions formed the basis of the coding strategy. The qualitative computer package QSR NVivo and the techniques of narrative analysis were used. A second researcher (AW) read all the transcripts and assisted with coding. Regular review and discussion of the evolving themes by the multiprofessional steering group and data from the focus groups contributed to data synthesis and interpretation.
Findings	Information and understanding of illness and prognosis: Many appreciated honesty, although a few patients, carers, and professionals colluded to avoid issues related to dying. Treatment options were discussed but most patients thought they should accept the professionals' recommendations. "As I say, these people are the experts and, you've got to, if you don't abide by what they tell you, its your fault then". Most patients and carers did not feel involved in decision making or empowered to work in partnership with professionals. "I wouldn't say that I take much part in the decision making really. It just happens. They decide and that's that"
	Service provision: There was some misunderstanding among patients, carers, and professionals about the roles of different professionals and agencies, which resulted in failure to access help.
Limitations and applicability of evidence	Little information on population details. Little information on potential bias of researcher. No examples of the interview guide. More details on analysis and how themes developed required. Applicable.

Study	Murray 2016[580]
Aim	To investigate caregiver perspectives on the acceptability and impact of advance care planning, documented in a letter format, for patients with motor neuron disease and their caregivers.

Study	Murray 2016[580]
Population	Former caregivers of deceased patients with motor neuron disease who had been referred to a multiprofessional MND service coordinated by a hospital specialising in palliative care and rehabilitation. 10 patients had created a disease-specific advanced directive, ‘Letter of Future Care’, and 8 had not. Those who had not entered the service just before the LFC was introduced or who for administrative reasons had not been offered the LFC. N=18
Setting	Multidisciplinary MND service
Study design	Qualitative cross-sectional study.
Methods and analysis	Semi-structured individual interviews conducted by a nurse with expertise in qualitative research methods, who was independent of the care team. The interviewer guided discussion concerning the quality of end-of-life decision-making experienced, whether the LFC was or would be helpful, limitations of the letter and how the letter or ACP process could be improved. Sample letters were shown to participants during interviews to facilitate recall of the LFC or enable hypothetical discussions to occur for those not familiar with the LFC. Interviews were audio-taped and transcribed verbatim. A narrative approach was used to synthesise data, capturing the essence of individual and collective ‘stories’. 8 transcripts were read and manually coded by 2 researchers, through a unified coding scheme. Any discrepancies in thematic coding were discussed between researchers, until consensus was reached. A single researcher coded remaining transcripts, in consultation with another researcher.
Findings	Readiness for death: Acceptance: documentation of patients’ wishes (ACP) was easier for patients and caregivers who accepted encroaching death. For example, one patient, who had witnessed her sister die from MND, was eager to make her wishes known. In some cases, acceptance appeared to precede LFC completions. Another participant surmised that it could be difficult for some patients if they are not facing reality that they will die. Some patients wished to maintain hope for as long as possible. Several participants thought that if initiated too soon, completing the LFC might be too confronting, emotional, conflictual and would diminish hope. Facilitating acceptance: some caregivers felt that documenting wishes enabled patients to ‘let go’. Despite several participants’ accounts of the LFC’s facilitative role, opening family communication, allowing patients to ‘let go’, confronting the inevitable and disallowing avoidance, others felt that the letter was unimportant or unnecessary. Some patients had already accepted death and knew their wishes.
	Empowerment: Patient autonomy and security: many caregivers felt that the LFC gave, or would have given, patients’ autonomy, feelings of control and courage to say what they wanted. One patient without a LFC, received a percutaneous endoscopic gastrostomy (PEG) tube although it may have been contrary to her wishes. The patients’ sister described the staff as pursing this option insistently and believed that her sister agreed only to ‘keep the peace’; she though a LFC may have helped her sister refuse the unwanted PEG tube. LFC completion engendered feelings of security in some patients, who were comforted by the knowledge their wishes would be respected. Caregiver preparation, negotiation and diminished regret: some caregivers thought the letter did, or would, help them feel prepared and know what to do.

Study	Murray 2016[580]
	Caregivers also described how the LFC helped them negotiate with the rest of the family. Many participants indicated that documented wishes did, or would, reduce decisional burden and help caregivers avoid regret. Informing staff: the LFC was deemed important for informing staff of patients' wishes. If staff were well informed, better outcomes were anticipated for everyone.
	Connections: Family discussion and agreement: several participants found the LFC assisted by opening family communication. The LFC generated meaningful discussion and facilitated agreement in several families Connection with others: in some cases, the LFC encouraged connections beyond the immediate family. Some caregivers felt strengthened by connections the letters seemed to cultivate.
	Clarifying decisions and choices: QoL and technology: preparing the LFC clarified for some patients and families the importance of weighing up QoL versus length of life. Some caregivers spoke of intrusiveness of medical technology and how it compromised patient comfort.
	Decisional roles: with regard to end-of—life decision-making and the preparation of the LFC, decisional roles were sometimes connected with previous roles assumed by the couple. Some caregivers advised that the LFC facilitated decision-making through input from expert and sensitive staff.
Limitations and applicability of evidence	No examples of interview guide. More details required on development of themes. Applicable.

Study	Phipps 2003[643]
Aim	To investigate differences in attitudes, preference, and behaviours regarding end of life in terminally ill patients and their designated family caregivers.
Population	African-American and white patients with stage III-B or IV colon cancer and their designated family caregivers. N=68
Setting	USA. Patients identified from: the Albert Einstein Cancer Centre office schedule, from the tumour registry, from the Cancer Centre Hospice program, and from Oncologists and other physicians.
Study design	Qualitative interview study
Methods and analysis	Qualitative analysis of responses to open-ended questions was undertaken to elucidate the reasons why people did or did not engage in actions related to advance care planning. As part of the interview, patients were asked whether they had discussed their preferences regarding the use of life-sustaining interventions with others. Open-ended follow up questions were then asked on the basis of their responses.

Study	Phipps 2003[643]
	Transcripts of the audiotaped interviews were processed for coding and analysis using Atlas-ti, a software package for computer-assisted qualitative data analysis. Reliability of codes was established using Kappa to measure inter-rater reliability. Systematic coding of all transcripts enabled the research team to categorise reasons that patients and caregivers cited in response to their answers to discrete questions such as “Do you have a living will?” and “can you tell me why you have one (or why not)?” Reasons cited in this report are the coding categories and are not study participants actual words, except where noted.
Findings	Reasons for living will/proxy directives: To exercise control over the future and to avoid confusion about treatment preferences. Other less commonly cited reasons were past or personal experience (with a terminal illness) and to protect or shield loved ones (from having to make difficult treatment decisions.
	Reasons for not having a living will or proxy directives: “no one has brought it up to me” or “it hasn’t come up”, indicating patients saw the initiative as coming from outside of themselves (external locus of control). Other reasons cited included the belief that formal documentation was not needed until they were near the end, concerns about emotional distress for either patient or family in discussing the topic of the patients illness and treatment preferences; and assumption that the patients family would know his/her treatment preferences without the need for formal documentation.
Limitations and applicability of evidence	Little information on potential bias of researcher. More details required about theme development. Themes not refined. Applicable.

Study	Piamjariyakul 2014[649]
Aim	To explore end-of-life preferences and determine the presence of signed end-of-life advanced directives.
Population	Patients with severe chronic cardiovascular illness (i.e. three-vessel coronary artery disease, end stage HF, malignant hypertension, and repeated bouts of atrial fibrillation); many of who also had renal failure and diabetes mellitus. N=30, mean aged decade=70 years.
Setting	USA. Interviews took place in participants’ homes.
Study design	Qualitative interview study
Methods and analysis	Semi-structured face-to-face interview with thematic qualitative analysis. The study took place in the patients’ home using open-ended questions. Patients were first asked about their decisions to have nursing care for their severe chronic cardiovascular illness at home. At the close of discussion, the interviewer was trained to state: “Now we would like to talk with you about some sensitive issues in a person’s last days”. Patients were then asked a) “Do you have a signed off

Study	Piamjariyakul 2014[649]
	end-of-life advance directive or a living will?"; b) "How did you obtain the end of life advance directive or living will information?" and c) "With whom did you discuss the end-of-life car and the types of care you would like to receive during the last days and minutes of your life?". Each interview lasted 30-45 minutes. Content analysis was used to summarise patients' responses into themes. Interviews were reviewed separately by two experienced nurse researchers (who did not provide clinical care to participants) who identified responses into single content units. These two nurses independently categorised the interview data units by topics according to terms found within the patients words and phrases. Then the two nurses compared their content units and the terms identified across all patients interview data. The nurses' discussion of their coding led to agreement about categorising these responses into five themes.
Findings	Presence of signed off advance directive or a living will: 50% of patients had signed standard advance directives as requested on entry of care home, remaining 50% had no written directive or living will. Patients expressed reasons for not completing an advance directing: "I never thought about this [end of life plan]", "I'm too sick now, I can't think about anything". It was also noted that Hispanic participants feared a risk of deportation if any form were completed or document signed.
Limitations and applicability of evidence	Little information on potential bias of researcher. No details of transcribing. Lack of data to support themes and themes could be more refined. Not a lot of details of transferability to other settings and limitations not discussed Applicable.

Study	Romo 2017[701]
Aim	To explore how older adults in the community with a limited life expectancy make healthcare decisions and the processes used when they are not in an acute crisis.
Population	Community-dwelling adults aged 67 to 98 with a life expectancy of less than 1 year.
Setting	USA: Medical programs and geriatrics clinics at the University of California, San Francisco, and the San Francisco Veterans Affairs Medical Center.
Study design	Qualitative cross-sectional study.
Methods and analysis	Interviews were audio recorded and professionally transcribed verbatim. The interview guide was developed to elicit the participants experience with decision making and explore the underlying process. Analysis was done through the iterative process of constant comparative analysis. Open coding was undertaken to label distinct concepts in the data, and focused and axial coding were used to relate concepts across the data and group them into meaningful categories. To assess the face validity of the emerging themes, interim findings were presented to independent professionals with expertise in aging, medicine, nursing, social work, and sociology. Data analysis continued until the data revealed no new themes or concepts that furthered the analysis or understanding of the phenomenon.

Study	Romo 2017[701]
Findings	Burden of decision making: Participants acknowledged that they were delegating decisions to others while also noting that they did not discuss their preferences with others. Participants relied on family because they believed family would make appropriate choices and alleviate burden of deciding.
	Avoidance: Some participants would actively avoid thoughts of declining health and end-of-life decisions.
	Trust: Lack of trust diminished participant's sense of control and placed social and emotional burdens on participants. In contrast, strong trust provided a sense of control and served as a resource for participants during acute illness.
	Communication: Direct communication involved making clear statements about priorities and goals to guide delegates; allowing participants to maintain a sense of control.
	Demands: Healthcare decisions created ambiguity that needed to be resolved. Health status increased complexity of decisions, particularly during acute episodes when providers were unknown to them.
Limitations and applicability of evidence	Applicable.

Study	Selman 2017[736]
Aim	To explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care.
Population	Older people (aged >65) with an advanced disease receiving specialist palliative care, who had been hospitalised for >24 hours and their carers.
Setting	UK/USA: Six urban hospitals (three in England, two in Ireland, and one in USA)
Study design	Qualitative cross-sectional study.
Methods and analysis	Interviews were face-to-face, audio recorded and professionally transcribed verbatim. Patients and caregivers were interviewed separately. Interview transcripts and field data were imported into NVivo v10.0. Direct thematic analysis was used. Analysis occurred over four stages: (1) analysis by site with line by line coding; (2) narrative summaries were produced for each data set and tabulated alongside themes; (3) integration of site-level findings where country level findings were compared and synthesised; (4) A cross-site narrative summary to draw out main findings.
Findings	Communication/information: Clinicians inadequate communication skills and deprioritisation of relational care hinder patients self-management, At all sites a lack of information from staff and poor communication with staff, particularly regarding end of life issues, prevented patients from taking a more active role in managing their disease and treatment, making decisions and planning for the future.

Study	Selman 2017[736]
	Environment: Busy routinised inpatient care restricted patients' choice and control. Patients and families noted a lack of power and choice at discharge. Continuous, flexible care provided patients with choice and facilitated communication. Strategies such as staff rostering and having a key contact person appeared to reduce fragmentation of care.
	Holistic care: Patient centred, holistic approach empowered patients by putting their perspectives, wishes and needs in relation to decision-making and information provision at the heart of care.
Limitations and applicability of evidence	Unclear if saturation was reached. Applicable.

Study	Simpson 2011[752]
Aim	To observe what is required for meaningful, acceptable ACP in the context of advance care planning.
Population	Eight families (eight patients with a primary diagnosis of COPD in an advanced stage according to CTS severity criteria and seven informal caregivers (person most involved with his/her supportive care)) were recruited by a physician or registered respiratory therapist.
Setting	Canada. Sessions took place in the patients house.
Study design	Qualitative interview study
Methods and analysis	Semi-structured face-to-face interview with thematic qualitative analysis. The study employed interpretive description, a qualitative research methodology developed by nursing professionals seeking the understand gaps in and improve clinical practice. Sessions were loosely structured according to a conversation guide. Each family was provided with a copy of the local health districts brochure entitled 'Patient and Family Education Document, March 2007: Let's Talk About Advance Directives', which also provided an advance directive template. The study included two visits with each family concluding with a request for participant feedback on experience as a way to assess acceptability and meaningfulness of the process for participants. Study sessions were digitally recorded, transcribed verbatim, and resulting data entered into Atlas.ti 5.6, a qualitative software program to aid analysis. While data analysis was not complete, it entails processes of identification and coding of concepts, patterns, and related themes, grouping of themes into thematic networks, interpretation of relationships between and among themes, and consideration of the implications of these findings with respect to the study question as relevant to the particular clinical context of ACP in advanced COPD.

Study	Simpson 2011[752]
Findings	Knowledge: The brochure and advance directive template facilitated family and patient learning more about end-of-life care options. Some families had already thought about end of life care, but were grateful to hear about and clarify the patients' end-of-life care preferences and reasons behind them.
	Countering silence around the subject: Study dialogue enabled increased awareness of patient illness-related social deprivation, fear, and end-of-life care preferences, subjects they had been unable to discuss before. "He doesn't like to talk to me about stuff because he thinks he is stressing me out". Families spoke about a patients' silence, a stance embraced prior to the study sessions. One patients purposefully avoided thinking or talking about death or dying because she was terrified about dying.
	Talking with an interested clinician: Some patients felt isolated by anxiety, and took the opportunity of the study to talk about their concerns, especially loneliness and fear.
Limitations and applicability of evidence	No details of data saturation. Methods for identifying or extrapolating themes required more details. Not a lot of details of transferability to other settings and limitations not discussed. Applicable.

Study	Spruyt 1999[771]
Aim	To describe the palliative care experience of Bangladeshi patients and carers in the Tower Hamlets area in the east of London.
Population	The bereaved carers of Bangladeshi patients under the community team between 1986 and 1993. N=18
Setting	UK. Tower Hamlets.
Study design	Qualitative interview study
Methods and analysis	Face-to-face semi-structured interviews. Patients were identified by review of all admissions to the team between 1986 and 1993. Case notes were reviewed for demographic data, evidence of communication difficulties, intensity of input of care and any special areas of concern. An introductory letter written in Bengali and English was sent to all carers traced. The interviews were conducted in Sylheti, using a semi-structured questionnaire designed for the study. Interviews were manually recorded at the time of the interview. The interviewer met frequently with the researcher for discussion of each interview, at which time additional information was appended.
Findings	Communication/language: Few patients were fluent in spoken English and fewer were literate in English. The one female patient and one female carer who were literate in English were both less than 30 years old. There was reliance on family members, and particularly on children, to interpret for health professionals. Poor communication as a problem in 16 cases. "Although I was the main carer, I was kept in the dark and not involved in any decision-making until my husband died". Two of the three carers who had a professional interpreter felt that it had been helpful.

Study	Spruyt 1999[771]
Limitations and applicability of evidence	Little information on role of researcher, data collection and analysis. Applicable.

Study	Walczak 2013[831]
Aim	To explore patients' perspectives across two cultures (Australia and USA) regarding communication about prognosis and end-of-life care issues and to consider the ways in which these discussions can be optimised.
Population	English-speaking adult patients with advanced, incurable cancer assessed by their oncologist as having life expectancy of less than 12 months. N=15 Australian and N=19 US patients. Australian demographics: age (mean (range)): 67.6 (54-86); male: 12(80%), female: 3 (20%). US demographics: age (mean (range)): 58 (34-75); male: 6 (31.6%), female 13 (68.4%).
Setting	Oncology treatment centres in Australia(2) and USA (1).
Study design	Qualitative study
Methods and analysis	N=15 Australian and N=11 US patients completed individual semi-structured interviews. A further N=8 US patients participated in a focus group. Participants were offered the option of participating in a focus group or completing an individual interview. Research assistants trained in qualitative methods conducted the individual semi-structured interviews and one US focus group. Sampling was discontinued when information redundancy was reached, and no additional information was forthcoming after three consecutive interviews. Interviews and focus groups were recorded and transcribed verbatim, and interpreted using thematic text analysis with an inductive, data-driven approach. Interview and focus group questions were designed by an expert advisory group comprising oncologists, palliative care physicians, psychologists, nurses, and a health services researcher. Participants were asked about their experiences of communicating about prognosis and end-of-life care issues, barriers and facilitators of such discussions and their views about how these discussions could be optimised. The research team reviewed and interpreted the data using NVvivo 7. The researchers read all the transcripts and four researchers independently developed codes to represent the meanings of the text. They met regularly to compared codes and achieve consensus about a code names and definitions. Recurrent themes were established along with illustrative examples. Comparison was made between coded Australian and US transcripts and identified recurrent themes to discern points of commonality and divergence between the two groups.
Findings	Readiness for discussions about prognosis and end-of-life issues: prior to a discussion of prognosis and end-of-life issues, participants felt that both the doctor and patient needed to be ready for the discussion. For the patient, this means that the desire to know the facts overrides any fear or ambivalence about discussing these issues. For the doctor, this means feeling comfortable, confident and able to

Study	**Walczak 2013**[831]
	discuss these issues, and clear that the patient desires this information. Readiness was felt to be necessary for discussions to achieve the best possible outcomes with the least discomfort.
	Adjustment and acceptance: a key precursor to patients achieving a sense of readiness to discuss prognosis and end-of-life issues was adjustment and acceptance. This involved being able to acknowledge their impending death while still maintaining realistic hope and a good quality-of-life. It also involved being able to accept the uncertainty inherent in their life expectancy, symptoms and general disease trajectory. -Some patients described continuing aggressive treatment to satisfy the wishes of family despite wanting to focus on comfort care. It subsequently appeared that patients and families were constantly influencing each other as they waxed and waned in acceptance and readiness. If the family accepted the status of the patient's illness and supported the patient's choices it was easier for the patient to accept their illness and make appropriate choices. Age also emerged as a promoting factor. Older patients surmised that adjusting to a life limiting illness would be more challenging for younger patients and that because they themselves had a long and full life, they could better accept the prospect of dying. -Having sufficient time to adjust to the disease enabled acceptance and readiness. Patients who had recently been diagnosed or who had only recently been told that their cancer was incurable seemed more ambivalent about discussing prognosis and end-of-life issues. None expressly stated that they were unwilling to ever discuss prognosis and end-of-life care issues, but some wanted to delay these discussions. - Having religious or spiritual faith also seemed to promote adjustment and acceptance, as did life experience that exposed the patient to death or fostered a pragmatic approach to situations beyond their control. -Exposure to the symptoms and physical evidence of their disease was also seen to promote adjustment and acceptance. While feeling well, the concept of death and dying seemed unreal and unbelievable to both patients and families. Seeing scans of the cancer growing in their bodies also promoted acceptance of the reality of their situation. Past experience of cancer or life threatening illness also promoted adjustment and acceptance as it gave the patient a point of reference against which to judge and normalise their current experiences. Past experiences could be patients' own or those of individuals close to them. Salient experiences such as a friend or relatives' poor quality of death due to inappropriate medical interventions acted to motivate the patient to accept their situation and discuss end-of-life care. -Mental space was also necessary for patient to engage in end-of-life discussions. Those struggling with depression or uncontrolled pain or symptoms found it difficult to focus on anything but their physical or mental suffering. A positive mood, control of pain and symptoms and an absence of unfinished business allowed patients the mental space necessary to adjust to and accept the realities of their condition.
	Skills, understandings and relationship elements: patients and health professional communication skills emerged as an important factor in creating the conditions for discussion of prognosis and end-of-life issues and in the discussions themselves. Patients felt that they needed to be open and assertive and communicate their needs, persist if the information or outcomes they desired were not forthcoming and cooperate with their doctor to facilitate discussions and goal setting. Patients' sense of self-efficacy and comfort in asking questions and communicating with their doctor also appeared to be helpful. Patients also identified important doctor skills in this context. These included maintaining a calm and open manner in all contact with the patient, treating the patient as an individual and

Study	**Walczak 2013[831]**
	being sensitive to their individual needs. Participants also indicate that control of discussion should be actively given to the patient, but that the doctor should also take the initiative to raise complex or difficult topics such as prognosis and end-of-life issues. In discussing these issues and responding to patients' questions, participants felt that doctors should be honest, acknowledge and explain uncertainty where it exists, and relate the stories of other patients to foster hope and illustrate uncertainty. -Also contributing to adjustment and acceptance was a good doctor/patient relationship that was characterised by patients as a feeling of comfort and trust in their doctor. It was also noted that continuity in this relationship was important. The doctor skills highlighted above were seen to contribute to this relationship. -A clear and explicit agreement and permission from both parties to discuss these complex and difficult topics was highlighted as an important step towards readiness to discuss end-of-life issues. Patients recognised that not only was it important for the doctor to invite discussion of prognosis and end-of-life issues, but also that the patient needed to give their doctor permission to raise these issues aswell.
	Outcome themes: a proximal outcome of these discussions was for patients to achieve some sense of control over their situation. This equated to getting the necessary facts about the illness and developing a consensus plan for future care with all involved parties including the patient, doctor and the patient's significant others. Patients felt there was considerable comfort in knowing that their wishes would be respected. A secondary outcomes of these discussions was a sense of being able to move on. Having discussed these issues and achieved some sense of control, participants valued maintaining a sense of normality in their everyday lives and a restoration or affirmation of their identity as a whole person rather than merely as a dying patient. This in turn enabled them to 'let go' of unrealistic expectations for future outcomes and embrace the idea of enjoying a good quality-of-life for however much time might remain to them.
	Participant group differences: the themes identified appeared to apply equally to Australian and US patients with both groups presenting similar perspectives on optimising discussions of prognosis and end-of-life issues. Differences did, however, emerge in the attitudes Australian and US patients displayed towards these discussion. US patients displayed a more sceptical attitude than Australian patients towards discussions of these issues, often questioning the accuracy or worth of such information and suggesting that their doctors would avoid discussing negative issues. Where Australian patients mostly spoke of their relationship with their doctor in a personal and positive way, US patients spoke about their doctor in a more detached and neutral way, perhaps indicating differences in the doctor/patient relationship between the two cultures.
Limitations and applicability of evidence	No details of the potential bias of researcher. No details of data saturation or opposing views in the data. Applicable.

Study	**Walczak 2015[832]**
Aim	To explore responses to a nurse-led CSP, incorporating a question prompt list (booklet of questions patients/caregivers can ask clinicians), promoting life expectancy and EOL-care discussions.

Study	**Walczak 2015[832]**
Population	English-speaking adult oncology patients with advanced, incurable heterogeneous cancer diagnoses and an oncologist-assessed 2-12 month life expectancy (n=31) and their English-speaking adult primary informal caregivers gave informed consent for participation (n=11). Consecutive patients and caregivers were identified by oncologists at six treatment centres in Sydney, Australia, were informed that the study was evaluating strategies to help with the difficult discussions and decisions they may face in the future and were recruited by research assistants.
Setting	Australia. Consecutive patients and caregivers were identified by oncologists at six treatment centres in Sydney.
Study design	Qualitative interview study
Methods and analysis	Audio-recording of community support programme (CSP) sessions, with thematic analysis. The communication support program (CSP) was informed by the self-determination theory of health-related behaviour change, and aimed to increase 'autonomous motivation' to discuss prognosis/EOL-care preferences and 'competence' to undertake such discussions. Two nurses were trained to deliver the intervention, consisting of 1) a face-to-face meeting and 2) a follow-up phone call. Patients (and their participating caregiver) attended a 60-90 minute face-to-face meeting at their treatment centre approximately 1 week before a follow-up oncology consultation. Nurses established rapport and introduced a previously developed and piloted QPL for patients with advanced, incurable cancer and their caregivers. It included questions regarding prognosis, treatment options/decisions, palliative care, lifestyle, patient/family support, ACP and caregiver-specific issues. The QPL was explored in depth, focussing on prognosis/EOL-care content, and participants were encouraged to choose questions for their next consultation. This analysis examined responses to the QPL and life expectancy and ACP content during the face-to-face meeting. The research team reviewed and interpreted the data using thematic text analysis with an inductive, data-driven approach, managed with NVivo. Transcripts were explored with respect to patient/caregiver responses to: 1) the QPL in general, 2) prompting to discuss life expectancy and 3) prompting to discuss ACP. Ten transcripts were initially analysed by two researchers (AW and IH) to form a preliminary code tree, which was applied to 6 further transcripts to refine codes and establish agreement. Remaining transcripts were individually coded. Through iterative reading, recurrent themes and illustrative examples were established. Successive rounds of discussion and resolution of code names/definitions and themes and review of coding procedures by investigators not directly involved in developing the coding framework ensured methodological rigor.
Findings	Readiness to discuss EOL-issues: appeared influenced by 1) appropriate timing and 2) personal coping style. Some participants stated they coped with illness by being realistic and not avoiding what was to come. Such participants were more likely to be ready for discussions and respond positively to the QPL. Others maintained that whilst discussing EOL issues may be worthwhile in principle, it was too early to consider them in their present circumstances.
	Realism and non-avoidance: "when it came down to that point and he said, "Do you really want to know and how much do you want to know?" He said, "Is there a point that you want me to hold back? Do you want the soft or the hard version? …it's always going to be hard but how do you want it?"… "I want every bit of information you can give me and as detailed as possible." I mean there's no point pussy footing around."

Study	Walczak 2015[832]
	Avoiding negative outcomes: Some indicated that they coped by consciously choosing to live day-by-day and focus on positive information rather than considering negative future outcomes. “I don’t think I’m going to die that quick… I’m not thinking I’m going to live a hundred years, I’m thinking I still have time really… You have to die one day, nobody can live forever [but] I feel better if I’m not thinking about it”
Limitations and applicability of evidence	Little information on population details. No details of potential bias of researcher. No examples of interview guide. Themes could be more refined and data presented per person rather than combined. Applicable.

Study	Whitehead 2012[848]
Aim	To gain a greater understanding of the experiences of living with MND in the final stages of the disease.
Population	A sample of 24 people with MND and 18 current and 10 bereaved family carers were recruited through a MND Care and Research Centre in Northwest England.
Setting	UK. In the community.
Study design	Qualitative interview study
Methods and analysis	Audio-recording of community support programme (CSP) sessions, with thematic analysis. A qualitative, phenomenological approach was deemed the most appropriate method. Interviews ranged from 45 minutes to two hours. A list of subjects was developed in the event that participants required a prompt. To incorporate the narratives of patients with severe speech difficulties, interviews were also conducted by email. The option to complete a personal diary (handwritten, computer typed, tape recorded or series of face-to-face interviews) was offered to patients and current carers so that their experiences of services could be documented for a period of up to one year to provide insight into how these experiences may have altered over time. Thematic analysis was considered the most suitable approach for organizing the data as a result of its highly sensitive and flexible nature. Transcription of the data was carried out and identifying information was removed. QSR Nvivo 8, a computerized data analysis tool, was used to assist the analytic process. Transcripts were read through a number of times; initial codes were identified, reviewed and revised. From these codes, overarching themes were then constructed that were considered to capture the ‘richness of the phenomenon.’ To increase rigour, the initial three transcripts were analysed first, discussed by three members of the research team and a coding frame was created that was then used to aid the formulation of themes in the remaining interviews and diary extracts. In order to ensure that the themes provided an authentic account of the individuals’ narratives, verification was obtained from some of the participants; due to the terminal and debilitating nature of the disease it was not possible to do this for all involved in the study.

Study	**Whitehead 2012[848]**
Findings	Information: Some participants felt there was a need for additional information to help them make decisions regarding end-of-life care. “And I would like to know how it will be managed and what my choices are”. One participant who was on non-invasive ventilation felt she was not being given enough information regarding her options. She did not feel that she was being included in decisions and this was having a detrimental effect on her self-worth “I asked about a possible trache and ventilator for the future. He said a definite ‘NO’, he wouldn’t advise it and neither would the other consultant there. The main reason was expense of care package. But what about what I want!!!! That didn’t seem to matter. He said to make a longer appointment next time to discuss it further, but that is not for another 6 months. Maybe he hopes by then I won’t be well enough to discuss it. I feel useless and as if my life isn’t even worth talking about”.
	Services at EOLC: A number of people felt that they had to cope with very little support from services. Limited general practitioner (GP) involvement and lack of continuity of care were frequently cited difficulties. Accessing supportive care was described as being extremely difficult, and for some people, it was provided at a very late stage in the disease trajectory “And right at the very end of his life, I mean this letter is dated at end of July, well he died beginning of August, they decided that he might qualify for care which would be free. They had to take it to a hearing, the district nurse had to go to a hearing, and they did a tremendous amount of work between them to get it set up. . . anyway he got it but he didn’t live long enough to get anything from it, really it should have been brought out six months before, probably more care at an earlier stage and for longer than that,. . . the continuing care came in too late”
Limitations and applicability of evidence	No details on potential bias of researcher. No details of data saturation. Transferability of findings to other settings not discussed. Applicable.