Advance care planning: what do patients want?

ABSTRACT

Introduction: Advance care planning is the process by which patients can make decisions about their future health care should they lose capacity. Such conversations are shown to improve quality of life and reduce institutionalization. This article explores the preferences and wishes of patients in terms of advance care planning.

Methods: CINAHL, Medline, Embase and Pubmed were searched. Key words included ‘elderly’, ‘advance care planning’, ‘advance directive’, ‘views’ and ‘opinions’.

Results: A total of 64 abstracts were screened and 20 full text articles read; 11 articles were included in the final study. Individual and cultural differences influence the level of decision making that patients want. Most studies agreed that conversations should be carried out opportunistically by a trained health-care professional. Patients value honest and open conversations, without which they may make misinformed decisions.

Conclusions: The level of shared decision making that individuals personally want should be established. Open and honest conversations should be initiated at the earliest opportunity.

Advance care planning is the process by which a patient may communicate his/her care preferences, goals and wishes for future medical care, to be taken into account should he/she ever lose capacity (Simon et al, 2015; Towsley and Hirschman, 2018). The population is ageing, and doctors are faced with increasing numbers of frail, elderly patients with multiple comorbidities and less often with a single clear-cut diagnosis (McMahan et al, 2013; Piers et al, 2013; Michael et al, 2017). These patients often face a slow and unpredictable decline; advance care planning allows patients to prepare for their reducing capacity and functional status through making anticipatory decisions (Michael et al, 2017). Such decisions are typically made through conversations between patients, families, carers and physicians (Gjerberg et al, 2015; Towsley and Hirschman, 2018). As well as establishing a patient’s care goals the process may include appointing a substitute decision maker, or proxy, to make decisions on behalf of a patient. This can be an informal arrangement or a legally binding decision; the latter of which is referred to as a lasting power of attorney under the Mental Capacity Act 2005 (Bollig et al, 2016; Mignani et al, 2017).

Traditionally, advance care planning involved completion of an advance directive document (Bollig et al, 2016). However, completion of this document alone has not been shown to reduce the stress that families and patients feel at making such decisions (McMahan et al, 2013). This is reflected in a UK study from 2017, stating that only 17% of patients had prepared an advance care planning document (Royal College of Physicians, 2009; Michael et al, 2017). Instead the term advance care planning has developed to encompass a series of behaviours and conversations (McMahan et al, 2013).

Advance care planning offers patients a better quality of life, reduces adverse outcomes, improves patient and family satisfaction, and leads to earlier hospice admissions and fewer inappropriate admissions to hospital and nursing homes (Stone et al, 2013; Gjerberg et al, 2015; Simon et al, 2015; Michael et al, 2017; Mignani et al, 2017). In their prospective study, Somogyi-Zalud et al (2002) found that 70% of patients want comfort care rather than life-prolonging measures, yet Ke et al (2017) found that 63% of patients over 80 years of age received one or more life-sustaining therapies. While patients commonly make plans for future practicalities such as finances and their funeral, they rarely discuss future medical care plans with doctors (Piers et al, 2013; Musa et al, 2015; Michael et al, 2017; Mignani et al, 2017). Much of the current literature researches specific conditions, such as a malignancy. The views of frail older people and the barriers they face in engaging with advance care planning are under-reported (Simon et al, 2015).

Aim

This literature review explored the preferences and wishes of patients regarding when they want conversations regarding advance care planning to take place, who they would like to be involved in the conversations and what they would like to be discussed.

Methods

Pubmed, CINAHL, Embase, Medline and Google Scholar databases were searched by two reviewers, together with the *Age and Ageing* journal. Studies were searched for with no publication date limits. Reference lists were then reviewed to identify further articles. The search strategy and results are summarized in *Table 1*.

Dr Lucy Owen, Junior Clinical Fellow, Department of Elderly Medicine, Barnet Hospital, Royal Free London NHS Foundation Trust, Barnet EN5 3DJ

Dr Anna Steel, Registrar, Department of Elderly Medicine, North Middlesex University Hospital, London

Correspondence to: Dr L Owen (lucy.owen2@nhs.net)

Table 1. Search strategy and results

Summary of review methods	Search criteria	Keywords used
	Population	Patient/residential home/elder/older/nursing home/care home/frail/geriatric/aged
	Intervention	Advance care planning/advanced care planning/living will/advance directive
	Outcomes	View/preference/perspective/opinion/thought
	Study type	Qualitative/survey/questionnaire/interview
Literature search	Databases searched	CINAHL, Medline, Embase, Pubmed, Google Scholar plus *Age and Ageing* journal
	Titles reviewed	225
	Abstracts reviewed	64
	Full articles read	20
	Studies included	9, plus 2 from reviews of lists of references
	Studies excluded	Remaining studies eliminated included those focusing on specific conditions, e.g. cancer or respiratory pathology, those that did not relate specifically to advance care planning or did not reflect patients' opinions. Further studies excluded were those focusing on resuscitation only

Results

Results of the literature search were analysed by both reviewers using a thematic analysis approach. Key themes are summarized below and the number of papers referring to each theme is indicated in brackets.

Thematic analysis

Shared decision making (*n*=7)

In their systematic review and thematic synthesis of the views of older people in long-term care facilities, Mignani et al (2017) found that while some residents do not wish to burden their family, many trusted the staff or their family members to make decisions on their behalf and in their best interests. Although many older people wanted to be involved with the decision-making process, very few wanted to be individually responsible for advance care planning (Bollig et al, 2016). Some elders assume that their treatment preferences for the end of life are already known by family members and health-care professionals (Piers et al, 2013; Ke et al, 2017; Mignani et al, 2017). Piers et al (2013) cite this as a reason for a patient's lack of engagement in advance care planning. However, conversely to what patients believe, there is a concerning lack of concordance between patients' treatment preferences and those predicted by their families (Bollig et al, 2016; Mignani et al, 2017). Furthermore, a poorly chosen surrogate may make emotionally charged decisions based on his/her own personal motivations and anxieties (Michael et al, 2017).

The level as to which patients would like to be involved in the shared decision-making process varies between individuals and also between cultures (Michael et al, 2017). For example western cultures promote individualism and discussion of death and dying while eastern cultures tend to focus on paternalism and often defer autonomy to families or authorities (Ke et al, 2017). Identifying the level of decision making that older people wish to have themselves, and also what decisions they wish their surrogates and physicians to make on their behalf, leads to less conflict further down the line (McMahan et al, 2013; Gjerberg et al, 2015).

Timing of conversations (*n*=8)

Eight of the included studies refer to the view that health-care professionals or care home staff should opportunistically discuss advance care planning with patients and that these conversations should be normalized (Piers et al, 2013; Stone et al, 2013; Gjerberg et al, 2015; Simon et al, 2015; Bollig et al, 2016; Ke et al, 2017; Michael et al, 2017; Towsley and Hirschman, 2018). In a survey of 1823 older peoples' attitudes towards advance care planning, only 5% of participants had been given the opportunity to talk about advance care planning but one third would be interested should sessions be available. A total of 60% of participants would only talk about advance care planning if the topic was initiated with them, and would not start conversations themselves. This study had no inclusion or exclusion criteria, and included patients over the age of 65 years. Had the study focused on older, more frail individuals, Musa et al (2015) believed that the numbers willing to discuss advance care planning could well have been be higher. The lack of opportunistic conversations can result in the deterioration of a resident being a trigger for advance care planning, and consequently conversations are had during a crisis period, which patients often find emotionally challenging (Stone et al, 2013).

Simon et al (2015) introduce the notion of 'just ask' in their Canadian study. Of 503 respondents to a questionnaire, many suggested that they would be willing to engage in conversations around advance care planning should they be initiated but suggest that patients will not offer information up themselves – instead clinicians should normalize advance care planning conversations. Mignani et al's (2017) systematic review found generally positive views of advance care planning, with many older residents willing to talk about end of life care. This is mirrored in Bollig et al's (2016) study which found that relatives and residents had often thought about their end of life preferences and were willing to talk about these with care home staff or health-care professionals but were often reluctant to start a conversation themselves.

In the care home setting, where cognitive impairment is particularly rife and the majority of residents die within a year of admission, it may be more appropriate to have conversations earlier on in the disease trajectory (Stone et al, 2013; Bollig et al, 2016). Michael et al (2017) support this view; they refer to a period of time called the 'grey zone' – a time over which cognition fluctuates yet is often the time when conversations are started as health and cognition deteriorate. Advance care planning conversations can be overwhelming if held too close to the time of admission, and having these discussions earlier on, at key points in a patient's life span instead, can reduce the emotional burden that patients and relatives may feel (Stone et al, 2013; Michael et al, 2017).

In their study, Piers et al (2013) suggest that doctors should be aware of a minority of patients who do not want to acknowledge that they are at the end of their lives, and that while many older people are able to stay positive but still engage in such conversations, there is a minority who are unable to reflect on the end of life. In another study, while 70% of patients reported their health as fair to poor, many of these did not feel that they were at the point when advance care planning was necessary or relevant to them. Others were 'living for the day', or found the subject of death too distressing, or emotional to think about (Simon et al, 2015).

A key aspect of advance care planning, discussed throughout the literature, is having conversations with patients before they lose the cognitive capability to discuss their preferences (Simon et al, 2015). Owing to ethical considerations, all but one of the studies (Piers et al, 2013) described in this review excluded patients with cognitive impairment. However, studies have shown that persons with mild to moderate memory impairment may still be able to accurately and consistently express their preferences for care (Whitlatch et al, 2005; Harrison Dening et al, 2016). Two systematic reviews reiterated these findings and highlighted that where conversations have not taken place previously, planning for patients with dementia is still possible (Ke et al, 2017; Mignani et al, 2017).

What to include in the conversation (*n*=10)

Patients are prepared for death but not the dying process. Many do not want heroic measures to keep them alive (Ke et al, 2017) but find it more helpful to focus on goals, values and beliefs rather than specific interventions (Gjerberg et al, 2015). People are able to express a preference for quality of life, a natural death, dying with dignity and without pain, and not being alone (Bollig et al, 2016; Mignani et al, 2017). Often, people relate to their past personal experiences and those of their loved ones when making decisions about their future care (McMahan et al, 2013; Piers et al, 2013; Musa et al, 2015; Michael et al, 2017; Mignani et al, 2017; Towsley and Hirschman, 2018). Negative experiences related to ageing, care and deaths of loved ones are particularly influential (Michael et al, 2017). Piers et al (2013) refer to pseudo-participation, meaning that when planning for certain scenarios, a patient's true wishes are not reflected as he/she is not able to make decisions for hypothetical situations based on his/her imagination. Indeed, terms such as mechanical ventilation, resuscitation or intensive care often have little meaning to patients. Furthermore, discussing one aspect of advance care planning did not prepare patients for other situations, for example discussing a do not resuscitate order does not help in planning for transitional care (McMahan et al, 2013).

Patients value open, honest and understandable conversations with enough information regarding prognosis and diagnosis for them to be able to plan for their future (Simon et al, 2015; Ke et al, 2017). It should not be assumed that patients have the information that they require to make a decision, for example in Sharma et al's (2016) study, 91% of 100 participants interviewed over-estimated the success rates of cardiopulmonary resuscitation. On the contrary, however, some patients do not wish to be fully informed and want to be protected against harmful information (Gjerberg et al, 2015).

A further barrier to older people engaging in advance care planning conversations is that they are concerned either that decisions will be followed too rigorously, or not followed at all. Of 1823 respondents to a survey 59% were worried that their wishes would not be respected if a care plan was prepared, and 35% worried that doctors would stop treatment too soon (Musa et al, 2015).

Who to have these conversations with (*n*=6)

Musa et al (2015) found that patients prefer an informal discussion with their family rather than with their health-care professional. Of 1823 respondents to their questionnaire, only 12% (219) had approached someone to talk about advance care planning. Of these, 73% had discussed plans with their family or friends, and a minority with health-care professionals (Musa et al, 2015).

When considering whether a health-care professional in a secondary care setting is more equipped to discuss advance care planning than a community health-care professional with whom the patient has a longer term relationship, patients do not seem to have a real preference. While some prefer a well-known and trusted GP, others believe that a doctor can establish him-/herself through good communication skills (Simon et al, 2015). This highlights the importance of building on communication skills at the undergraduate level and throughout a doctor's training. A health-care professional's reluctance to initiate conversations because he/she feels uncomfortable, unprepared or concerned about causing distress is a commonly cited barrier to advance care planning in the literature (Musa et al, 2015; Simon et al, 2015; Towsley and Hirschman, 2018). Highlighting the importance of education, in Stone et al's study (2013), a teaching session was undertaken with nursing home staff, following which they delivered advance care planning to residents. Within a week, semi-structured interviews took place with residents. The quality of advance care planning varied enormously according to the training received, and it was apparent that nursing home staff did not have any clear concept of what advance care planning was, with only pre-defined questions being asked in a prescriptive manner. One facilitator role modelled an advance care planning discussion, which helped to facilitate the learning process with good outcomes. This study suggests that end of life care discussions should become part of mandatory training and in particular role modelling should be encouraged as an effective way of assisting nurses.

In care homes, it may be appropriate for staff to have conversations with residents and relatives themselves and Bollig et al (2016) suggest that nursing home staff should routinely offer the opportunity for residents to discuss death, dying and their wishes for future care.

Discussion

Doctors should routinely offer family consultations with patients and their relatives, and from the outset explore the level of shared decision making that patients would like (Simon et al, 2015). Careful consideration of who the patient's proxy is should be encouraged, ensuring that this is not necessarily the patient's next of kin but someone who feels able to be involved in the patient's chosen level of shared decision making free from emotional coercion, even at the time of crisis (Michael et al, 2017). This chosen proxy, as well as the level of decision making that the patient would like, may change over time and this should be communicated to the patient (Gjerberg et al, 2015).

The appropriateness of advance care planning conversations should be judged on an individual basis taking into account family and cultural considerations (Gjerberg et al, 2015; Simon et al, 2015). While there remains a minority of patients who will not wish to engage, the majority of older people will be willing to express their views and preferences for their future care, and these should be opportunistically discussed and conversations normalized (Simon et al, 2015). Older people and their families should be reassured that advance care planning is a continuous process that adapts to the patient's conditions and needs, to be reviewed over time as priorities, relationships and quality of life changes (McMahan et al, 2013; Gjerberg et al, 2015; Musa et al, 2015; Michael et al, 2017).

In deciding issues that are important to them, patients will draw on previous personal life experiences and experiences of their family to make decisions (McMahan et al, 2013; Piers et al, 2013; Musa et al, 2015; Mignani et al, 2017; Towsley and Hirshman, 2018). Health-care professionals' role should be to ascertain the patient's priorities and beliefs underlying his/her decisions. Rather than focusing solely on what interventions a patient may choose, patients should be equipped with as much information as they would like so that they can make informed and supported decisions (Piers et al, 2013).

Strengths and limitations

Much of the current research focuses on advance care planning within care homes, which is both a strength and a limitation. While this eliminates a large proportion of elderly patients who are still living at home, 19% of deaths occurred in a care home in 2012 and this is a key population to target. The majority of patients who died did so within a year of admission (Stone et al, 2013). Among the nursing home population, those with cognitive impairment may form a majority. In Norway, 60–80% of those living in nursing homes have a degree of cognitive impairment, and in the UK between 2001 and 2010, 55% of people suffering with dementia died in a care home, yet researchers are unable to fully explore this group's views because of ethical considerations (Bollig et al, 2016).

Universally accepted tools for critically appraising qualitative research are lacking. A limitation of qualitative data is that the sample size will always be small and will rely on the accuracy of the data collectors in specific studies; however, it allows the investigation of individuals' perspectives. The vast majority of studies included here used convenience sampling, for example advertising on newsletters delivered to a specified sub-set of the population, which may be a global limitation as views portrayed may not be entirely representative of the general population, but of individuals who have particularly strong opinions. However, this can also be a strength as participants are more likely to have contemplated their choices with regards to advance care planning conversations in more detail.

Globally, the frail, older population remains under-represented in the literature, with many studies focusing on hospital inpatients, nursing homes or acutely unwell patients. In particular, studies within the UK are limited. Having said this, despite not putting a time limit on this literature search the majority of articles were published in the last 5 years, suggesting that the topic is becoming better researched and considered.

Conclusions and implications for future practice

Patients want to make an informed choice about the future at a time that is right for them. Advance care planning needs to be tailored to individuals, as the preferred amount of information, level of decision making and timing of conversations varies. Patients will rarely initiate conversations themselves, often presuming that relatives and doctors already know their wishes. Therefore, there is a need to rely on health-care professionals' willingness to initiate advance care planning conversations and an urgent need to enhance health-care professionals' knowledge and skills in this area. Training should be offered at both undergraduate and postgraduate level on advance care planning conversations, and role play has been shown to be an effective educational resource. Locally, these findings have influenced an advance care planning simulation day for junior doctors, nurses and allied health professionals.

Patients value open, honest conversations relating to scenarios, feelings and symptoms that they can relate to rather than planning for hypothetical scenarios or for specific treatments. Decisions should be re-visited over time and conversations not be too prescriptive but aim to cover fears, thoughts and wishes. Health-care professionals should recommend that the patient involves a proxy, and that the proxy's role and level of involvement in decisions is established early on. While there will remain a minority of patients who do not feel ready or able to talk about advance care planning, the literature has clearly demonstrated the benefits of advance care planning for the majority of patients. Clinicians should strive to offer advance care planning to all patients in whom it is appropriate in order to facilitate excellence in end of life care. **BJHM**

Conflict of interest: none.

KEY POINTS

- The level of shared decision making that patients want depends on individuals and cultures.
- Patients often assume that their treatment preferences for end of life are known.
- Advance care planning conversations should take place opportunistically.
- Patients value open, honest conversations focusing on goals, values and beliefs rather than specific interventions. They often draw on past personal experiences.
- Training, in particular role play, has been shown to improve the quality of advance care planning conversations.

Bollig G, Gjengedal E, Rosland JH. They know!—do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliat Med. 2016 May;30(5):456–470. https://doi.org/10.1177/0269216315605753

Gjerberg E, Lillemoen L, Førde R, Pedersen R. End-of-life care communications and shared decision-making in Norwegian nursing homes - experiences and perspectives of patients and relatives. BMC Geriatr. 2015 Dec;15(1):103. https://doi.org/10.1186/s12877-015-0096-y

Harrison Dening K, King M, Jones L, Vickestaff V, Sampson EL. Advance care planning in dementia: do family carers know the treatment preferences of people with early dementia? PLoS One. 2016 Jul 13;11(7):e0159056. https://doi.org/10.1371/journal.pone.0159056

Ke LS, Huang X, Hu WY, O'Connor M, Lee S. Experiences and perspectives of older people regarding advance care planning: A meta-synthesis of qualitative studies. Palliat Med. 2017 May;31(5):394–405. https://doi.org/10.1177/0269216316663507

McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. J Pain Symptom Manage. 2013 Sep;46(3):355–365. https://doi.org/10.1016/j.jpainsymman.2012.09.006

Michael N, O'Callaghan C, Sayers E. Managing 'shades of grey': a focus group study exploring community-dwellers' views on advance care planning in older people. BMC Palliat Care. 2017 Dec;16(1):2. https://doi.org/10.1186/s12904-016-0175-7

Mignani V, Ingravallo F, Mariani E, Chattat R. Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. Clin Interv Aging. 2017 Mar 3;12:475–484. https://doi.org/10.2147/CIA.S128937

Musa I, Seymour J, Narayanasamy MJ, Wada T, Conroy S. A survey of older peoples' attitudes towards advance care planning. Age Ageing. 2015 May;44(3):371–376. https://doi.org/10.1093/ageing/afv041

Piers RD, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, Van Den Noortgate NJ. Advance Care Planning in terminally ill and frail older persons. Patient Educ Couns. 2013 Mar;90(3):323–329. https://doi.org/10.1016/j.pec.2011.07.008

Royal College of Physicians. 2009. Advance care planning—national guidelines. (accessed 15 September 2018) https://www.rcplondon.ac.uk/resources/concise-guidelines-advance-care-planning

Sharma R, Jayathissa S, Weatherall M. Cardiopulmonary resuscitation knowledge and opinions on end of life decision making of older adults admitted to an acute medical service. N Z Med J. 2016 Jan 8;129(1428):26–36.

Simon J, Porterfield P, Bouchal SR, Heyland D. 'Not yet' and 'Just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families. BMJ Support Palliat Care. 2015 Mar;5(1):54–62. https://doi.org/10.1136/bmjspcare-2013-000487

Somogyi-Zalud E, Zhong Z, Hamel MB, Lynn J. The use of life-sustaining treatments in hospitalized persons aged 80 and older. J Am Geriatr Soc. 2002 May;50(5):930–934. https://doi.org/10.1046/j.1532-5415.2002.50222.x

Stone L, Kinley J, Hockley J. Advance care planning in care homes: the experience of staff, residents, and family members. Int J Palliat Nurs. 2013 Nov;19(11):550–557. https://doi.org/10.12968/ijpn.2013.19.11.550

Towsley GL, Hirschman KB. Talking about end-of-life care: perspectives of nursing home residents. Geriatr Nurs (Minneap). 2018 Jan;39(1):72–76. https://doi.org/10.1016/j.gerinurse.2017.07.002

Whitlatch CJ, Feinberg LF, Tucke SS. Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. Gerontologist. 2005 Jun 01;45(3):370–380. https://doi.org/10.1093/geront/45.3.370