**Title**

Important conversations – understanding what is important to older people living with frailty in relation to Advance Care Planning

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**Abstract**

***Background***

Advance Care Planning provides opportunities for people to make decisions about future care. Internationally the approach to this varies. Older people living with frailty could considerably benefit from discussing and undertaking advance care planning, however this has not traditionally been a particular focus of their care.

***Aim***

To provide recommendations to support nurses and health professionals to undertake ACP conversations with older people living with frailty through a review of contemporary literature.

***Methods***

The following electronic databases were searched: CINAHL, British Nursing Index and the Cochrane Library. All papers that met the inclusion criteria were included. Information about the process and outcome of undertaking an ACP conversation with older people living with frailty was extracted and categorised in relation to care setting.

***Findings***

Sixty-nine papers were identified of which eight met the inclusion criteria. The research included in the review is reported in relation to care setting. Key considerations highlighted within these papers included: preconditions required to undertake an ACP conversation; recommendations when undertaking an ACP conversation; and the outcomes emerging from such conversations. From these five clinical recommendations, one policy recommendation and two research recommendations are made.

***Conclusions***

Maintaining and improving wellness is important to older people living with frailty. From this review to be acceptable and meaningful to older people living with frailty ACP conversations should: include the opportunity to discuss both ‘current’ and ‘future’ care; be focused on their goals of care; and, be offered routinely.

**Background**

People who are frail find their usual in-built body reserves are unable to respond to a minor stress/illness. It is a distinctive health state that can be related to the ageing process, in which multiple body systems gradually lose their reserves. People living with frailty may be identified from: their personal circumstances; through an assessment using specific tools; or, by the presence of pre-specified criteria (Moody et al 2017, Fried et al 2001). In relation to personal circumstances, following a minor stress such as an infection, those living with frailty can experience a sudden large deterioration in health and do not return to their previous level of health (Clegg et al 2013). In relation to assessment, the recommended methods of identification of frailty include the use of specific tools (Moody et al 2017) and the presence of pre-specified criteria, for example three of the following: unintentional weight loss (10 lbs in past year), self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity (Fried et al 2001).

Globally it is estimated that one in six older people living in the community may have frailty (Ofori-Asenso et al 2019). Older people referred to within this paper are individuals aged 65years and over. Whilst frailty is not an inevitable consequence of ageing it becomes more prevalent as age increases, with around 4% of people aged 65-69 being frail, rising to 26% for those over the age of 85 and 65% in those aged 90 or over (Ofori-Asenso et al 2019, Clegg et al 2013, Gale et al 2015). Juxtaposing this increasing prevalence with increasing age and size of the population for many countries there are, and will be, increasing numbers of older people living with and dying from frailty. In the UK, for example, the proportion of the population aged 65years and older is the fastest growing (Office for National Statistics 2020a). In the United Kingdom frailty is a recordable cause of death (The Royal College of Pathologists 2020). A population-based observational study, undertaken in England using death registration data from 2001-2010, reported that the main certified causes of death for those over the age of 100 years were pneumonia and frailty (Evans et al 2014). The Royal College of Pathologists (2020) guidance advises such deaths are reported to the coroner if the deceased is under 80 years of age. In relation to completing a medical certificate a second document advises that frailty should only be recorded, as the sole cause of death, in a specified range of circumstances (HM Passport Office 2020). These two guidance documents aim to ensure clarity for recording frailty as the cause, or as contributing, to death.

In England, person-centred care is promoted in the NHS Long Term Plan (NHS 2019). Its intent is to involve people in decisions about their own care throughout their life span. The focus on personalised care is to enable clinical decisions to be based on the values, preferences and needs of a specific person. With respect to care at the end-of-life, the NHS Long Term Plan states *‘we will introduce proactive and personalised care planning for everyone identified as being in their last year of life’* (NHS 2019 p25). The intention of this provision; to reduce avoidable emergency admissions, and the outcome; to enable people to die in the place of their choosing, is clear (NHS 2019 p25). Given that in England of the 505,859 deaths in 2018, 428,770 were of people 65 years old and older (Office for National Statistics 2020b) this further highlights the importance to offer such planning to older people living with frailty. There is less clarity, however, on exactly how such recommended, but ambitious, ‘person centred care’ will be achieved.

People can be supported and facilitated to make decisions about their own health and wellbeing i.e. to achieve ‘person centred care’ through skilled conversations which, ideally, occur over time. Internationally the terms for such planning and decision making vary but include Anticipatory Care, Advance Directives, Advance Care Planning (ACP) and Future Care Planning. In the UK such conversations are usually referred to as known as ACP. ACP is defined as enabling:

‘*Individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals’ concerns across the physical, psychological, social, and spiritual domains.’* (Rietjens et al 2017 p.e546).

Older people living with frailty may have multi-morbidities, mental capacity issues and, during their last year of life, may reside in a variety of care settings. Enabling conversations about future plans and wishes can therefore be challenging. To achieve this the NHS Long Term Plan recognises partnership working to engage patients in decisions ‘*We will support and help train staff to have the conversations which help patients make the decisions that are right for them’* (NHS 2019 p25).

**Aims**

To achieve person centred care at the end-of-life, the NHS Long Term Plan recommends the provision of training and support to staff to enable them to identify and support relevant patients. This paper draws on existing literature and aims to:

1. Review the evidence supporting this recommendation for older people living with frailty.

2. Provide broad recommendations to guide and support nurses and other health care professionals (HCPs) to guide conversations with older people living with frailty about advance care planning.

**Method**

The focus of the review was shaped in consultation with a clinical academic with expertise in ACP in relation to people living with frailty. Searches were undertaken of the electronic databases CINAHL, British Nursing Index and the Cochrane Library from 1990 to 2nd May 2020 using terms related to frailty, older people, ACP and person centred care. Details of the search strategy in CINAHL are provided in Box 1.

 Inclusion criteria were:

* Papers that reported completed research studies of any methodology examining aspects of ACP/personalised care planning with people over the age of 65 years, with capacity, who were at risk of adverse outcomes /defined as frail.
* Reported in English

Papers that included people under the age of 65 and/or with dementia/severe cognitive impairment were excluded. We included international literature, with the recognition that the approach and the process to ACP, outside of the UK may vary, as the aim of this review was to provide broad recommendations.

Identified studies were reviewed by title and abstract. For those studies potentially meeting the inclusion criteria, full text articles were requested and reviewed. The references of full text included papers were reviewed and papers obtained where they met the inclusion criteria. Finally, the recommendations that emerged were shared with a clinical academic expert who assisted before commencing the review, and an academic/researcher, for comments.

**Please Insert Box 1 here**

**Results**

Sixty-nine abstracts were reviewed. Fifty-two were identified through CINAHL, 12 from the British Nursing Index and five in the Cochrane Trial Library. In total 18 papers met the inclusion criteria. Four of these papers were systematic literature reviews. As 10 of the of remaining papers meeting the inclusion criteria were referenced and their findings incorporated within these, they were removed from the review. A total of eight papers are therefore included in this review [the four systematic reviews and the four papers that were not referenced within them]. The following details were extracted from the included eight papers: the publication year; the dates of data collection; the method; the country the study was undertaken in; the sample; the population size (where reported); and, the care setting. Table 1 provides details of these.

**Please Insert Table 1 here**

The four systematic reviews, detailed in Table 1, took different approaches. Gilissen et al (2017) reported the collective findings from two systematic reviews of published literature. Combes et al (2019) deliberately undertook a substantially wider systematic integrative review from diverse sources. This was an intentionally wide review with no quality review of the records included. Hopkins et al (2020) and Sharp et al (2013) undertook a systematic review and narrative synthesis. They both utilised Gough’s Weight of Evidence Criteria to grade the records meeting their inclusion criteria. Hopkins et al (2020) undertook their review after a preliminary scoping review to identify search terms. Finally, Sharp et al (2013) undertook an electronic database search of published research. Of the 78 papers, included within the three reviews that graded the quality of the papers they sourced, nine were reported as high quality (Gilissen et al 2017, Sharp et al 2013, Hopkins et al 2020).

The remaining four papers were conducted using either quantitative and/or qualitative methods. Two used randomised controlled trial (RCT) methods, and two incorporated qualitative exploratory methods. Of the RCTs, Overbeck et al (2019) reported the cost of providing a facilitated ACP conversation within a Cluster Randomised Controlled Trial (CRCT) alongside its effect on the cost of medical care provided. The CRCT followed Consolidated Standards of Reporting Trials (CONSORT) guidelines (Campbell et al 2012). Chan et al (2018), undertook a parallel-group RCT with repeated measures, which reported the effects of a facilitated structured post discharge ACP programme. Whilst recruitment to the study occurred in medical wards, the intervention occurred at home with the older person living with frailty and a nominated family member (Chan et al 2018).

In the two papers incorporating qualitative methods, Chan and Pang (2007) interviewed older care home residents, using a modified Quality-of-Life Concerns in the End of Life Questionnaire (QOLC-E), to understand their preferences on, and identify any concerns about, end-of-life care. They report both qualitative and quantitative findings. The final paper, a qualitative exploratory study by Piers et al (2011), reports on the views of older people who had terminal cancer, were frail or had end-stage organ failure.

The settings in which the included research was conducted represented primary and secondary care, i.e. hospital, care homes and community settings. The findings, are therefore reported in relation to these contexts: those occurring across all care settings and those that were setting specific. The important considerations highlighted within the included papers were collated and summarised under three core headings: preconditions required to undertake an ACP conversation; recommendations when undertaking an ACP conversation; and the outcomes emerging from such conversations. These are summarised in Table 2.

In relation to preconditions required to undertake an ACP, the provision of training and support to staff to enable them to identify and support relevant patients, as recommended within the NHS Long Term Plan, was highlighted to be important across all care settings. Very much linked to this was recognition that to have such a conversation required skill. However, cumulatively, the eight papers highlighted other important preconditions. These included having time, using standardised documentation, and where prognosis is likely to be limited establishing with the older person living with frailty’s their understanding of the possible outcomes. Further detail is provided in Table 2 of these, and as well as other precondition requirements that were identified as setting specific.

With respect to all care settings several recommendations were made, within the included papers, to guide clinicians when undertaking ACP conversations. Older people living with frailty recommended offering such conversations routinely i.e., as part of usual care, basing them on their own personal life experience. They also, mainly, expected such discussions to be initiated by an HCP rather than themselves. It was also reported that when an older person living with frailty had good experiences of death and dying and trusted family and physicians to make good end-of-life care decisions they were less likely to proceed with an ACP conversation. HCPs highlighted the challenges of such conversations with this population as the trajectory of their disease was often uncertain. Table 2 contains further details of these as well as site specific recommendations.

The outcome of such conversations reported within the NHS Long Term Plan was to enable people to die in the place of their choosing. Reference to this is reported within one Randomised Controlled Trial (RCT). The RCT found that, within the in-patient care setting, the end-of-life care wishes of older people living with frailty, who died within 6 months of completing an ACP, were more likely to be both known and followed. Further detail of the outcomes across this, and other care settings, are provided in Table 2.

The classification in Table 2 identifies important considerations when undertaking an ACP conversation with older people living with frailty within specific care settings. However, and perhaps more importantly, it also provides the opportunity to consider how evidence across the care settings can be linked. Where applicable, the evidence within Table 2 supporting a Clinical (\*C), a Policy (\*P) or a Research (\*R) recommendation is highlighted. Each recommendation is then discussed.

**Please Insert Table 2 here**

**Discussion and emergent recommendations**

The eight recommendations listed below both incorporate and go beyond, the current recommendation in the NHS Long Term Plan to provide training and support to staff to identify and support patients in their last year of life. They also provide detail on how to have conversations with older people living with frailty that supports them to make decisions about their health and wellbeing. The information, identified within Table 2 (as numerical **\*C**, **\*P** and **\*R**), that supports the five clinical recommendations, one policy recommendation and two research recommendations below is incorporated and discussed. Wider literature relating to, but outside the inclusion criteria, is drawn on to further inform these recommendations.

***Recommendations for Clinical Practice***

**Recommendation 1:** *The importance of ACP for older people living with frailty should be incorporated into ACP education* ***(\*C1)***

Across all care settings, older people living with frailty and their family members/friends have misunderstandings about ACP and/or its relevance to frailty. For such conversations to occur information was not only required about ACP but also how it related to that specific person’s life, which included their medical conditions. With training and support, it may be realistic that HCPs will better understand ACP but it is less likely that they will all have detailed knowledge of frailty and/or the multi-morbidities that this population live with. An example of how this was addressed for elderly people living with Chronic Kidney Disease (CKD) was through the provision of a specific practical guide for conservative care which enabled early ACP conversations with experts, and the ability to establish personal goals of care (Raghaven and Holley 2016). The importance of patient centred decision-making was stressed. The approach taken here, in relation to ACP, may be useful for older people living with frailty as well as the HCPs they interact with.

**Recommendation 2:**  *HCPs should offer an ACP discussion to all older people living with frailty from diagnosis* ***(\*C2)***

Having an ACP conversation was welcomed by most older people living with frailty. Other than where older people had past experiences that had generated anxieties or fears about end-of-life care, ACP was only discussed when an HCP introduced it. Notably, older people living with frailty suggested that ACP should be part of the routine i.e., standard questions they are asked. Given this, all HCPs, in all care settings, should consider including questions relating to ACP in their core assessment for older people living with frailty. This will enable ACP to begin to become a routine question, just as currently asking for details of their next of kin is.

The importance of ACP becoming a routine question would eradicate the challenge of identifying the last year of life for older people living with frailty. Only offering a conversation to this population at this time, will result in missed opportunities. It could be argued that given, by definition, this population is unable to respond to a minor stress/illness, the offer of such a conversation should occur at diagnosis. This is already recommended for people diagnosed with dementia [NICE 2019].

**Recommendation 3:**  *ACP conversations with older people living with frailty are enabled by focusing on goals for care rather than on specific treatments for particular conditions* ***(\*C3)***

Regardless of care setting, HCPs need to be aware of the importance of providing a personalised ACP conversation. Some of the literature linked ACP with undertaking a conversation about end-of-life care. This review highlighted the importance of a personalised, not a standardised, approach to ACP. For older people living with frailty, ACP conversations are interpreted in light of their lived experiences and personal goals. Therefore, an older person living with frailty may want to discuss end-of-life care if they view dying as a possible outcome. Taking time, through storytelling, to get to know an older frail person in relation to their life lived first, is essential to enable care preferences to be both expressed and interpreted in an individual way.

For most older people living with frailty the opportunity for an ACP conversation with a HCP is welcomed. Several of the included studies stress the importance to older people living with frailty of both maintaining and improving wellness. It is therefore important that ACP conversations offer the opportunity to discuss both ‘current’ and ‘future’ care. Given the importance of ‘wellness’, discussions with older people living with frailty need to go beyond the concept of ‘frailty’ (Nicholson et al 2017). To achieve engagement, the conversation needs to incorporate what the person can do, not just focus on their limitations. Dealing with current issues is as important as discussing potential future challenges. This approach may help facilitate exploration of deeply held personal values, which may then lead to the discussion of future medical care, including end-of-life care. Even if this does not occur, knowledge of the goals of care of an older people living with frailty in the community, may enable future decisions about their care to be made should they lose capacity.

**Recommendation 4****:**  *ACP conversations are enabled when; they are undertaken by a HCP who has sufficient skills and time; and, when family members are present* ***(\*C4)***

If possible, ACP discussions need to be undertaken by professionals known to the older person living with frailty who have time to both initiate and then follow up on conversations. The HCP needs compassion and skill. ACP conversations were found to be enhanced when everyone was involved and so, where possible, incorporating family members is important. This is more challenging when families and/or patients and/or professionals have differing views. Given the current medical and nursing health care system, where collaboration in service provision occurs, establishing a relationship with one individual professional for on-going ACP conversations may not be realistic. It is important that the multi-disciplinary team (MDT) is explained to the older people living with frailty, and their family. Explaining this at the outset should establish realistic expectations that future ACP discussions may occur with other members of the MDT that they engage with.

**Recommendation 5:**  *ACP conversations occur over time and so need to be documented and shared locally* ***(\*C5)***

Achieving a personalised ACP conversation will only be possible through everyone working together. Updated information needs to be shared across care settings. If ACP conversations occur in hospital, a system enabling this to be followed up with a further conversation in the community after discharge needs to be established. The hospital HCP must ensure the community HCP is aware of the need for a post discharge review. The challenges of achieving such a shared system are enormous and at present in the UK are reliant on localised systems e.g. in London Coordinate My Care (CMC) <https://www.coordinatemycare.co.uk/>. The use of standardised documentation may enable this.

As conversations are not always fully recalled by older people living with frailty, documenting ACP conversations will ensure current agreement and clarity and hopefully enable future recall. This is of particular importance when such conversations are started in hospital as older people living with frailty report it hard to engage fully in this setting and accurate accounts are not always recorded in medical files.

***Recommendations for Policy***

**Recommendation 1:** *Frailty screening from age 65 onwards* ***(\*P1)***

Given the challenge of determining prognosis in older people living with frailty, one solution suggested within the literature reviewed was the use of ‘triggers’. Such ‘triggers’ are defined clearly by Marie Curie (2015). GPs offering an annual frailty screening to all patients over 65years may be one way that such ‘triggers’ could be identified. At each review opportunities for health and wellbeing could be maximised and any reduction in function identified with future actions planned. A longitudinal study demonstrated that routine use of an electronic frailty index supported clinicians to identify people with frailty who were deteriorating, and this allowed time for intervention (Stow et al 2018).

***Recommendations for Research***

**Recommendation 1:** *To develop the evidence base in relation to ACP with older people living with frailty* ***(\*R1)***

In this review, most evidence is from small qualitative studies reporting on the experience of people undertaking ACP rather than specific measurable outcomes. The growing number of people living with frailty provides the opportunity to learn with them about how best to continue to deliver holistic personalised care, at all times, regardless of an individual’s physical, emotional, spiritual or cognitive function. In relation to research, significant gaps are identified which include:

* a validated operational definition of frailty
* evidence of what older people would like to achieve through ACP
* measurable outcomes of ACP conversations. However, before measurement occurs establishing what should be measured needs to be identified first. This should incorporate what older people living with frailty identify as important.

**Recommendation 2:** *HCPs and researchers work together, across care settings, to ensure that clinical issues are translated into research questions and research findings are disseminated into practice* ***(\*R2)***

Research needs to be clinically relevant. Several papers reported that ACP conversations were more likely to occur with a whole systems approach. Older people living with frailty move across care settings. Given this, linking professionals across settings together is more likely to generate clinically useful research-based ACP recommendations. Such research should incorporate process as well as outcomes.

Whilst the evidence from this review is relates to older people living with frailty and not the wider population, it has synergy with a recent rapid review on ACP in the community, conducted during the Covid-19 pandemic (Selman et al 2020). Interestingly there is also synergy across the literature in relation to ACP with older people living with frailty and other long-term conditions e.g. people with dementia and multiple sclerosis (Wendrich-von Dael et al 2020, Harrison Dening et al 2019, Cottrell et al 2020).

**Limitations**

This was an overview of the literature not a systematic review. The eight recommendations made were not shared with older people living with frailty, their family members, or HCPs.

International literature was included. The literature reviewed identified that ACP conversations, with older people living with frailty, were influenced by culture. For example, Chan and Pang (2007) highlighted in China, that the physician was regarded as the most reliable person when treatment decisions needed to be made. Culture needs to be considered when transferring these recommendations into practice.

**Conclusion**

The NHS Long Term Plan promotes an increase in proactive and personalised care planning for people who are older and frail in their last year of life to reduce avoidable emergency admissions and enable this population to die in the place they have chosen. Given the predicted increase in numbers in the UK for this specific population group, this is a growing and important area of practice where there is potential for much to be achieved. However, these important outcomes are more likely to occur though clinicians, policy makers and researchers paying attention to the additional recommendations emerging from this review. These go beyond the current recommendation of providing training and support to staff to enable them to identify and support relevant patients. To achieve this, meaningful ACP conversations should be offered to older people living with frailty at the point of diagnosis. A key recommendation was that to enable truly personalised current and future care the conversation should be focused on goals of care, as identified by the older person living with frailty.

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**Conflict of interest statement**

None

**Reflective Questions [3-5]**

1. In your locality, what Advanced Care Planning (ACP) training and education opportunities are available?
2. Do you have any documentation in your locality that patients and their families/friends can read to guide them about ACP and the options available to them?
3. Are you aware of which aspects of ACP are legally binding?
4. Do you have access to ACP documentation that you could offer to/complete with an older patient living with frailty to document their wishes and preferences?
5. Are you aware of the process, in your locality, for sharing ACP documents between your own and other care settings?

**Keywords**

Advance Care Planning, elder, frailty, older person, personalised care