

Uncertainty and advance care planning in older adults living with frailty.

Collins, Pippa; Hopkins, Sarah; Milbourn, Helen; Etkind, Simon

Corresponding author - pippa.collins@nhs.net

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Key points:

- People living with frailty face an inherently uncertain future.
- Advance care planning is inseparable from uncertainty.
- Uncertainty presents a barrier to decision making and advance care planning.
- Advance care planning discussions can be an opportunity to address uncertainty.

Introduction

Older people often live with multiple serious illnesses and frailty with a reduced biological reserve (O’Caoimh et al 2021). People living with frailty face an inherently uncertain future with the unpredictable dying trajectory of frailty being widely recognised (Murray et al 2005). Uncertainty can also result from healthcare systems, from fragmented care due to multiple illnesses, or patchy communication between services. It can leave patients, carers, and health professionals distressed and overwhelmed (Etkind et al 2022).

Advance care planning seeks to help individuals articulate their preferences and priorities for care in the face of an uncertain future (Box 1). Advance care planning is thus intertwined with and inseparable from uncertainty, yet the relationship between the two is relatively under-recognised and under-investigated. The papers in this themed collection explore aspects of this relationship in the context of frailty. Some of the included papers discuss uncertainty explicitly, while in others, uncertainty is implicit in discussions of advance care planning, reflecting that uncertainty is often an important undercurrent in these situations. We discuss how uncertainty is commonly conceptualised as a barrier to advance care planning, but advance care planning can also be seen as an opportunity to help people live well by supporting them to make sense of ongoing and irreducible uncertainty.

Box 1: concepts of advance care planning and uncertainty.

A. Advance care planning

Advance care planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care (NHS England 2022). This discussion is "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" (Sudore et al 2017). Although ACP can happen at any stage of health, conversations are often triggered by serious illness, be that cancer, organ failure, or frailty, which is our focus here.

B. Advance care planning and frailty

Advance care planning is seen as an important intervention in frailty, given its potential to support individuals to avoid receiving low value care. The British Geriatrics Society recently recommended a system wide expansion in end of life care training for health professionals. This aligns with the stated purpose of advance care planning to "accommodate and anticipate a person's future" and to "lay out values, beliefs and preferences related to daily life, right through to anticipated situations in which a person may wish to specify very explicitly the limits of treatments intended to sustain life" (British Geriatrics Society 2020).

C. Uncertainty

Health uncertainty can be defined as the subjective perception of ignorance, or more simply as ‘known unknowns’ (Etkind et al 2022; Han et al 2011). Arising from ambiguity, complexity, unpredictability, and lack of information (Han et al 2011; Mishel 1988), uncertainty may relate to scientific (diagnosis, prognosis, treatment), practical (care structures and processes), or personal (psychosocial, existential) domains, and can be experienced by health professionals, patients or carers. In advanced multimorbidity, the multidimensional nature of health uncertainties may result in a distressing experience of ‘Total Uncertainty’.

Whilst many uncertainties, particularly those relating to health systems and care fragmentation are reducible and can be resolved by effective communication; others, such as those about the future, are irreducible and cannot be removed.

Uncertainty as a barrier to advance care planning

Current approaches to advance care planning originated in palliative care for people living with cancer, which typically has a relatively predictable disease trajectory (Murray et al 2005). In contrast, the norm in frailty is a more ambiguous trajectory characterised by an uncertain future, where any plans must necessarily be adaptable to future changes in circumstance.

A common response when individuals are faced with uncertainty is reluctance or inability to think and plan ahead, which can make advance care planning challenging. Such reluctance may be driven by the constant change and unpredictable cycles of illness and recovery that are common in frailty and multimorbidity (Murray et al 2024). Living with a body that is constantly changing impacts how a person copes within the day and between days (Aberg et al 2020) and can leave people struggling to find a "new normal" (Etkind et al 2019). If things may change on a day-by-day basis, planning weeks or months ahead can be particularly difficult. Uncertainty is therefore a barrier to decision making, including advance care planning.

This is reflected in low rates of advance care plans among individuals living with frailty (Hopkins et al 2020a; Sharp et al 2013). In part this may be because older people living with frailty do not necessarily see themselves as 'ill'. Frailty has been characterised as a persistent liminal state inside which feelings of uncertainty and loss accompany progressive physical and psychosocial changes and an increased awareness of finitude (Nicholson et al 2012). This absence of an overriding diagnosis can result in ambivalence towards advance care plans. People may see death and dying as part of life and may not wish to 'waste time' planning for an uncertain future (Combes 2021).

Advance care planning requires an ability to formulate care preferences for the future. People's preferences are neither static nor independent of their social world, but are shaped and constantly changed by illnesses, individual and social factors (Etkind et al 2019). Preferences can be influenced by a desire to "get back to normal", however the unpredictable and uncertain nature of illness can mean that this is unachievable (Etkind et al 2019), which could result in a reduced ability for some to express future preferences. If advance care planning is about "understanding and sharing personal values, life goals, and preferences" (Sudore et al 2017), then uncertainty, if it inhibits expression of preferences, will also inhibit advance care plans.

Advance care planning as a process for addressing uncertainty.

Although uncertainty is a barrier to advance care planning, paradoxically an important role of advance care planning is to enable people to live well when facing an uncertain future. Addressing uncertainty may take two forms depending on whether uncertainty is reducible, or if it cannot be resolved.

Where uncertainty is reducible, coordinated consistent communication as part of an advance care planning process can help to address some uncertainties about future care, particularly where these relate to practical or health service-related concerns. Whilst uncertainty in stroke palliative care was noted to be an overarching theme, some uncertainties could be reduced with cohesive communication and a consistent message (Connelly et al 2021). In contrast, where communication between patients, family and staff was difficult and fragmented in the noisy and chaotic environment of hospital settings, uncertainty can potentially be increased rather than decreased (Ananatapong et al 2022). Additionally, the variable and often vague nature of recalled

conversations with clinicians can leave people in a state of greater uncertainty (Bowers et al 2022; Bristowe et al 2015)

Many uncertainties cannot be reduced or eliminated in frailty, even if information provision is optimised. In these situations, a focus on supporting sense-making and reappraisal of uncertainty to enable people to plan may be more helpful. How irreducible uncertainty is appraised is vitally important, indeed Mishel argued that the first step as people respond to uncertainty is its appraisal either negatively as a threat, or positively as an opportunity (Mishel 1988). If seen as a threat, uncertainty can be paralysing and a barrier to advance care planning.

Yet it may be possible to support reappraisal of uncertainty so that even if it is not seen as an opportunity, it is considered less threatening, helping individuals live well day-to-day and to plan ahead. A key component of uncertainty management interventions such as the AMBER care bundle, is to elicit preferences and support a clear plan when uncertainty cannot be resolved (Carey et al 2015)

Living well day to day is a key priority of older people living with frailty (Combes et al 2021). People living with frailty often struggle to make sense of their situation and this is associated with reduced well-being (Lloyd et al, 2016). This maybe in part due to living in a state of persistent liminality and uncertainty (Nicholson et al, 2012). Through advance care planning conversations, clinicians can potentially help individuals to address this uncertainty and make more sense of their situation, which may in turn improve well-being.

Reconsidering the goals of advance care planning

How does addressing uncertainty fit with current goals in an advance care plan? Trials of advance care planning often focus on health service outcomes, such as how many participants have made a plan, or how many people are readmitted to hospital. For example, Garden et al (2022) found residents in care homes who participate in advance care planning were more likely to die in their care home but number of hospital admissions was not affected. Bavelaar et al (2023) similarly found an advance care planning support intervention resulted in no difference to the number of hospitalisations. Systematic reviews have found mixed evidence for advance care planning (Malhotra et al 2022a) leading some to call into question the value of advance care planning itself (Morrison et al 2021).

Others have argued that the main benefits of advance care planning for individuals living with frailty come from the process of having meaningful conversations. Such conversations may help to shape a jointly constructed life story, provide support through the experiences of living and dying with frailty and bereavement, and strengthen relationships (Hopkins et al, 2020b). Measuring the success of advance care planning interventions requires moving beyond numbers and towards an assessment of quality of implementation (Malhotra et al 2022b).

Helping individuals to live with and make sense of ongoing uncertainty may be an important element of meaningful advance care planning conversations that warrants further investigation. There is evidence that when staff were enabled to undertake such conversations, family caregivers experienced less uncertainty in decision-making, were more satisfied with the nursing home care for their relative, felt informed and clear about their values and experienced less decisional conflict (Bavelaar et al 2023). Conversely, within care homes multi-professional and relatives' involvement in advance care planning can be disjointed, and processes both internal and external to the care homes

can be poorly aligned, with a lack of clarity as to who has overall responsibility for co-ordination of the plan (Andrews and Myall 2023). This may create additional uncertainty, potentially increasing distress for all involved (Etkind et al 2022).

Conclusion

The relationship between uncertainty and advance care planning in frailty is clinically important and deserves further exploration. Uncertainty is an inescapable part of frailty and is primarily seen as a barrier to advance care plans. We suggest the relationship between uncertainty and advance care planning is more complex than this, and that making sense of illness experiences in the face of uncertainty might be a key role of advance care planning, especially for those living with frailty.

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