Reassessing advance care planning in the light of covid-19

Focus on creating a shared narrative not recording choices

Sarah A Hopkins geriatric medicine registrar, Roberta Lovick patient and carer representative, Louisa Polak visiting researcher, Ben Bowers doctoral student, Tessa Morgan doctoral student, Michael P Kelly senior visiting fellow, Stephen Barclay academic general practitioner

Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK

Compared with younger people, older people and those with frailty are more likely to die from acute infections, such as covid-19, and less likely to survive intensive care.1,2 This has prompted calls internationally for advance care planning in these vulnerable populations, focusing on documenting individuals’ preferences for resuscitation and hospital admission.3-6 We suggest that the benefits of advance care planning derive more from its process than from the plans it produces, and that recognising this is essential for provision of optimum care for patients and their families. Moreover, an overemphasis on achieving individual choice, the stated purpose of advance care plans, may paradoxically undermine good care.7

**Process versus product**

Covid-19 guidance on advance care planning has largely focused on its product: a plan recording an individual’s treatment preferences.3-5 Yet evidence suggests that some of the main benefits that frail patients and their loved ones experience from advance care planning are strengthened relationships with each other and their clinical teams, and support through the experiences of living and dying with frailty and bereavement.6-9 These benefits come largely from the conversations that constitute the planning process, particularly when these occur over time and include the patient’s family and loved ones.

Such conversations help to shape a jointly constructed life story that gives meaning and context to decisions and informs ongoing person centred care.10 The importance of this approach to older people is shown by their high prioritisation of not being a burden to family, a goal that the process of advance care planning can help to achieve.11 Thus individuals do not act alone; rather, they consider the priorities and concerns of those around them.1,3,10,12 This is reflected in a relational model of autonomy: decisions are situated within social contexts, and social relationships enhance autonomy.10

If we do not adequately appreciate the inherent value of compassionate, collaborative conversations with patients and their families, we risk reducing advance care planning to a tickbox exercise focused on a predetermined list of preferences, including place of care, level of treatment, and resuscitation status.7 This reductive “choosing” exercise prioritises clinically directed issues, paradoxically undermining autonomy by sideling other factors that may be more important to the person and those around them.12 It also misses opportunities to create shared meaning and strengthen relationships, both essential ingredients of person centred care.

The consequences of focusing on the plan rather than the process have already been witnessed in the UK pandemic. Some care home residents have been sent standardised letters asking them to specify their treatment preferences without having had individual conversations with their clinicians.13 This has caused understandable confusion and distress, raising concerns about denial of treatment.13 Rather than contributing to these concerns, good advance care planning should help to alleviate them.

How, then, should we approach advance care planning during the pandemic? Research has investigated the experiences and priorities of frail and older people in planning their care.7,8,11,14 However, few attempts have been made to collaborate with patients and their loved ones to design approaches to meet their needs.8 Thus translating evidence about patients’ priorities into best practice remains largely a matter of clinical expertise. Many frail people prioritise living day to day to day over future planning, and conversations might first need to explore how to adjust to the new circumstances of living with frailty during the pandemic, before they feel able to look to the future.8,14

We suggest that advance care planning should focus on encouraging people to voice their concerns and priorities, providing the information they want, and facilitating conversations between loved ones at this emotionally and logistically difficult time. For some, such conversations might sensitively enable an understanding of the possibility of dying in the near future and help to identify goals and priorities for treatment and care. This might result in people declining certain treatments or being gently told that some treatments would be medically inappropriate.
New challenges, new opportunities

While social distancing and remote consultations make advance care planning especially challenging, there are also potential opportunities. Rates of advance care planning with frail patients are low; having a “trigger” to initiate conversations is a key facilitator. Some may find the universal threat of covid-19 a more acceptable reason to discuss future care than a diagnosis of frailty, a label many find pejorative. 

Heightened public and professional interest provides an opportunity to establish a more nuanced, relational approach to choice, founded on co-creating shared narratives. This reflects existing best practice which recognises that advance care planning is an important facilitator of meaningful conversations, providing support through the experiences of living and dying with frailty. During and after the pandemic, policy and practice should focus less on advance care plans and more on the planning process.

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7 Pollock K, Wilson E. Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life. NIHR Journals Library, 2015.


13 Care home residents claim they are being asked to sign letters agreeing they won’t go to hospital if they get coronavirus. Daily Mail 2020 Apr 16. https://www.dailymail.co.uk/news/article-8226675/Care-home-residents-asked-sign-letters-agreeing-WONT-hospital-COVID-19.html


