Reassessing advance care planning in the light of covid-19.

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Reassessing advance care planning in the light of covid-19. Focus on co-creating a shared narrative to avoid reducing ACP to a tick-box exercise.

Compared to 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.\textsuperscript{1,2} This has prompted calls internationally for advance care planning (ACP) in these vulnerable populations, focussing on documenting individuals’ preferences for resuscitation and hospital admission.\textsuperscript{3,4} We suggest that the benefits of ACP derive more from its process than from the plans it produces and that recognition of this is essential for optimum care provision for patients and their families. Moreover, we argue that an over-emphasis on achieving individual choice, the stated purpose of ACP, may paradoxically undermine good care.\textsuperscript{5}

Process versus product

COVID-19 guidance has largely focused on the product of ACP: a plan recording an individual’s treatment preferences.\textsuperscript{3,4} Yet pre-COVID evidence suggests that some of the main benefits frail patients and their loved ones experience from ACP are strengthened relationships with each other and their clinical teams, and support through the experiences of living and dying with frailty, and bereavement.\textsuperscript{6,7,8,9} These benefits come largely from the conversations that constitute the ACP process, particularly where 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.\textsuperscript{10} The importance of this approach to ACP with older people is demonstrated by their high prioritisation of not being a burden to family, a goal that the process of ACP can help to achieve.\textsuperscript{11} Thus individuals do not act alone; rather, they consider the priorities and concerns of loved ones.\textsuperscript{5,10,12} This is reflected in a relational model of autonomy: decisions are situated within social contexts and social relationships enhance autonomy.\textsuperscript{10}

If we do not adequately appreciate the inherent value of compassionate, collaborative conversations with patients and their families, we risk reducing ACP to a tick-box exercise, focused on a pre-determined list of preferences including place of care, level of treatment, and resuscitation status.\textsuperscript{7} This reductive “choosing” exercise prioritises clinically-directed issues on the tick-list, paradoxically undermining autonomy by side-lining other issues that may be more important to the person and those around them.\textsuperscript{12} It also misses opportunities to create shared meaning and strengthen relationships, both essential ingredients of person-centred care.
The consequences of product-focused ACP have already been witnessed in the UK pandemic. Standardised letters have been sent to some care home residents, asking them to specify their treatment preferences, without prior individual conversations with their clinicians. Understandable distress and confusion have been caused.

How, then, should we approach ACP during the pandemic? Pre-COVID research has investigated the ACP experiences and priorities of frail and older people. However, few attempts have been made to collaborate with patients and their loved ones to co-design approaches to meet their needs. Thus translating evidence about patients’ priorities into best practice remains largely a matter of clinical expertise. Many frail people prioritise living day-to-day over future planning, and conversations might first need to explore how to achieve a “new normal” when living with frailty during the pandemic, before they feel able to look to the future. We suggest that ACP 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 ACP during COVID-19 especially challenging, there are also potential opportunities. Rates of ACP 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 ACP than a diagnosis of frailty, a label many find pejorative.

ACP and treatment escalation decisions have rarely been so prominent in the media, with concerns over denying treatments to frail individuals. Good ACP should help alleviate these fears. Conversely, a consumerist approach, which foregrounds individual autonomy and measures care quality by adherence to specific treatment preferences, risks undervaluing other components of good care and contributing to worries about treatment denial. 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 ACP is not an isolated and reductive tick-box exercise but rather an important facilitator of meaningful conversations, providing support through the experiences of living and dying with frailty.
and after the pandemic, policy and practice should focus less on the plans ACP produces and more on its process.

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