

Annex E

Advance care planning and medical decision making in ICU situations

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1. This paper examines ethical considerations when dealing with advance care planning and medical decision making in the ICU, where many patients lack capacity.
2. A lack of consistent terminology to describe advance decisions can cause confusion amongst healthcare providers when considering their legal impact. 'Advance care plans', 'advance statements' and 'advance decisions' are terms used interchangeably to describe decisions made by individuals and clinicians with little distinction on whether interventions are proposed by clinicians or declined by the individual.
3. In this paper, the writer will focus primarily on ethical considerations relating to decision making through advance care planning.
4. Advance care planning (ACP) is a process that supports adults at any age and stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care.¹ Regardless of the clinical scenario, ACP should be proactive and capable of being reviewed and adapted as an individual's condition changes.
5. ACP is a collaborative process involving patients, families, and healthcare providers. It may be the starting point for discussions on future medical treatments offered and decisions made and recorded in an Advance Directive. Indeed, an ACP may set a goal of making an Advance Directive. Conversely, an Advance Directive is a formal legal document directing healthcare decision making. It is acted upon when the person has lost the ability to make decisions for themselves.

¹ Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JAC, Korfage IJ, Ritchie CS, Kutner JS, Teno JM, Thomas J, McMahan RD, Heyland DK. *J Pain Symptom Manage.* 2017;53(5):821. Epub 2017 Jan 3.

Autonomy

6. ACP traditionally used an individualistic approach to autonomy, modelled on informed consent. The clinician provided relevant information and then stood back as the patient made decisions about their future. However, in recent years there has been increasing recognition that ACP should be treated as a process, as opposed to a decision that happens at a discrete point in time and is determined by the presence or absence of documentation.²
7. Johnson et al.³ observed that the notion that ACP is concerned primarily with the patient's right to self-determination through control over treatment choices at the end of life may misrepresent the way that these decisions are made and conflict with the deeper needs of patients, who experience ACP as a relational, emotional and social process. Nevertheless, despite encouragement toward a flexible and collaborative process, evidence of formal ACP related documentation is still expected in clinical practice.
8. Meyers⁴, argues that it is not sufficient to merely present an individual with an uncoerced choice, as with informed consent, when considering ACP.
9. This writer does not intend to comment in detail on informed consent; suffice to say, the legal position was clarified by the Supreme Court in *Montgomery v Lanarkshire Health Board*⁵, when the bench effectively applied the standard of the General Medical Council (GMC)⁶ at the relevant time to the facts of the case. The GMC had long advocated a collaborative process with healthcare providers tailoring the potential benefits and harms to each patient.
10. Indeed, during submissions on behalf of the GMC, Andrew Smith QC confirmed to the court that the expectation of the GMC was that a doctor has a professional and ethical duty to fully advise a patient of the options of treatment and the benefits of each option,

² Sudore RL and Fried T. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med* 2010; 153(4): 256–261.

³ Johnson S, Butow P, Kerridge I, et al. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology* 2016; 25(4): 362–386.

⁴ Meyers DT. Decentralizing autonomy: five faces of selfhood. In: Christman J and Anderson J (eds) *Autonomy and the challenges to liberalism: new essays*. Cambridge: Cambridge University Press, 2005, pp. 27–55.

⁵ [2015]UKSC 11

⁶ General Medical Council Good Medical Practice 22 April 2013

and it was then for the patient (not the doctor) to advise which option they wished to choose.

11. When considering the principles of autonomy and self-determination in clinical settings, this writer questions whether the pendulum swing from paternalism to self-determination can place an uncomfortable responsibility for healthcare decision-making on patients without appreciating the imbalance of power and knowledge between a doctor and their patients. Clinicians may unintentionally undermine patient autonomy by depriving individuals of professional guidance when making informed decisions, especially in critical care situations. Defensive medicine may further encourage the delegation of difficult decisions to patients and their families by clinicians hoping to circumvent criticism or avoid litigation.

Individualistic autonomy

12. Beauchamp⁷ defines personal autonomy as “self-rule free of controlling interferences by others.” However, this approach has been criticised in healthcare settings for failing to appreciate the importance of patients' social circumstances, including cultural identity and relationships. In some cases, it exaggerates patients' actual capacity for agency and self-direction, especially during periods of acute disease exacerbation⁸. Treatment preferences are likely to have been documented at a fixed point with limited understanding of severe illness and available treatment options. How individuals think they will react when confronted with severe illness compared to how they react may differ significantly.

Relational autonomy

13. Relational autonomy recognises that self-determination is defined and pursued in a social context that influences an individual's opportunity to express or develop autonomy⁹. Relational autonomy also recognises the right of an individual to refuse or accept treatment even if family or others oppose the decision, for example, a teenage minor accessing covid vaccination against their parents' wishes.

⁷ Beauchamp TL. Principlism in bioethics. In: Bermudez PS and Seoane JA (eds) Bioethical decision making and argumentation [International Library of Ethics, Law, and the New Medicine]. Cham: Springer, 2016, pp. 1–16.

⁸ Polzer JP and Power E. Neoliberal governance and health: duties, risks, and vulnerabilities. Montreal, QC, Canada: McGill-Queen's University Press, 2016.

⁹ McLeod C and Sherwin S. Relational autonomy, self-trust, and health care for patients who are oppressed. In: Mackenzie C and Stoljar N (eds) Relational autonomy: feminist perspectives on autonomy, agency and the social self. New York: Oxford University Press, 2000, pp. 259–279.

14. The role of social support and family influence in decision-making may be viewed with suspicion by healthcare providers and misconstrued as coercion, manipulation, or undue influence. However, social support can be a valuable tool in enhancing a patient's autonomy.
15. Relational autonomy acknowledges the role of social support when making challenging healthcare decisions. Cardiac failure or other neurological processes may limit a patient's ability to comprehend information. Similarly, pain and fatigue can severely impact a person's ability to recall information. Individuals who suffer from chronic illness often rely on social support through friends and family members to help them exercise autonomy, allowing for the fluctuating nature of autonomy in serious illness.
16. Current definitions of ACP emphasise the importance of relationships in the ACP process, including the potential for personal representatives, or a surrogate decision maker, to be appointed if patients can no longer make decisions for themselves, so their preferences and values can best be upheld¹⁰. If autonomy is considered a continuous, fluid process that occurs over time, using a relational understanding of autonomy may improve future decision making from both the patient and doctor's perspectives.

When should ACP be promoted?

17. When is the right moment? Should it be as people age or their health worsens? ACP interventions for severely ill hospitalised patients might be too late to be effective, and when undertaken clumsily, end of life discussions can cause additional emotional distress. A preferable situation is that all adults are encouraged to consider future treatment options based on their goals and values and review them regularly throughout their lives - thereby normalising the process of having such discussions and educating the public regarding future health matters. The flip side is the difficulty for individuals visualising life-threatening situations during periods of good health.
18. In a critical care setting, clinicians may unintentionally restrict autonomous decisions if they fail to provide individuals with opportunities to engage in decision-making. Critical

¹⁰ Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017; 18(9): e543–e551.

care patients and their families are particularly vulnerable due to the seriousness and urgency of the clinical situation. In addition, the intimidating environment of an ICU can severely limit options to engage in meaningful discussion.

19. The timing of ACP discussions plays an essential part in managing the expectations of patients and their families. Lothian Health Board recently adopted Treatment Escalation Plans (TEP), which involve discussions on appropriate care if a patient's condition deteriorates. The TEP explicitly documents treatment options available (as determined by clinicians) and what will happen in the event of deterioration. In addition, clinicians record resuscitation status. The process intends to promote honest discussions at an appropriate time. For example, discussions with patients with significant comorbidities might include the offer of a time-limited trial for treatment, such as admission to ICU for ventilation but not haemodialysis.
20. Clinicians can justify such an approach using clinical prediction models that assess prognosis but allow them more time to arrive at ethically justifiable decisions on further escalation or withdrawal of treatment based on a patient's circumstances. Additionally, patients and their families are involved and supported in reaching consensus, albeit the choices will inevitably be limited to a level of support determined by the treating clinicians.

Justice versus scarcity of resource

21. Healthcare is expensive, and intensive care medicine is particularly costly. No society can afford to treat its entire population with all possible therapies, irrespective of the outcome. Proportionality of treatment must play a role in medical decision-making in the ICU when balancing justice for patients against justice for society. Clinicians must weigh up the burden of intensive care treatment against the estimated chance of recovery. For example, considerations such as age, diagnosis, the severity of organ failure, comorbidities, frailty, and pre-admission condition are all relevant factors when considering the burdens of ICU survivorship (medical, social, psychological, and financial).
22. Age was a relevant selection criterion during the pandemic, when considering admission to ICU. The use of age as a selection criterion of scarcity may be justified when considering that older patients have already reached a mature age, which has given them fair equality of opportunity. However, an ICU admission might be more

appropriate for a fit and active 70-years-old patient when compared to a medically vulnerable 50-years-old patient.

23. Does an age selection criterion amount to age discrimination or simple triage principles applied in times of scarce resources? Age was heavily weighed as a risk factor for poor outcomes during the pandemic, but it cannot be justified to deny ICU admission to all patients above a certain age.
24. Is pure survival a realistic goal when considering resourcing in intensive care medicine? There must come a point when critical care is rationed, as the balance shifts from treatment delivering benefit to treatment causing harm. Nevertheless, ICU clinicians report external influences in medical decision making such as pressure from families, threats of litigation and ICU statistics as factors in over-treating patients.
25. Prognosis assists clinicians when withdrawing treatment by balancing benefits and harms against each other and determining futility. However, prognosis uncertainty is not uncommon.
26. Clinicians working in ICU, oncology, and care of the elderly should be skilled in addressing withdrawal of treatment and issues relating to end of life care and dying. Unfortunately, uncertainty regarding the legal status of advance decisions and whether clinicians have legal protection can discourage a proactive approach when balancing benefits and harms.
27. Confusing and complicated terminology, legislation, and bureaucracy impede opportunities to achieve the best outcomes for healthcare providers and their patients, as became apparent during the pandemic. Following concerns raised by legal practitioners and relatives in the early part of 2020, the Scottish Welfare Commission examined a 10% sample of all hospital to care home moves from March 2020 – 31 May 2020 to assess whether those moves complied with legislation. The findings were damning, showing that patients had been moved without the protection of legal authority by healthcare providers who misinterpreted legislation designed to protect the most vulnerable adults.
28. The Scottish Government has now published the terms of reference for the Public Inquiry into handling of the pandemic, chaired by Lady Poole. The Inquiry will focus on twelve key elements ranging from pandemic planning and the delivery of testing,

outbreak management and self-isolation to financial support and guidance to businesses. Of particular relevance to healthcare and ACP will be the pressure on the elderly to make DNACPR (do not attempt cardiopulmonary resuscitation) decisions.

29. Hospitals, GP practices and care homes may face additional legal scrutiny in civil claims, Fatal Accident Inquiries and potentially, health and safety prosecutions. While this might seem harsh for NHS employees who put themselves at risk to care for Covid 19 patients, proper legal scrutiny might compel lawmakers to provide a framework that clarifies advance care planning and medical decision making, ultimately benefiting patients.

Conclusion

30. The GMC¹¹ acknowledges that certain groups of patients experience inequalities in accessing healthcare services and in the standard of care provided. Today's multicultural societies require new skills from providers to learn and respect the diversity of patient values.¹²

31. With a scarcity of resourcing and increasing time pressures, it is unsurprising that medical decision making can be contentious. Forte et al¹³ suggest a bioethical framework where the first step discusses exclusively the disease, aiming only at accurate probabilistic predictions. Only then would the clinician learn about the patient's biography and values. Then considering evidence-based practice and patient's values, healthcare providers could determine which treatments to recommend before involving the patient and their family in ACP discussions.

32. One must never forget that the patient alone is subject to the burden of ICU treatment, which includes pain, delirium and an outcome that may have far-reaching consequences on their quality of life. ACP can promote early discussions and manage expectations between clinicians, patients and their loved ones on what success might look like when making advance decisions on future medical treatment and end of life wishes.

¹¹ General Medical Council Treatment and care towards the end of life; 1 July 2010

¹² Childress JF. The place of autonomy in bioethics. *Hast Cent Rep.* 1990;20(1):12–77.

¹³ Forte, D.N., Kawai, F. & Cohen, C. A bioethical framework to guide the decision-making process in the care of seriously ill patients. *BMC Med Ethics* 19, 78 (2018). <https://doi.org/10.1186/s12910-018-0317-y>