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Challenges in advance care planning: the interface between explicit instructional directives and palliative care

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Challenges in advance care planning: the interface between explicit instructional directives and palliative care

This case study highlights some important legal and ethical considerations related to advance care planning

A 71-year-old man with vascular risk factors including hypertension and hypercholesterolaemia lived at home with his wife and enjoyed reading, listening to music and discussing global issues. Immediately on disembarkation from a long flight, he experienced a sudden reduction in consciousness with accompanying right hemiplegia and neglect. He was diagnosed with a large left middle cerebral artery infarct and underwent thrombolysis. Following the procedure, he was haemodynamically unstable, with further investigation revealing massive pulmonary emboli. He was anticoagulated and his condition stabilised.

Over subsequent days, his hemiplegia improved, and it was felt that with time and ongoing therapy he would be able to stand independently and mobilise with assistance. Unfortunately, he remained severely globally dysphasic and this was considered unlikely to improve. He was unable to feed himself but was easily fed thickened fluids by nursing staff.

He had documented an advance care plan (ACP) 5 years before his stroke. His ACP stated that in the event of impairment rendering him “incapable of rational existence” he would not want to be kept alive via artificial means but rather be allowed to die free of pain and distress. About 3 months before his stroke, he updated his ACP to include an advance care directive (ACD) stating what mattered most to him, as well as his worries for the future. His greatest concern was that he might “linger on in a home, with unacceptable quality of life”. He stated that “acceptable quality of life has at its core the ability to understand one’s circumstances, to be able to communicate with other people, the ability to be mobile and not being reliant on others for the basics of life such as having to be washed, dressed and fed”. If he was not able to do these things, his wishes were that he be allowed to die as quickly and peacefully as possible.

His ACD specifically stated that if he was “in advanced stages of Alzheimer’s disease or other incurable, advanced dementing disease and if my appointed health care agent concludes after consultation with my primary health care provider that I am unable to make informed decisions about my health care, and I am unable to feed myself, continuing life would have no value for me”. In that situation, he directed that all life-

prolonging therapies should be withdrawn, including “the provision of nutrition and hydration whether provided artificially or medically or by hand or by assisted feeding”. The ACD was even more explicit about this as it included the directive that “if I am suffering from advanced dementia and appear willing to accept food and fluid by hand offered by assisted or hand feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth”.

When his lack of cognitive recovery was apparent, his wife, as his appointed medical treatment decision maker, was concerned that his wishes, as specified in the ACD, were not being honoured and queried whether he should continue to be fed by hand. Given the complexity of the situation, a palliative care consultation was sought, along with guidance from representatives of the hospital’s clinical ethics committee, including the Chief Medical Officer, legal counsel and representatives from involved clinical teams. Ultimately, the decision was made in close consultation with his wife to respect his ACD. His anticoagulation was ceased and food and fluid discontinued. He died 4 days later, about one month after his stroke.

Discussion

Our patient had a very clear, and as it transpired, remarkably prophetic ACD. The question as to whether his desire to refuse oral intake was something his treating teams were legally and ethically obligated to follow is worthy of further consideration.

The *Medical Treatment Planning and Decisions Act 2016* (Vic) came into effect in Victoria in March 2018.^{1,2} The Act seeks to provide a single framework to ensure that medical treatments align with an individual’s preferences in the event that they are unable to make decisions for themselves. The Act supports ACPs that can incorporate the creation of an ACD, as well as the appointment of a medical treatment decision maker to act as a surrogate decision maker should decision-making capacity be lost. An ACD can contain:

- *instructional directives*, which, if a person lacks decision making capacity, take effect as if the person had consented to or refused a specific medical treatment; and/or
- *values directives*, which are broader and can encompass desires, worries and acceptable outcomes.

Palliative care is defined in the Act to include medical treatments aimed to relieve suffering, as well as the reasonable provision of food and water, which is generally accepted to exclude artificial hydration or enteral feeding.³ To ensure that dying patients receive appropriate end-of-life care, the Act distinguishes palliative care from other medical treatments in two ways. First, it specifically prohibits making an instructional directive refusing palliative care. Any statement in an ACD relating to palliative care is given the status of a values directive, meaning the statement can guide but not mandate decisions. Second, the Act allows a clinician to provide palliative care even if this may not align with a patient’s wishes and/or the medical treatment decision maker does not agree.

Following his stroke, our patient was assessed to lack decision-making capacity in

relation to feeding. His apparent acceptance of supported feeding was therefore not considered an informed decision and thus his ACD and medical treatment decision maker provided the most appropriate guide to future health care management.

When considering whether his treating teams were legally obligated to follow his directives in relation to refusal of oral intake, the following would seem pertinent.

- His wishes in relation to oral input were very specific and labelled as instructional.

Although these statements were written in relation to deterioration in the setting of dementia, it would be difficult to argue that his wishes would not also apply in the context of his stroke with its resulting profound disability and dependence.

- Despite being designated instructional, the directives probably constituted a refusal of reasonable food and water and thus of palliative care. Under the Act, these can be values directives only, and while the team must take patient preferences into account, the directive would not be binding.

Although the Act does therefore appear to allow the treating team to override an individual's wish not to be fed, the law provides little assistance regarding the circumstances in which this would be ethically permissible. Published guidance for clinicians faced with this specific situation is very limited. Although there is literature discussing the clinical and ethico-legal issues associated with voluntarily stopping eating and drinking,⁴⁻⁸ this is typically in the context of someone whose decision-making capacity was intact at the time of commencement. There is conflict in the literature regarding the ethics and legality of ACDs that request the cessation of handfeeding in progressive dementia.^{5,9-11}

In our patient's case, although the directives were not legally binding, the health care team felt that the ACD, along with his wife's input, was the best guide to appropriate care provision, particularly when it became increasingly likely that he would not regain his previous cognitive abilities. Ultimately, regardless of the instructional or values-based designation of his written instructions, there was uniform agreement that he could not have made his wishes any clearer, and accordingly this was respected.

This case holds some important lessons for patients writing ACDs and for their health care providers. First, had our patient's directives been less detailed, or had he been admitted to an alternative health care setting with different ethical or religious values, support for his refusal of feeding may not have been regarded as acceptable practice. This might have led to mandated ongoing oral feeding, which may have led to significant conflict between the health service and our patient's wife, and considerable distress for all involved. Second, the case highlights the importance of adequate education for clinicians guiding, and the public completing, ACPs. Third, while the law provides some guidance to clinicians regarding the refusal of palliative care, including food and water, each case will require careful individual consideration and reflection on the different ethical issues at play. Finally, while every state and territory of Australia recognises ACDs in either legislation or case law, differences exist across jurisdictions in how they are recognised and interpreted. Importantly, although there is scope to give effect to an ACD created in another jurisdiction, had our patient's flight arrived in a different state than where he resided and completed his ACD, this would have added another layer of

legal complexity given that Australia does not have a unifying legal framework for the application and interpretation of ACDs.¹²

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