

Advanced Dementia and Advance Directives: Ethical Issues

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A 77 year-old male presents with advanced dementia and a GI bleed. He is anemic (with a hemoglobin of 95), but his family states that he has written advance directives specifying that he does not desire any invasive scoping of bodily orifices. In this situation, diagnosis and management depend on what type of anemia the patient presents with, and whether an upper or lower GI bleed is suspected, but will likely involve a colonoscopy or gastroscopy to discover the source of the bleeding.¹ Since this contradicts the patient's written directive, we are presented with a dilemma. I will examine some factors specific to this patient's situation, discuss the application of advance directives, and outline a management plan.

Patient Specifics

The patient's mental condition complicates decision-making in this case. Advanced dementia is defined as a "state of profound physical and cognitive disability that is the end result of a variety of neurodegenerative diseases, the most common of which is Alzheimer's disease."² The Global Deterioration Scale scores patients from 1 to 7, with 7 representing advanced dementia. Patients scoring with a 7 have speech limited to less than 5 words, are unable to recognize family members, are functionally dependent, unable to ambulate, and are incontinent.³ This discussion is significant

¹ Travic, A. C., and J. R. Saltzman. "Evaluation of Occult Gastrointestinal Bleeding." In *Uptodate*. Edited by D. S. Basow. (Waltham, MA: UpToDate, 2013).

² Mitchell, S. "Palliative Care of Patients with Advanced Dementia." In *Uptodate*. Edited by D. S. Basow. (Waltham, MA: UpToDate, 2013).

³ Mitchell, S. L., B. S. Black, M. Ersek, L. C. Hanson, S. C. Miller, G. A. Sachs, J. M. Teno, and R. S. Morrison. "Advanced Dementia: State of the Art and Priorities for the Next Decade." *Annals of Internal Medicine* 156, no. 1 (2012): 45-51.

because when we discuss agency and informed consent, a baseline level of mental competency is usually assumed.

The patient's age and prognosis are some other complicating factors in this case. Our patient is 77, and advanced dementia has a poor prognosis. In one study of patients with advanced dementia, 54.8% of the cohort died over 18 months.⁴ Complications such as pneumonia (probability of 41%), febrile episodes (44.5%), and eating problems (38.6%) are associated with increased mortality, and distressing symptoms like dyspnea (46.0%) and pain (39.1%) are commonplace.⁵

This patient's situation might be different than the one described above. However, clinical decision-making should be based on both the natural history of advanced dementia and the unique characteristics of this specific patient. The focus must be on the patient's best interests, and the negotiated goals of care (which will be described later).

Patient Relationships and the Advance Directive:

How are the patient's best interests inferred when the patient experiences significant cognitive degeneration? The Catholic Health Association of Canada outlines two fundamental values to consider in any type of healthcare: that every human person possesses inherent dignity and worth, and that human beings exist in an *interconnected*

⁴ Mitchell, S. L., J. M. Teno, D. K. Kiely, M. L. Shaffer, R. N. Jones, H. G. Prigerson, L. Volicer, J. L. Givens, and M. B. Hamel. "The Clinical Course of Advanced Dementia." *New England Journal of Medicine* 361, no. 16 (2009): 1529-1538.

⁵ Ibid.

web of relationships with others.⁶ These core values seem to be a reasonable place to begin the discussion of best interests.

Advance directives speak to both patient dignity and patient relationships. In this case, we know he wrote the directives approximately 4 years ago, and that he wishes to avoid invasive diagnostic procedures that involve the scoping of bodily orifices. It would be prudent to speak with the family in order to determine who the patient has appointed as proxy decision-maker (an individual with legal power to make decisions on behalf of the patient), ensure that they are aware of the directives, and to educate them about the patient's prognosis and current medical needs.

CMA policy outlines appropriate use of advance directives and states that they should be respected when available and applicable. It is not possible to honour advance directives in all cases; difficulties can arise when the directive is too specific (making it irrelevant in certain circumstances), or too general (which often fail to give any useful guidance to the physician).⁷ Ultimately, the patient has the right to accept or reject any treatment or procedure, even if medically indicated or potentially life-saving.^{8,9}

I would still want to find out the patient's reasons for writing the directives and how strongly he felt about them. It might also be prudent to consult with gastroenterology. Colonoscopies involve extensive preparation, and lower GI bleeds

⁶ Catholic Health Association of Canada. *Health Ethics Guide*. (Ottawa: Catholic Health Association of Canada, 2000): 14.

⁷ "Advance Directives for Resuscitation and Other Life-Saving Or Sustaining Measures." [cited 2013]. Available from <http://policybase.cma.ca/dbtw-wpd/PolicyPDF/PD92-02.pdf>.

⁸ Catholic Health Association of Canada, *Health Ethics Guide*, 15.

⁹ Province of Alberta. *Personal Directives Act*. (Edmonton, AB: Alberta Queen's Printer, 2000).

can be hard to treat. However, gastroscopies are less invasive, and some upper GI bleeds might be repaired with minimal difficulty. In any case, a proper risk-benefit analysis and different treatment options should be discussed with the proxy decision-maker.¹⁰

If the proxy still maintained the directives were to be followed, I think that honouring that choice, if not in conflict with professional judgement, ethical principles, or the law,¹¹ would be a reasonable course of action.

How to Proceed: Palliative Care and Dementia

The patient's age, prognosis, and his advance directive would cause me to consult with a palliative care specialist, or to access any other palliative care resources available in the community.

In essence, palliative care can be thought of as treating *that which we cannot cure*. It does not exclusively involve end-of-life care, although it does provide this service along with many others. Palliative care seeks to address the issues associated with chronic illness: medical management, physical symptoms like pain, psychological and social challenges, spiritual well-being, practical considerations like ADLs (activities of daily living), end-of-life care, and grieving.¹² Three aims of palliative care, succinctly put, are to treat all active issues, prevent new issues from developing, and foster the

¹⁰ Saltzman, J. R. "Approach to Acute Upper Gastrointestinal Bleeding in Adults." In *Uptodate*. Edited by D. S. Basow. (Waltham, MA.: UpToDate, 2013).

¹¹ *Personal Directives Act, 2000*.

¹² Canadian Hospice Palliative Care Association. *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. (Ottawa, ONT.: Canadian Hospice Palliative Care Association, 2013): 5.

opportunity for meaningful experience, self-actualization, and growth (personal and spiritual).¹³

The Canadian Hospice Palliative Care Association has thoroughly outlined the norms of practice and principles to be used when providing palliative care.¹⁴ The patient should first undergo a thorough medical and psychological assessment to characterize his medical issues, risks, and concerns. The family and proxy should be educated about the patient's condition, prognosis, and the nature of palliative care.

Care-planning for this patient is holistic, and involves the patient, proxy, and family. Alberta Health Services has published a matrix for determining goals of care (see appendix 1). Goals of care are negotiated by all involved parties. We might reasonably designate this patient into the M1 or M2 category, which involves medical care and interventions for cure or control of illness, but excludes the option of ICU care (either because the patient chooses not to accept ICU care, or would not benefit from ICU care).¹⁵ It is also important to distinguish the patient's *active* medical condition (his GI bleed) from his *underlying* medical condition (advanced dementia). His underlying medical condition is incurable, but we must determine if his *active* medical condition will reverse with treatment, or recover along with supportive care. I would also discuss the

¹³ CHPCA, Norms of Practice, 6.

¹⁴ Ibid., 12-17.

¹⁵ "Goals of Care Designation Order." [cited 2013]. Available from <http://www.albertahealthservices.ca/ps-1023351-103547-acp-gcd-order.pdf>

possibility of transfusion if the patient's condition deteriorates, and attempt to obtain consent early enough to allow requisite blood-testing to be performed.¹⁶

Care planning considers the whole person, and not just medical management. Thus, we also need to consider the patient's dignity and relationships, and seek to promote flourishing and self-actualization whenever possible. In cases of advanced dementia, self-actualization might be realistically be limited to ensuring the patient's active and underlying medical conditions are managed, that he is not in pain, has adequate human contact, is treated with dignity, and is not suffering from distressing symptoms.

Once a care plan is decided, it should be implemented in a timely and competent fashion, and assessments of efficacy should be carried out. This involves gauging the patient's and proxy's understanding, stress level, satisfaction, concerns, and addressing any questions.¹⁷

In addition to the discussion on palliative care, it is important to discuss preparation for the end of life with the patient's proxy. When the time comes, issues such as life-closure, legacy creation, preparation for expected death, and other pragmatic concerns will need to be dealt with in a sensitive and comprehensive manner.¹⁸

¹⁶ Callum, J. L., P. H. Pinkerton, K. Karktoui, J. M. Pendergrast, N. Robitaille, A. T. Tinmouth, and K. E. Webert. *Bloody Easy: Blood Transfusions, Blood Alternatives, and Transfusion Reactions*. 3 ed. (Ontario: Ontario Regional Blood Coordinating Network, 2011): 14.

¹⁷ CHPCA, Norms of Practice, 17.

¹⁸ *Ibid.*, 5.

Conclusion

This patient will require a physician who understands the nuances of geriatric medicine, palliative care, and the ethical issues surrounding advance directives. By keeping the *whole* patient in mind, the healthcare team and the family can work together to ensure that the patient receives the best possible care.

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Goals of Care Designation Order

Physician to initial in the box beside the chosen designation (Please choose only ONE) ↓			
R Medical Care and Interventions, including Resuscitation followed by Intensive Care Unit		R1	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care and resuscitation.
		R2	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care and intubation, but excluding chest compression.
		R3	Patient is expected to benefit from and is accepting of any appropriate investigations/ interventions that can be offered including the option of ICU care, but excluding intubation and chest compression.
M Medical Care and Interventions, excluding Resuscitation		M1	Goals of Care and interventions are for cure or control of illness, excluding the option of ICU care. For non-hospital patients, transfer to an Acute Care facility is considered if required for diagnosis and treatment.
		M2	Goals of Care and interventions are for cure or control of illness, excluding the option of ICU care. For non-hospital patients, transfer to an Acute Care facility or surgical intervention, are not generally undertaken for an acute deterioration but may be considered in special circumstances to better understand or control symptoms.
C Medical Care and Interventions, focused on Comfort		C1	Goals of Care and interventions are for maximal symptom control and maintenance of function without cure or control of underlying condition. Transfer may be undertaken in order to better understand or control symptoms. Surgery may be undertaken in special circumstances to better understand or control symptoms.
		C2	Goals of Care and interventions are for physical, psychological and spiritual preparation for imminent death (usually within hours or days). Maximal efforts directed at compassionate symptom control. Transfer is usually not undertaken.
<div style="text-align: right; margin-right: 100px;">(yyyy/mon/dd)</div> <hr/> Physician (Print Name) _____ Signature _____ Date _____			
<hr/> Current Location of Care (name the specific facility/service/office) _____			