

Advance Directives and the Problem of Informed Consent

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ABSTRACT

Advance directives in Canada are instructions made by capable adults that pertain to future healthcare treatment choices at a time of incapacity. My experience as an ethicist working in an Ontario long-term care facility that provides medical treatment to patients with Alzheimer's Dementia portrays a range of important ethical concerns that arise out of the use of advance directives, at least in terms of their current use. In this article I present a particular case and identify and analyze one of the more prominent ethical challenges that exist. My conclusion is that advance directives in Ontario do not meet the criteria for autonomous decision-making in the sense of informed consent. They may have initially been conceptualized as cohering to the standard of informed consent (and thus to the traditional principle of autonomy), but in reality, generally they do not. This point is well evidenced in the forthcoming case of Mr. Black.

Key Words: advance directives; dementia.

Introduction:

I work as an ethicist in a long-term geriatric facility in Ontario where many patients with a diagnosis of progressive dementia reside. Generally speaking, Alzheimer's, the most common type, is often regarded as a fate worse than death and depicted as a disease that robs persons of their selves. Many fear that, as a result of technological advances, they will be kept alive much longer than they would like to be, suffering from the indignities of old age and dementia. They worry that the protective instincts of medical professionals or sheer bureaucratic inertia might result in prolonging their lives under conditions they consider hellish from their current perspectives. Or perhaps their loved ones or legal guardians would be not so well intentioned and would make decisions according to their own best interests and not according to those of their relatives with dementia.

This is where the idea of an *advance directive* can become very alluring.¹ It is often seen as the answer to one of our biggest worries - that we will have no control over our lives when we are old, sick, demented and suffering miserably. The biggest nightmare seems to be that we will have lost the right to say "no" to life-sustaining treatment. This grave concern, and sometimes an

associated one that we will become a burden to our children in our old age motivate people to complete an advance directive. There are a number of other potential benefits from creating an advance directive as well. Some people might feel gratified to think that they have relieved their loved ones from making difficult decisions on their behalf. Their loved ones may share this relief as well as experience a sense of comfort believing they have honoured their loved ones' end of life wishes. Having an advance directive might decrease disputes amongst family members, as well as between healthcare team members who have differing opinions amongst themselves and/or with family members regarding medical treatment decision-making.²

According to Canadian common law capable adults are allowed to provide instructions about their health care choices during a time of future incapacity. These directives might include preferences about treatment wishes regarding acceptance or refusal under certain situations.³ In Ontario, capable adults may also appoint an individual (or individuals) to speak on behalf of them at a time of future incapacity. These designated persons are called substitute decision-makers (SDMs), also known as *proxies*.⁴

Many people verbally express their wishes to their loved ones. A smaller number put them in writing. As a result of some recent landmark cases (where there was a great deal of conflict ensuing about whether to withdraw life-sustaining treatment from people in vegetative states), there has been a rapid increase in people completing their advance directives. Basically its future use is mainly for SDMs to help guide medical decision-making. When you write an advance directive you are (allegedly) projecting your medical treatment wishes into the future. This document will speak for you through the voices of your SDMs if you are unable to do so yourself.

The statements in directives regarding future treatment wishes are often framed in general terms. Occasionally more specific details are given regarding the conditions that should be in place in order for a specific treatment wish to be complied with.⁵ The documents are often downloaded from legal websites and there may not be a great deal of thought put into the writing of them. Wishes might be impulsively scribbled onto a cocktail napkin, or more thoroughly contemplated and formally documented. Sometimes lawyers are involved and offer additional input as far as benefits and consequences of writing a directive goes. Sometimes loved ones participate in the process. The directive may be updated, or forgotten about.

The Case of Mr. Black

Five years ago, at the age of seventy-five, Mr. Black, a retired defense lawyer, married and father of three adult children, began to experience short-term memory lapses explained by his physician as due to normal aging. As an attorney, he knew something about the merit of advance directives. Frightened by the future prospect of a potential full-blown dementia (he had witnessed his best friend's physical and mental demise due to dementia) he spent a few days considering what he should write in his own advance directive. He had been primed by his lawyer to think about his current values and interests and to ensure he took them into consideration when he wrote his living will. Mr. Black completed the advance directive form, stating that if he could no longer enjoy the kinds of activities he found pleasurable, such as traveling with his wife, playing golf, dining at fine restaurants or engaging in debates with his adult children, he would wish to receive no treatment except pain treatment, if diagnosed with an incurable disease. He stated that living under those conditions would be unbearable for him.

Currently, Mr. Black is an eighty year-old gentleman in a long-term nursing home in rural Ontario. He has moderate to severe stage Alzheimer's Dementia. He spends most of the day sleeping. Mr. Black does not speak, has trouble swallowing due to reflex impairment, and is fed pureed foods. His physician is concerned about his decreasing ability to swallow. Given Mr. Black's inability to provide informed consent, the physician turned to Mr. Black's wife who was his substitute decision-maker.⁶ He informed her that she will need to consider the option of having a feeding tube inserted, since Mr. Black is unable to intake enough nutrition to maintain his daily nutritional needs.

The doctor reviews the potential benefits, risks and consequences. In particular, he stresses the potential adverse consequences of having a feeding tube in great detail. These possible consequences include a stomach rupture, with resultant bleeding, recurrent aspirations, heart failure as well as infection at the insertion site. Mrs. Black reminds everyone that her husband has an advance directive and a copy of it is in his medical chart. It stipulates what his wishes would be at a later point in time, if not competent to express himself. The doctor reads the advance directive aloud. There is unanimous agreement that the situation Mr. Black described in his advance directive seems to match the current situation. Since he is not able to express competent wishes at this time, nor has he been able to do so for a long time, the advance directive is referred to as it represents his most recent capable wishes. In line with what he had written, everyone is in agreement that he should not receive any treatment for his pneumonia, with the understanding that his death will likely occur in a few days. He will be provided with comfort measures only, including continued pain medication. Mr. Black dies in his sleep four days later with his family at his bedside. Professional team members and family members feel that they have done the 'right thing' by allowing him to die, in accordance with his advance directive.

Ethical Issues and Discussion

Does the advance directive meet the minimum standard for informed consent?

The Ontario legal requirements for informed consent are a

minimum standard.⁷ The legal requirements include being able to understand the information that is provided, including risks and benefits; being able to appreciate the consequences of accepting or refusing the medical treatment; and being able to make choices voluntarily. Even a *prima facie* straightforward case like Mr. Black's shows us that these requirements are not equal to the subtleties and complexities of situations in which consent becomes an issue. I propose augmenting the requirements in the following way: a person writing an advance directive must also understand and appreciate the risks and benefits of having an advance directive versus not having one. This, in turn, would require being informed about other legal standards and procedures that come into play in the absence of an advance directive. We are not only talking about understanding the information regarding treatment wishes and appreciating their consequences. We also need to understand the information pertinent to an advance directive in general, including one's own specifically.⁸ Each of these elements, crucial to making an informed decision about an advance directive, is both practically and conceptually fraught with problems, yet I have never seen practical or conceptual clarification explained for people contemplating an advance directive. These conditions are particularly hard to meet, simply because so little information is available on the topic. As a professional working in the field, I think it seriously undermines the moral and possibly legal authority of advance directives if the consequences of having one are not understood.

Did Mr. Black meet the requirements of informed consent when he wrote his advance directive? Probably not; probably, nobody could. To have done so would mean that he understood he could become incapacitated to the point where he would be unable to experience the pleasures he enjoyed in interacting with his spouse and adult children. There is no definition provided in Ontario's *Consent to Treatment Act* of the term "understand", but generally it seems to mean having the rational ability to grasp the concepts involved.⁹ In theory, Mr. Black would need to be able to understand the various scenarios. He would also need to be able to "appreciate" the consequences of what he was requesting. Again, there is no definition of "appreciation" in the relevant legislation in Ontario. The usual understanding of "appreciation" is that one must be able to understand what it means for a specific scenario to be applied to oneself. Sometimes it is termed *emotional understanding*.

So, at the time he is writing his advance directive, Mr. Black needs to be able to imagine himself as incapacitated and quite "otherwise" to how he is currently. Furthermore, he needs to be able to predict how he will experience himself in the context of his life as someone incapacitated. The challenging, perhaps impossible, task he faces is to make an informed decision *now* - in the context of being competent and having the life he has now, the values, beliefs, wishes and dreams as applicable to him currently - about his *future* self in a very different context as a very ill dementia patient. Mr. Black has to be able to imagine what that future life would be like for him and what his subjective experience of it would be, including what it would "feel like" for him. And on the basis of this imagining, he also has to make predictions *now* about what kind of medical treatment he would *subsequently* want to refuse or accept.

An advance directive written with contemplation of a dementia diagnosis in the future requires vastly greater imaginative prowess than do most other kinds of decisions that we tend to make. I

doubt we are capable of the task. To complicate matters further, I have rarely (if ever) heard of any advance directive that was written with any input from a medical practitioner. In order to understand the information pertaining to refusal or acceptance of any medical treatment, let alone be able to appreciate the consequences, there would need to be relevant and sufficient medical information given to the person to ponder. *This is rarely done.*

However, if we assume for the moment that Mr. Black would in fact receive some relevant medical information about a future scenario, it is probable that he would be able to understand it, although the amount of information would always be incomplete because nobody could anticipate the fullness of every possible scenario. We cannot know now what advances in medical research and technology will be available in the future. Furthermore, I think that regardless of how imaginative Mr. Black's mind might be, being able to appreciate himself as being quite different than he is currently is a very tall order. Of course I cannot prove this. However, I think we have evidence in general to the contrary, mainly owing to the fact that our beliefs and values can indeed shift in unforeseen and surprising ways when we experience significant life changes. Research demonstrates that we are in fact poor predictors of what will matter to us and what wishes and values we will hold dear in such a situation.¹⁰ Reliably exercising this personal and moral imagination would require answering some clearly vexing questions. What if I am so different in the future that I no longer hold the same values or wishes? What if I change my mind and cannot competently express this change of mind? What if I am able to express myself, but others think I am incompetent so they do not place much value on what I am saying? Will I be a stranger to my past self?

The difficulty in answering these questions about the future is underscored by the reasonable suspicion that we do not always know ourselves so well even in the present. Currently, as long as we are considered to be competent, we are allowed to change our minds, about most things anyway. If we are considered incompetent in the future, we will no be allowed to do so, at least from a legal point of view. If these concerns, which constitute some of the relevant consequences of having an advance directive, are not considered by us, let alone *appreciated*, how could it be argued that there was informed consent? I doubt very much that most people in the midst of writing an advance directive are even alerted to the existence of these kinds of limitations.

Furthermore, we cannot know if the level of appreciation that Mr. Black experienced met suitable standards because we do not have any objective criteria of measurement (recall that the Ontario *Consent to Treatment Act* does not even provide a definition of "appreciation"). This leaves us to glean the extent of Mr. Black's grasp of his advance directive from fragmentary and indirect evidence. Mr. Black did witness the demise of a loved one in a similar condition. Perhaps he had some personal experience with competency issues in his own past. We can hardly guess with any confidence. These kinds of experiences might add some weight to an "appreciation score" so to speak, though perhaps only to the "understanding" part. In addition to the problem of not knowing how to measure these "abilities" of imagination and prediction, there is, as mentioned, the additional problem of now knowing what criteria the "assessor" is using, or if there even is such a person who is guiding the author of the directive. Perhaps the culture

of dementia will in the future itself have changed significantly as well, with people not fearing the disease as much. Who knows? Certainly we do not know this currently. Advance directives are fraught with such unknowns, rendering the question of informed consent a deeply problematic one.

When we are of sound enough mind to consider future decision-making scenarios, at a time when we are no longer able to express a competent treatment decision, we are deeply influenced not only by what we see when we observe people with dementia, but by how our society depicts the experience and meaning of such an illness. There already exist important differences in the way different socio-cultural groups view and respond to Alzheimer's disease.¹¹

Currently the most dominant North American understanding of the meaning of Alzheimer's disease is that it is a neurological illness entailing "loss of personhood" or self, largely due to memory impairment. This definition is intertwined with other notions such as diminished competence, questionable ability to consent to medical treatments and negative personality changes. If Mr. Black entertains thoughts about how his life might be were he to develop Alzheimer's Dementia, he will likely view that disease in the negative light in which it is usually depicted. Will he also entertain thoughts that the current stereotypes of this disease might change over time? Will Mr. Black consider that by the time he could be diagnosed, he might consider this diagnosis less or more ghastly than he does now?

When Mr. Black wrote his advance directive, who guided him? Aside from some minimal advice from his lawyer, who assumed that because of Mr. Black's legal background he was already somewhat informed about advance directives, Mr. Black received no professional advice or support to complete his advance directive. We might assume that the lawyer who signed off for Mr. Black was satisfied, but we do not know if he provided Mr. Black with even the minimum standard of information required (whatever that might be), or a thoughtful enough *process* to ensure that Mr. Black could satisfy the requirements of an autonomous and informed decision. And yet, astonishingly, Mr. Black's efforts went well beyond what is actually required for an advance directive to be official. An advance directive does not require that a lawyer support or inform the process. Mr. Black could have hurriedly scribbled a few lines on an airplane dinner napkin and that would have qualified as an advance directive. Or, he may have downloaded a directive from the internet and filled it out hurriedly, perhaps after downing a few too many beers, and nobody would have known the difference.

Mr. Black was a practicing attorney for many years, so chances are he was aware of the legal status and benefits and consequences/limitations of a living will in general, probably more so than the average person would be. Nonetheless, we do not know if Mr. Black seriously considered all the risks and benefits of having an advance directive and was really able to appreciate them. As well, being a lawyer likely has no bearing on how skilled he might be in the areas of imagination and prediction. In fact, it is possible that as a lawyer who appreciates intellectual debates, it might have been harder for him to imagine himself as cognitively incapacitated. As well, there was no known concern about his competence level at the time. Mr. Black's immediate family believed that his advance directive was well thought out and not an impulsive undertaking, which in their minds gave them greater confidence in believing

it represented “who he was” and “what he really wanted.” At no point did any team or family member ever raise any concerns or questions about the legitimacy of his advance directive. The integrity of his advance directive seemed to be beyond question for them. This is not in the least bit unusual. Rarely does anyone raise this kind of question. Having an advance directive is still a fairly rare event and often the knee-jerk response is to be grateful that one even exists. Usually, there is no event that would result in someone suggesting such a review of the advance directive’s legitimacy. The general attitude toward advance directives in the medical care professions is positive and little attention has been paid to any cautionary tales, so most people would not think to question their usefulness. The preparation process of an advance directive can be severely lacking and yet the directive is often assumed by those charged with applying it to be not only valid, but highly valued.

It should be obvious by now that there are reasons to doubt the soundness of the very notion of an advance directive. Let us say that Mr. Black knew enough to consider that sometimes people with dementia might have a change of heart, or might no longer perceive Alzheimer’s to be such a terrible thing. In fact, suppose that he himself had witnessed some people in this exact situation. Or, let us assume that he knew that his predictive ability was somewhat faulty. Would this knowledge add credibility to his advance directive? Potentially it could, particularly if he were to cite this concern and suggest how the substitute decision-maker might respond to any caution specifically noted in his directive.

Lurking in the background of these specific issues with Mr. Black is a crucial and more general question:

Are the decisions we make in the form of an advance directive (based on precedent autonomy) in the event of future “incapacity” significantly different from the more usual decisions we make?

The short answer is yes.

One difference has to do with the amount of time that elapses between when the decision is made and when it is to be carried out. The other has to do with the degenerative nature of dementia and the subsequent changes that occur in the person. The specific problems that arise are generally associated with one or both of these factors.

I think it is fair to assume that as more time goes by there may be more opportunities for unanticipated events to intrude. In the case of the advance directive, once an individual is incapacitated and can no longer change these instructions, it could become increasingly misrepresentative and misleading. For example, perhaps Mr. Black might even enjoy the kinds of experiences he could have when demented. Likely, he did not know or appreciate that social/emotional memories might linger into even the most advanced stages of dementia, and that he would reap great rewards from having his wife sit at his bedside daily. Perhaps, shortly after his last pneumonia, there would be a cure for dementia. In Mr. Black’s case, however, his advance directive was not written decades before, so chances are it was more relevant than if it had been written years before.¹²

In summary, then, there are two major problems with the responsible implementation of advance directives: irreversibility of decision and predictive difficulties.

Plausibly, it would be prudent to assume that irreversible decisions ought to be made with particular certainty. But how can we increase certainty given that, by definition, the kind of future circumstances relevant to informed advance directives remain largely unknown, unpredictable, and impossible to appreciate?

Of course, many types of decisions that we make also involve imagining ourselves to be in situations not easily imaginable, and are also made without a great deal of certainty. The decision to become parents is a prime example. It is not uncommon for new parents to claim that no amount of information or imagination sufficed as ample preparation. “You have to experience it to know it” is a sentiment expressed fairly regularly by new parents. As already stated, research supports the view that we are poor predictors of how we will experience ourselves in radically different situations. Perhaps our values might radically change and, so too, our ideas about what constitutes a good life. Many able-bodied persons imagine they would never want to live if paralyzed and wheel-chair bound. Yet, when faced with that situation, many do not wish to have their lives ended. Not all adjust well, but many report that their quality of life is at least satisfactory.

Indeed, there are similarities between advance directive decisions and the more common types of everyday decisions. However, a living will that addresses future dementia has additional limitations. Persons need to be able to imagine both physical and cognitive changes, including memory impairment. Some people worry that they will “no longer be the same person” and may not experience themselves to be “them”. Their transformation might be so drastic as to render previous considerations of the future life to be nothing more than chance guesses.

Let us remember that once someone is deemed incompetent, there can in practice be no effective changing of one’s mind. Through writing a living will, Mr. Black is binding himself in the future to what he presently decides about his future self. Paradoxically, what constitutes an act of freedom to make a choice now for oneself could later also be experienced as imprisonment. In practical terms, the original Mr. Black cannot change his mind after he is deemed incompetent, should he wish to reverse his earlier decision to refuse treatment. Perhaps post-dementia he does not really care that he can no longer energetically debate with his children. Maybe he has had enough of travelling and prefers to spend most days resting in bed. And perhaps he would want to receive medical treatment even if still he cared about debates and travel. Unfortunately, once judged incompetent, Mr. Black cannot confirm his earlier choices, nor can he refute them.¹³

Here we have the crucial distinction between advance directive decisions and the many other kinds of decisions we make that also cannot be “undone” or reversed. While we cannot travel backward in time and change the past, outside of our imagination, we can still decide to do something in reaction to a past decision we currently wish we had not made, if we are still deemed competent. We can alter the future to some extent, provided our autonomy is intact. For example, while we cannot reverse the decision to bear a child after the child is born, we can place the child for adoption or

surrender the child to a children's welfare agency. There are usually options we can take to continue to exert some control in our life. But with an advance directive aimed at refusal of life-sustaining treatment, there is no further action of self-determination after this one.

Concluding Thoughts

The case of Mr. Black did not raise any particular ethical issues for either the family members or the healthcare team in terms of applicability of his advance directive. It appeared to be quite straightforward. Nobody raised any questions or concerns about predictability, irreversibility of decision, or issues related to informed consent. There was consensus amongst all the stakeholders involved that the conditions stated in his advance directive matched his current circumstances, thus triggering the need to comply with the wishes stated in his directive.

Generally, as an ethicist I am called upon when there is lack of agreement amongst either the family or healthcare team members (or between both groups) about interpretation of the directive. Less often, concerns about predictability and issues related to informed consent are raised. Nonetheless, everyone involved in the case of Mr. Black felt that the "right" action was taken when the advance directive was followed. Perhaps they are correct. However, if they are, surely it cannot be based upon the principle of precedent autonomy or its practical application, informed consent, foundational to the conceptualization of the advance directive in the first place.

Endnotes

1. Advance directive is also known as a *living will* or *directive*.
2. Judith A. Wahl, *Options for Advance Care Planning* (Ontario: Advocacy Centre for the Elderly, updated February 2009).
3. Currently in Ontario directive requests to refuse or withdraw treatment carry more legal weight than do requests for treatment.
4. Many people designate an SDM to speak on their behalf, regardless of whether or not they have an advance directive. The legal term for such a person is *Power of Attorney*. If there is no legal power of attorney, then there is hierarchical ranking of persons from which one is selected, eligible to fulfill that role. The designation of SDM is used in these circumstances. However, for simplicity sake, I will use the term SDM to refer as well to the power of attorney.
5. The term *treatment wishes* is used both to denote treatments the author wishes to receive as well as treatments the author wishes to refuse in the future.
6. Even when asked simple questions requiring a 'yes' or 'no' response, there is no discernable indication that Mr. Black understands, nor is he able to respond in a meaningful way.
7. The attainment of "fully" informed consent is an ideal which cannot be achieved, but nonetheless should be strived for. As the late Benjamin Freedman said, "There is no end to 'fully informing' patients". See Benjamin Freeman, "Chapter 6: Informed Consent and the Competent Patient," in *Readings in Biomedical Ethics: a Canadian Focus*, 2nd ed., edited by Eike-Henner W. Kluge (Scarborough: Prentice Hall, 1999): 71. We should, I add, try to ensure *everyone* is "sufficiently informed" though there are of course differing opinions on what exactly that means.
8. For example, in some Canadian provinces, including Ontario, a substitute decision-maker is the person responsible for applying/interpreting the terms of the directive, not the physician.
9. However, there is a requirement that the treatment provider who is requesting consent describe the treatment in ways that a *reasonable* person would be able to understand (emphasis added). I am not sure at all I would be able to even begin to know how to define a "reasonable" person for this context.
10. Angus Dawson, "Advance Directives," *General Practice and Ethics*, ed. Christopher Dowrich and Lucy Frith (London: Rutledge, 1999) 130-171; Christopher James Ryan, "Betting your life: an argument against certain advance directives," *Journal of Medical Ethics* 22, no. 6 (1996): 96-99.
11. See M.B. Holstein, "Ethics and Alzheimer's disease: widening the lens," *Journal of Clinical Ethics* 9, no. 1 (1998): 13-22.
12. However, while the increasing passage of time does allow for more unanticipated events to occur, there could be examples where the passage of more time could work to one's benefit. For example, because we cannot predict how someone with dementia might respond, it is equally possible that someone might respond in a way that coheres with what was anticipated in the advance directive. So, in this context passage of time would not be the significant factor, given the randomness of chance. In general, however, people do not radically transform themselves within a very short time period. In this sense the passage of time would be more relevant. Also, it is probably more likely that significant medical advances will occur over the longer rather than shorter haul, rendering the advance directive less informed than it would be if written closer to the time of when it would be enacted, especially if news of upcoming advances was made public.
13. In fact, DeGrazia asks if one can neither confirm nor refute an earlier choice, to what extent is it actually an "earlier" choice rather than a "current" one? One could thus argue that there is no precedent autonomy on that basis. One needs a current decision to differentiate it from a former decision, or vice versa. See David DeGrazia, "Advance Directives, Dementia, and 'The Someone Else Problem,'" *Bioethics* 13, no. 5 (1999): 373-391.

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