



Trying to Gain Control over an Uncontrollable Event: Reflection on Completing an Advance Directive

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Abstract

Even though the timing and possible causes of death cannot be controlled, medical advances have allowed patients to live longer, providing the opportunity for patients and their families to make certain end-of-life (EOL) care decisions. Advance directives were implemented to try to gain control of an uncontrollable event and prevent disputes by outlining specific wishes of the patient. Even though specific stipulations are outlined in an AD, their ability to control EOL care and decisions is limited.

Keywords: End-of-life care; Advanced care planning; Advanced directive; Death and dying; bioethics

Abbreviations: EOL: End-of-Life; AD: Advance Directive; ACP: Advance Care Planning

Introduction

There are problems associated with completing an AD (if they are even completed at all), such as the inability to predict specific medical illnesses and conflicts of interest among patients, families, and doctors. Here, I reflect on my personal experiences completing an advance directive from the University of Toronto Joint Centre for Bioethics, which includes instructional and proxy directives. It is evident that there are many factors to consider that one doesn't acknowledge until one partakes in this insightful process. Religious beliefs, organ donations, proxy selection, and other considerations like family relationships or dynamics should be taken into account when discussing advance care planning, compelling philosophers to better understand human personal values and beliefs, which might try to further answer, in a broader sense, controversial discussions about the definition and determination of death.

Even though the timing and possible causes of death cannot be controlled, medical advances have allowed patients to live longer, providing the opportunity for patients and their families to make certain end-of-life (EOL) care decisions. Stipulations regarding EOL health and personal care can be specified in an advance care planning (ACP) document, called an advance directive (AD), which aims to make decisions easier for the decision-maker(s) termed proxy(ies) by outlining the beliefs,

values, and wishes of the patient when medical problems arise [1,2].

Even though specific stipulations are outlined in an AD, their ability to control EOL care and decisions is limited. There are problems associated with completing an AD (if they are even completed at all), such as the inability to predict specific medical illnesses and conflicts of interest among patients, families, and doctors. These problems are only apparent after one completes an AD him- or her-self; only then do the multitude of considerations present in and the complexity of the AD process become apparent.

Here, I reflect on my personal experiences completing an advance directive from the University of Toronto Joint Centre for Bioethics, which includes instructional and proxy directives. I will explore the following topics, discussing my own experiences as well as providing support from published research and lectures: religion, organ donation, and proxy or family conflicts of interest. I conclude with a discussion of further problems associated with AD and offer possible suggestions to better ACP in the future.

I first want to start off with some general comments about the experience completing an advance directive. When I first sat down to complete the AD from the University of Toronto

Joint Centre for Bioethics, I was sorely under the impression that the process would be easy. Just filling out the initial proxy information on the first page created, for me, a whole slew of thoughts, and I immediately realized why completing an AD can be difficult. Questions of proxy values aligning with your values and the potential for proxy disagreements immediately came to mind. When prompted to fill out which particular proxies I wanted to make health or personal care decisions and if I wanted my wishes to be followed exactly or give leeway, I paused. It was extremely challenging to think about what I really wanted for the end of my life (especially since it is your own life and not someone else's).

I felt a certain vulnerability and was even hesitant about the finality of what I was writing specifically about being put on a ventilator in the case of a mild stroke, for example, or how I wanted my nutrition and hygiene handled. To me, this information was very personal and really detailed, and I was nervous that maybe these directions would not be followed or that they might be too outdated for future use. When completing the AD, I tried to be specific enough without being too specific because, to me, I understood that, realistically, not every specific situation could be accounted for nor could every specific wish be upheld. When talking to my proxy 1 and proxy 2 about what I had stipulated in my AD, there were certain topics that brought about some conflict and were discussed more in detail.

First, when reading out my advance directive to my proxy 1 and proxy 2 (my parents), surprisingly, conflicting interests in religious beliefs were discussed most frequently. I wanted to make it clear in my AD that having a blood transfusion, for example, would not be a problem and also indicated that I am an atheist since I thought including this information might help proxies make better decisions in situations that weren't specified in the AD, even post-mortem decisions of burial (financial, school, and burial matters were not asked in the AD). I was not prepared for the reaction my mother solely provided; she was actually shocked to hear that I was an atheist and started questioning whether I felt lost in life not believing in a higher power or whether my upbringing could have changed this.

My father is Jewish and my mother is Catholic, and I found this conversation interesting and quite unexpected, since my family never attended temple or church regularly growing up. Religion was simply not a big part of my life, so why did it matter in an EOL decision?

In realizing that this might be a conflict of interest, previously unforeseen, I worried what the consequences of this might be for when it came time for my proxies to fulfill the wishes written in my AD. In fact, a recent review examined factors like location and religion that might affect EOL decisions in ICUs around the world [3]. Interestingly, it was found that religious people "choose more active life-sustaining measures than would nonreligious people".

This same result was observed in a study conducted in 2012 more specific to my situation, that examined differences

in EOL and patient autonomy between religious and affiliated individuals in questionnaire responses among Protestants, Catholics, and Jews in European countries [4]. In talking with my proxy 1 and proxy 2, I noticed that my response to not be put on a ventilator or tube feeding in the case of permanent coma was different from that of my mother's, who considers herself more religious. In contrast, she wanted these life-saving measures, since she believed that it was possible for the coma to be reversed, and that God would save her. This conversation brought to light the challenges to EOL care, due to differences in religion.

In support of my feelings and concerns, Shinall et al. [3] cite that understanding the patient's wishes might be problematic when the family's wishes differ from those of the patient [5]. However, it is worth mentioning that for my particular circumstance, my mother respected my decisions as an independent, mature, and educated adult. Knowing this did lessen my concern that my wishes might not be followed due to differences in religious beliefs. Discussing religious differences are necessary, as certain beliefs affect decisions in the case of physician-assisted suicide or euthanasia, which is less likely to be employed by religious persons, as they feel that human life is sacred [6]. Feelings towards organ donation might differ between the religious and non-religious individuals, as I experienced.

The second major discussion point I noticed, when reading out my AD to proxy 1 and proxy 2 circled around organ donation. In my AD, I tried to make decisions for proxies easier by being specific about post-mortem consequences, such as whether or not I wanted my organs to be donated or not. In my AD, I stipulate that I would like to be an organ donor, a decision that stems from my university studies and agreement with philosophers who argue that there is nothing after death and so the body should be put to use for someone who needs them [5]. My mother, being more religious than I am, respected my decision, but did not agree with me. Interestingly, though she expressed a willingness to help someone else in need of an organ, she believed that God wanted to see her whole, and not violated or mutilated, when she ascended to heaven. This made me realize that for some, decisions are made on more than religious beliefs, but also on personal or family connections. As Soute et al. [7] indicate sensitivity for cultural and religious beliefs is needed in EOL care and decision-making; they cite that in some religions, organ donation before the moment when all brain wave activity has ceased would be unacceptable. Delaney et al. [5] write that an organ draft would violate the first amendment too, the right to religious freedom.

Being interested by this conversation with my mother, I wanted to research beyond the course material why religious beliefs affect organ donation beliefs. I found a link between the two in a recently published article in which the authors studied the discrepancy between the organ transplant waiting list and organ donors in an African American population in a cross-sectional study [8]. The willingness to donate was actually

negatively correlated with religious beliefs. This finding relates to my personal experience, as my mother's religiosity decreased her willingness to donate and became a reason for her not to donate, though this might be only one factor among many [2]. This study provided support that religion plays a major role in some people's lives and influences their EOL decision-making and views on organ donation. Differences of belief may affect who patients appoint as their proxy or proxies in the AD.

Aside from the religion and organ donation [9] talk with my proxies, I found that deciding who to appoint as my proxies (and in what order) was a difficult decision that required me to truly reflect on my own interests and if they aligned with the proxies' interests as well as reflect on who would know me well enough to carry out my wishes and make appropriate decisions in this monumental moment in life. I knew I wanted to choose my parents, but not in what order. Placing my father or mother first as the decision-maker might create unnecessary conflict and favoritism.

I decided to place my father first because I thought that he would be less emotional, plus his business and legal background might influence his decisions. Surprisingly, establishing a hierarchy in this case did not create a conflict; my mother agreed that she too would want my father to be first for similar reasons. This part of the conversation made me realize that I should not underestimate my family's response during times of crises. To support this feeling, it has been shown that better family functioning and higher levels of emotional support increased the probability of partaking in informal discussions and completion of ACP [10,11]; therefore, understanding family dynamics is a crucial influence on how EOL decisions will be made. My mother was very open and talked freely about the issues discussed here, while my father actually became very upset that I was discussing this because I was his daughter. He refused to provide further comments. Although this was unexpected, I still felt that my proxy indications should remain the same, but questioned my perception of others.

Particular to my situation, I have a little brother who is 14 years old now and thought about making him a proxy too. However, due to the uncertainty of when this AD would be used, I decided against it. This was a conflicting decision, since I would want all members of my immediate family to participate in the decision, but thought that even if my brother was 40 years old at the time when the AD was read, I would not want to burden him. This is because I feel that I am very close to him and this event would be very painful and emotional for him. Actually, a study by Khodyakov et al. [12] found that sibling relationship quality and closeness declines after parental death. This study provides great evidence that talking about EOL care with family is extremely necessary, especially to avoid unwanted conflicts or harmful relationships to those surviving the patient.

Most importantly, what I have learned from this experience of completing my own AD is that the process is complex; in

every section, there is something further to consider. From this experience, having space to write my health care and personal decisions was beneficial, as it allowed me to freely express my wishes; however, I felt that it was difficult to know what to stipulate for each section. For example, there were some questions to think about regarding how you would like your safety to be managed, but understanding what the safety section means might prevent one from accurately completing the section. It was difficult to be specific enough to allow proxies to make easier decisions, but to also be flexible in accounting for uncertain future events. I observed this in my own grandparents' will, which they lent to me, and realized that being too vague would cause proxies to question what should be done in certain situations. According to Dr. Jonathon Breslin's Lecture 9, phrases like "common accident" might be too vague and would require interpretation.

Another problem I observed while filling out the treatment table was that it is impossible to predict every specific situation (and medical advancement) that could arise [2]. It was difficult to imagine myself in each scenario; one's feelings while filling out the AD might be different once that person is in the actual situation (similar to the AD lecture case-study). As Henry Perkins [1] writes, AD "promise more control over future care than is possible"[1].

An additional source of confusion with the treatment table might be the use of technical terms. For laypersons, understanding exactly what having a 'moderate stroke', for example, entails symptomatically might be problematic when accurately completing the AD. Finally, allowing proxies to make decisions as a group or to side with the majority might cause controversies similar to being in a business group that has to decide on one proposal. Breslin Lecture 9 [2] also cites in his lecture that some people may just prefer to leave EOL decisions to proxies, ignoring their AD, and proxies might not even be aware of their selection. Even in places where I have made specific stipulations, it might be difficult for proxies to know if they are carrying out the stipulations effectively [1]. Other barriers include: not completing an AD at all, not having documents readily accessible when needed, and not updating the document for a long time (i.e. I would probably change my mind from 20 years old to 50 years old) [2]. How accurately one can make predictions about future desires is a question often raised; the Margot Bentley case nicely illustrates this problem.

Conclusion

To conclude, from my experience completing an advance directive, it is evident that there are many factors to consider that one doesn't acknowledge until one partakes in this insightful process. Religious beliefs, organ donations, proxy selection, and other considerations like family relationships or dynamics should be taken into account when discussing advance care planning. I felt some comfort in knowing that I can indicate end-of-life choices for myself and was able to truly reflect on

who I am as a person; however, I did not feel a total sense of control over my end-of-life decisions due to the realization that in an emotionally-pressured and fast-paced time, physicians and proxies might not even read or fully be able to implement the specific stipulations in the moment. After studying the many problems and limits associated with advance directives, I feel that my view of their reliability and credibility was negatively altered when completing the AD. After being through this process, I might not want to fill one out at all in reality.

In order to address these problems, it might be best to have conflicts resolved by a team leader, as following one person might provide a clear line of reasoning in a chaotic time and might avoid confrontations among proxies. As suggested by Perkins [1], we should evolve our thinking about advance care planning to advance care preparing to help avoid confusion and non-reasonable decisions during end-of-life care, when uncertainties and difficulties arise (51). In speaking with the Palliative Care Team at Sick Kids Hospital in Toronto, it was made clear that in practice, formal documents were not signed; rather, five wishes or points were talked through with patients and proxies [13]. This hints at the ineffectiveness of AD in practical settings, for which the transfer of AD theory to practice needs further research.

Death is an uncontrollable event, yet advance directives were implemented to try to gain control of an uncontrollable event and prevent disputes by outlining specific wishes of the patient [2]. However, there are complex historical, cultural/religious, and social factors to consider that might influence end-of-life decisions and interests, compelling philosophers to better understand human personal values and beliefs, which might try to further answer, in a broader sense, controversial discussions about the definition and determination of death.

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