

Virtual Mentor

American Medical Association Journal of Ethics
August 2009, Volume 11, Number 8: 571-581.

CLINICAL CASE

Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest

Commentary by Ryan E. Lawrence, MDiv, and Daniel J. Brauner, MD

Mr. Abbot was taken to the local hospital from the nursing home where he had lived since his dementia became too severe for him to be unsupervised for any length of time. At 70, his health had been good, enabling him to enjoy the amenities of the nursing facility, stroll on the grounds, participate in art and music therapy, and visit with family and pets on a weekly basis. He was admitted to the hospital with a diagnosis of pneumonia and was in respiratory distress, which was likely to require intubation.

Years prior, before losing decision-making capacity, Mr. Abbot had documented in his advance directive that if he ever became demented and was unable to recognize his family or friends, he would prefer that no attempts be made to resuscitate him, should it ever be necessary. Mr. Abbot's family, which included three children, made no effort to hide this directive, which was in his medical record, but insisted that it should not be acted upon. The children explained to the doctor that, despite his compromised cognition, their father was currently enjoying his day-to-day life in the nursing home, and should be intubated.

Commentary 1

by Ryan E. Lawrence, MDiv

When patients cannot make their own decisions it is often difficult to know how to proceed. One approach, described by Allan Buchanan and Dan Brock in their book, *Deciding For Others*, is to employ a hierarchy of principles [1]. First and foremost, decision makers should consider any directives the patient articulated when competent. The second-line approach is substituted judgment, wherein those who know the patient best carry out the course they think the patient would have chosen were he competent. If these options cannot be employed, decision makers may act on what they believe is in the patient's best interest. This hierarchical approach has been highly influential in medical ethics, but it has limitations that are visible in the case provided. These shortcomings are the focus of this commentary, which aims to discern how applicable Buchanan and Brock's paradigm is to this and similar situations involving patients who are no longer competent.

Advance Directives

Respect for patient autonomy is often the dominant principle in medical ethics and, according to some, in all of medicine [2, 3]. Arguably, following advance directives

provides the best means of respecting the patient's wishes and preserving autonomy when the patient no longer has decision-making capacity. Most patients (76.5 percent in one survey) expect their wishes to be carried out in the event that they cannot make decisions for themselves [4]. Therefore, few would disagree that advance directives have a strong *prima facie* weight—overlooking them requires serious justification.

Even if all parties agree with using advance directives to respect patient autonomy, many decision makers still face difficult questions about what interventions and situations are covered by the directive. In the present case, Mr. Abbot said he would not want resuscitation but did not specify what forms of resuscitation he would not want. Fluid resuscitation is rather benign; chest compressions are not, and intubation may not even count as resuscitation—many hospitals separate “do not resuscitate” (DNR) from “do not intubate” (DNI) when specifying goals of care.

Alzheimer's dementia affects persons gradually, allowing for good days and bad days. Would Mr. Abbot's advance directive take effect on the first “bad” day on which he did not recognize a family member, or did he intend to wait until he no longer had good days? Difficulties in discerning a patient's intended meaning limit the usefulness of advance directives.

Moreover, a strict application of an advance directive may not reflect the patient's autonomous choice in its entirety. Patients often harbor misunderstandings about the interventions they are choosing or rejecting and even the implications of *having* advance directives [5]. Physicians, too, may misinterpret the patient's wishes. A case report described one nursing-home resident who was said to be DNR, based on his living will, but after developing a gastrointestinal bleed and being taken to the hospital, he told the doctors that he was *not* DNR, adding, “I know I am an old man, but if the condition is treatable, I would like the chance to be treated” [6].

Patients may also place varying emphasis on their autonomy. In a 2005 study by Thorevska and colleagues, most patients (59 percent) created their living wills in consultation with a family member [5]. Similarly, Mazur and colleagues reported that most patients (62.5 percent) preferred shared decision-making models involving their physicians over solely patient-based approaches (preferred by 15.5 percent) [7]. Those who include others while formulating their advance directives may well want to include others in the implementation of those directives. Thus, strictly applying advance directives may not do justice to all of the patient's wishes.

Substituted Judgment

The second-line approach, substituted judgment, generally does not overrule advance directives, but may play a role when questions emerge about how to interpret and apply advance directives. In the present case, substituted judgment might be important when considering whether Mr. Abbot's instructions would have changed had he known the details of his present situation: his happy existence despite Alzheimer's, the acute course of his pneumonia, and his family's unified desire for a

short-term trial of intubation. Yet, limitations of the substituted judgment principle also emerge when it is applied here.

Because of Mr. Abbot's medical condition, his true wishes cannot be known, so there is no objective way of determining whether his family's judgment is a true substitute for his. The family's decision to override the plain reading of his advance directive suggests that they may be merely substituting their own preferences under the guise of "substituted judgment." Following the advance directive, however, would leave questions about whether the family gave adequate weight to important details the patient did not anticipate (his happy existence, his medical condition, and his family's wishes).

Shortcomings of substituted judgment are not limited to the present case, but affect the principle more broadly. In one study, medical students could accurately describe substituted judgment but made important mistakes when applying it; if doctors struggle to apply the principle correctly, surrogates might have even more difficulty [8]. When testing the approach, proxy decision makers using substituted judgment were correct only 70 percent of the time [9]. Moreover, patient preferences change over time, making it difficult to anticipate what a patient will choose. In one study, 10 percent of survey respondents who did not want mechanical ventilation in 1999 had changed their minds 3 years later [10]. On the whole, evidence suggests that substituted judgment can be difficult to understand and apply, making it an unreliable means of preserving patient autonomy.

Best Interest

The last option in Buchanan and Brock's paradigm, the principle of best interest, likewise has limitations. In the present situation, Mr. Abbot's best interest is debatable. Generally, patients' best interest involves having their autonomy respected and their rights of self-determination protected—which would push decision makers in this case toward following the advance directive. Yet it is not in a patient's best interest to have prior instructions misinterpreted or applied in ways the patient did not intend. Furthermore, many patients would not consider it in their best interest to create conflict for their families. These observations rightly make clinicians cautious about implementing the advance directive under the banner of serving the patient's best interest.

Another tempting approach, invoking a patient's *medical* best interest as grounds for dismissing an advance directive, is problematic when the patient's future course is unclear. In one study of elderly patients with severe pneumonia, researchers observed a 40 percent mortality rate among those who required intensive care (87 percent of all study patients were intubated). Furthermore, survivors spent 15.6 days on average in the ICU [11]. A cognitively impaired patient might find this experience bewildering and distressing, to the say the least, and might still die in the end. There is also no guarantee that the patient would return to baseline health status following the illness. A study of nursing-home residents with dementia found that, 3 months after a lower respiratory infection, 21 percent had a decline in functional

status (33.2 percent were dead, 45.8 percent were alive with no decline) [12]. Overall these odds are not bad; they just might not be good enough to justify violating an advance directive. These data also highlight that, while it is tempting to frame the question as one of choosing life or death for the patient, the real question is whether or not to choose aggressive treatment. Medical uncertainties temper enthusiasm for acting unilaterally on behalf of the patient's best interest.

Often it is not clear which path best serves a patient's interest, medical or otherwise, for it is difficult to know which of the patient's interests should be given priority and at what cost to the other interests. This does not preclude decision makers from discussing the patient's best interest, but it does suggest that the principle is not a simple or unfailing rule for making complex medical decisions.

Leaving the Principles Aside

Advance directives, substituted judgment, and best interest all have limitations that constrain their usefulness when making medical decisions for patients who cannot choose for themselves. Awareness of these limitations allows us to shift attention to other observations that may provide guidance when patients cannot make their own decisions.

First, when the patient cannot make his own decisions, someone else must make them in his behalf. This point is itself controversial; some believe that surrogates who merely report a patient's prior wishes are not making genuine decisions [13]. Surrogates at no point abdicate their role as decision makers, since, even when the patient's wishes have been expressed previously, the surrogates still make crucial interpretive decisions about when and how to implement those stated wishes. In the present case, unless the physician, the state, or some other designated party steps in and decides how to interpret and implement Mr. Abbot's advance directive, the family retains some latitude in deciding whether his advance directive will apply.

Second, those who make medical decisions for incompetent patients may, and indeed must, consider factors beyond patient autonomy and advance directives. In an era dominated by autonomy, this point is rarely explicitly made but does have some supporters. A recent survey found that many U.S. physicians do not exclusively hold a patient's expressed wishes as their highest concern when making ethically complex medical decisions [14]. Likewise Jonsen, Siegler, and Winslade advocate that physicians consider all the facts of a case in order to arrive at a more balanced judgment [15]. In this context, the family is permitted to consider factors other than the patient's advance directive.

Finally, in light of these observations, refusing to implement an advance directive does not necessarily disrespect the patient. This is particularly true when there are questions about the applicability of advance directives or when additional information exists that probably would have influenced the patient's decision.

In the present case, the family should be allowed to offer the final verdict on whether to intubate Mr. Abbot. The physician can make an extra effort to educate the family about the pros and cons of each possible decision and about current theories in medical ethics, but the physician should not forbid intubation based on the patient's advance directive. (Incidentally, these arguments also allow room for physicians to challenge patients' advance directives on occasion. How to resolve physician-family disagreements over patient care is a separate question that warrants its own commentary.) Hierarchical decision-making paradigms such as that offered by Buchanan and Brock may be helpful at times, but when they create more ethical ambiguity than they resolve, it is appropriate to set them aside.

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Acknowledgement

I would like to thank Farr Curlin for his helpful comments on an earlier version of this commentary.

Commentary 2

by Daniel J. Brauner, MD

In the preceding case commentary, Ryan E. Lawrence presents a spot-on portrayal of the principle-based paradigm in 21st century North America for making end-of-life medical decisions for those who are unable to speak directly for themselves. He then sets the paradigm aside, in favor of allowing the family to make decisions with input from the physician because of the ethical ambiguity inherent in applying principles of autonomy articulated in advance directives to an actual medical situation. This phenomenon is repeated countless times in similar situations and closely reflects the reality of modern medical decision making.

Many aspects of Mr. Abbot's case deserve mention, including the assumption of his lack of decision-making capacity due to the extent of his cognitive impairment—an assumption that needs to be grounded in some attempt to include him in discussion of his medical care [1]. Even finding that Mr. Abbot lacks decision-making capacity does not necessarily mean that his voice should not be part of the decision-making discourse along with those of his family and doctors [2].

Some time ago, Stephen Post and others raised the question that this case asks: should we honor the wishes of the “then” (precedent autonomous) self or the “present” self in persons who are transformed by their dementia [3]. In this regard, it is important to consider why recognition of family members stands as such a watershed moment for Mr. Abbot and so many other patients with dementia. Failures of recognition usually make a greater difference for family caregivers, who understandably become distressed when the person with whom they shared so much no longer recognizes them. National and local context also plays a role. If Mr. Abbot lived in Holland, for example, a country rated highly in its care to the elderly, and was a nursing-home resident, he would most likely not be transferred to the hospital,

regardless of his family's preferences, and intubation and CPR would not be options [4]. This forces us to ask whether a person with dementia who resides in a nursing home should have his or her care options limited compared to a person with the same degree of problems who is able to continue living at home because of better resources.

Exploration of the Language of Advance Directives

To better understand the case of Mr. Abbot and others like him, it is helpful to explore the history and evolution of advance directives, recognize why they fail to help us to make decisions, and encourage a rethinking of current practice. Although it is not explicitly stated in the scenario, the advance directive that Mr. Abbot signed was in all probability a DNR order to take effect in the future when his dementia had progressed to the point that he did not recognize family members. It is the question of whether to order a DNR that often frames discussion about the future and is stated here as Mr. Abbot's desire that "no attempts be made to resuscitate him." As Lawrence points out in his commentary, the meaning of resuscitation is not entirely clear. The DNR order was the first codified limitation of therapy, and it ushered in a revolution in end-of-life care by providing important options for gravely ill and dying patients. The way DNR is currently used in end-of-life discourse, however, has become an obstruction to clear communication and good care.

Asking every patient who might die—ultimately all patients—whether he or she wants to be resuscitated has become standard practice in the United States and is generally thought of as a marker of good end-of-life care. In its latest incarnation as a central component of the goals-of-care conversation, the question is usually introduced when a patient's prognosis is grave and doctors have run out of what they consider reasonable chances of successful curative therapy. The DNR order of the 1970s was a logical response to what can now be recognized as a failed experiment, begun early in the history of the modern age of resuscitation with the notion that everyone who died would first be in cardiac arrest and should therefore undergo resuscitation. This was a radical shift from prior practice.

Prior to this shift, as noted in *A Manual on Cardiac Resuscitation* published in 1954, the indication for resuscitation procedure was "cardiac arrest or stoppage of the heart in the operating room," most commonly from a catastrophic reaction to anesthesia [5]. Until 1960, cardiac resuscitation involved the application of open-cardiac massage to a limited number of patients, usually via thorocotomy and almost exclusively in the operating room. But in response to the high success rate with the first 20 patients to be resuscitated using closed-chest compressions (70 percent survival), reported in 1960, the study authors decided to take their technique to the rest of the hospital and explicitly changed the definition of cardiac arrest [6]:

Cardiac Arrest is [now] the sudden and unexpected cessation from whatever cause of circulation producing cardiac activity. *This term once applied only to the sudden death associated with anesthesia and surgery* [7].

Within a very short time, despite the much grimmer success rate of chest compressions when more generally applied, and without any widely vetted public policy debate, cardiac arrest became accepted as a new stage in the human experience of dying, and cardio-pulmonary resuscitation (CPR) became the universal default for all patients in cardiac arrest in the hospital [8].

A cascade of ensuing forces then led to the development of the “order not to resuscitate” (ONTR) in 1974, followed most significantly in 1976 by a mandate that patients or their families be allowed to make this decision [9]. These changes arose because the early expectations of dramatically altering life expectancy were dashed by CPR’s lack of efficacy in the vast majority of patients to whom it was applied. The escalating public debate about the ambiguous value of many life-prolonging therapies and the growing patients’ rights movement reached a climax with the Quinlan decision in 1976, which authorized the first publicly acknowledged removal of ventilatory life support in a person who was still alive [10].

The Quinlan decision set the stage for open discussions about actually limiting treatment, as heralded by an editorial in the *New England Journal of Medicine*, “Terminating Life Support: Out of the Closet” [11]. One of the papers in this series was precedent-setting in its call for the active participation of the patient and family in deciding whether or not to forgo CPR [12]. The idea of giving patients and families ultimate choice was again supported by the President’s 1983 Ethics Commission, which suggested that the concept of futility was inherently too uncertain to allow for the creation of “clear and workable categories” for limiting CPR [13].

Legacy of Cardiac Arrest and DNR

Although much has changed in the past 30 years, the case of Mr. Abbot shows that much has also stayed the same. The repercussions of the establishment of cardiac arrest as the liminal state between life and death and the subsequent DNR order for withholding CPR still echo in our present-day conversations with patients and families. The choice of whether or not to perform CPR was the first specific, mandated decision in which patients and families were explicitly given a voice in determining their care. As such the “code” discussion served as an early prototype for decision making with patients and families. It is still often used as a point of entry to talk about future care, both with gravely ill patients in the hospital and, as in Mr. Abbot’s case, with healthy individuals when considering the more distant future.

Physicians can use the advance-directive frame or code discussion as a barometer to gauge desired intensity of care. In some circumstances, physicians will go beyond the question of code status to discuss with patients exactly what level of aggressiveness they want, ranging from everything except CPR to various other possible limitations. This practice is further reinforced by the use of “partial DNR” orders, in which patients and surrogates choose from a menu of options parsed out from the CPR protocol, including intubation, cardioversion, compressions, and use of antiarrhythmic and vasopressor drugs. Over time, these choices have been

expanded to include procedures that are not necessarily related to resuscitation, but to more general advance care planning, such as the use of artificial hydration and nutrition. The DNR discussion can thus serve as a springboard for other aspects of care.

The great irony of this legacy is that the CPR procedure, which stimulates all of this discourse, will most likely not be effective in significantly altering the outcome of the illness or process from which most of us will die. (Of course, there are many conditions related to acute, sometimes iatrogenic events that are reversible by CPR/advanced cardiac life support (ACLS) and deserve its rapid application.) Nevertheless, in homage to the history of resuscitation, cardiac arrest, DNR, and the spirit of patient autonomy, we are left with a ritualized discussion that compels physicians to offer a therapy which will most likely be ineffective.

Recommendations

From the perspective gained through this historical review, let's get back to Mr. Abbot. He had chosen DNR in the event his dementia became intolerable to his "then" self. This is a reasonable choice, especially in a nursing home, where the rate of successful resuscitation is even lower than in the hospital and where some have advocated to not even offer CPR [14]. We may also be justified in assuming that his DNR order signifies "then" Mr. Abbot's desire for less-aggressive therapy in general [15]. But the DNR tells us little about what he would want now, and assumptions about aggressiveness based on a DNR order are nebulous. Ever more detailed advance directives based on the flawed cardiac arrest model have not yielded significant improvements [16-18].

There are several decision points that make more sense than DNR in contemplating Mr. Abbot's situation. The "do not hospitalize" order functions as a much more powerful advance directive and can be applied to nursing-home residents who have reached a point in their disease trajectory where the burden of hospitalization overwhelms the potential benefit it offers [19]. Once Mr. Abbot is in the hospital, the decision to intubate for impending respiratory failure must be clearly differentiated from the intubation performed as part of CPR/ACLS. Elective intubation for impending respiratory failure associated with a potentially reversible condition like pneumonia, although fraught with higher rates of morbidity and potential mortality for Mr. Abbot than for a younger, healthier patient, as Lawrence points out, is a life-saving procedure in the majority of patients in a study he cites. A time-limited trial of intubation with aggressive antibiotic treatment for pneumonia is often a quite palatable choice for older patients who share the understandable dread of spending the last days of their life in a prolonged death on a ventilator.

This time-limited trial would be the choice I would offer to the family if Mr. Abbot is not able to be involved in the decision. It appears that they are making decisions based on his best interest and his current, quite decent quality of life and want him to be treated if there is a reasonable chance of his returning to that life. If, after a reasonable time, the duration of which should be clearly stipulated beforehand, he

does not appear to be improving, he would be extubated. Aggressive palliative care should be part of his treatment during his entire hospitalization, with special considerations if he is extubated because of lack of improvement. Of note, if he is extubated because of lack of response, when his heart stops he should not be considered to be in cardiac arrest but dying, and CPR would not be indicated.

Of course, to follow the procedure that I advise would require some conceptual and bureaucratic changes, but perhaps it is time for us to move beyond the current paradigm.

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Acknowledgement

I'd like to thank Jeff Rees, PhD, Sarah Grusin, and Barbara Chubak, MD, for their insightful editorial comments.

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