ETHICS IN MEDICINE

From advance directives to advance care planning: current legal status, ethical rationales and a new research agenda

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Abstract

This paper uses a case example to review the current legal status of advance directives, as well as their ethical rationale. We draw attention to ongoing efforts to institutionalize advance directives, and to some of the tractable and intractable reasons why advance directives are ineffective. We then introduce the concept of advance care planning, and argue that we should not assume that advance care directives have a place in this process. We conclude by offering three reasons why this assumption may operate, and by suggesting that contingency and uncertainty may sometimes overwhelm all rational approaches to medical care. (Intern Med J 2005; 35: 563–566)

Key words: advance directives, advance care planning, decision-making, terminal care, case report.

BACKGROUND

During the twentieth century, chronic diseases displaced infectious diseases and injury as the leading cause of death in industrialized societies. At the same time, advances in medical science and technology radically changed the practice of Western medicine. In the 1970s and 1980s advance directives (also called living wills) emerged in response to perceptions that modern ‘techno-medicine’ was prolonging the process of dying from chronic disease through overzealous, burdensome and futile attempts to keep patients alive.

Advance directives are treatment decisions made in advance, either in writing or orally, in anticipation of some future time when the patient will be mentally incompetent or otherwise incapacitated to the extent that he/she cannot make or participate in such decisions himself/herself. They most often incorporate pre-emptive refusals of particular medical interventions, or of life-sustaining treatment, which become valid only when a patient becomes incompetent. Pre-emptive demands for treatment are less common. Advance statements express a patient’s preferences or values with the aim of guiding decisions about medical treatment and care rather than making them in advance. Statements thus leave more room for professional judgement than directives. Both directives and statements may nominate a friend or relative who should be consulted in medical decisions, or who can make decisions on a patient’s behalf in the event he/she becomes incompetent (a health-care proxy, surrogate decision-maker or enduring guardian). Most jurisdictions will require some formal process for this appointment (unless the friend or relative is otherwise authorized, for example, under guardianship legislation). This means that family members do not automatically have legal authority to make decisions about the care of an incompetent patient.

We can explore the legal and ethical relevance of advance directives to medical practice by considering Mary’s case.

Mary’s case

Mary had strong views about the end of her life. Twenty years before her own death, her husband Ben suffered a stroke. Ben was a sculptor whose main enjoyment in life was company. His stroke robbed him of speech, artistic ability and the ability to read. He regained some speech but it was a parody of what it had been. He still listened to and understood conversation, but could no longer join in. When he did say something, it commonly related to what had been said some minutes before. Although people still loved Ben for what he had been, and were therefore kind to him, he was desperately unhappy. When he developed a recurrence of an abdominal cancer that had been treated 7 years before his stroke, he refused treatment and died in hospital 3 weeks after being admitted for terminal care. During that process he told a close family friend that the worst part about his dying was that it was ‘so bloody boring’. Mary was appalled more by Ben’s slow deterioration than by his death, and she was determined that it must not happen to her. A month after Ben’s funeral, she announced that she had written a ‘living will’ which was in a drawer in her desk. It said that if she should suffer slow deterioration, she wanted the minimum of care consistent with maintaining reasonable dignity; she did not want to be kept alive in the face of incapacity. Mary...
said that those who had known her well for many years would know what she meant by incapacity. It would mean such things as loss of independence, loss of words and loss of ability to share congenial company.

Soon after her 83rd birthday, Mary had a major, left-sided cerebral haemorrhage and rapidly became comatose. The computed tomography scans suggested that she was unlikely to survive more than a few days. She developed pneumonia. Several of her close friends, also aware of her advance directive, begged her doctor to let her die.

CURRENT LEGAL STATUS OF ADVANCE DIRECTIVES

While the law does not recognize a right to die, it does recognize the right for every competent adult to refuse medical treatment, for whatever reason, even if it leads to their death. It is generally accepted that Australian common law (i.e. the principles developed by judges in cases before the courts) also recognizes the principle that patients may refuse treatment in advance. Some Australian jurisdictions also have legislation that recognizes this principle. At common law, pre-emptive or anticipatory refusals of consent are considered legally valid, whether spoken or written, provided they meet five criteria (Table 1).

The main decision facing the medical team in Mary’s case was whether to use life-sustaining treatment given her advance directive. Was her advance directive legally valid? She was certainly competent when she formulated it, and there were people present who could have vouched for that. Her refusal also appears to have been made voluntarily and without duress. Whether it was unequivocal would depend on how she worded her document. What she is reported to have said at the time of her husband’s death sounds unequivocal. Regarding the third criterion, Mary’s spoken comments might be construed as an offhand remark, but the fact that she took pains to formalize her refusal in writing and tell others about its existence and location tends to suggest that it was firmly intended. Her refusal certainly meets the fourth criterion, as it was formulated in response to her husband’s deterioration after a stroke, which was in fact what subsequently happened to her. We could question the validity of Mary’s refusal on the fifth ground. She suffered her stroke 20 years after making her advance directive, and medical treatments had changed significantly over that time. Arguably, however, her main concern was not the treatments so much as the degree of incapacity she expected, and the medical team had access to close friends who could interpret the import of various degrees of incapacity for her personally.

Mary’s advance directive is thus likely to be legally valid, in which case there could have been serious legal implications for her medical team had they given her lifesustaining treatment: it may have constituted a battery. If, however, her directive were legally invalid, withholding treatment in accordance with it may have constituted a breach of their duty of care.

ETHICAL RATIONALES FOR ADVANCE DIRECTIVES

The original moral impetus for advance directives was concern for human suffering. However, ethical and legal scholars usually frame the rationale for advance directives in terms of autonomy. This principle holds that persons should be free to determine what happens to them, and therefore free to accept or refuse treatment. Autonomy rather than care is also the ethical basis of law about advance directives. If the medical team in Mary’s case had ignored her express wishes and treated her, their actions could have been widely considered to be morally wrong and may have been legally actionable.

Autonomy, however, is not the only ethical consideration. Other ethical considerations include the medical team’s duty to act in Mary’s best interests and not harm her (the principles of beneficence and non-maleficence). We might also consider whether discontinuing treatment is a form of discrimination against the elderly and disabled, or whether the resources devoted to ‘futile’ treatments might be better used in other ways (questions concerning the principle of justice). Other approaches to ethics would extend this analysis in different ways, for example by exploring the relationships, virtues, or rights and duties of those involved in the case. Some people would assert that all human life is sacred, and that it is therefore always morally wrong to terminate treatment. However, we will not examine here the various arguments for and against termination of treatment, and how they might be affected by different ethical perspectives on Mary’s case. Our aim is rather to stimulate critical reflection and debate about ongoing efforts to institution- alize advance directives.

Table 1 Criteria for legal validity of anticipatory refusals of treatment

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<td>1. The person must have been competent when he or she formulated the advance directive.</td>
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<td>2. The refusal of consent must have been made voluntarily, unequivocally, and without duress.</td>
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<td>3. The refusal of treatment must represent a ‘firm and settled commitment’ rather than an offhand remark that informally expresses a reaction.</td>
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<td>4. The advance decision must have been made with reference to and intended to cover the particular circumstances which subsequently occurred.</td>
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<td>5. The person must have known in broad terms the nature and effect of the treatment to which he or she was refusing consent.</td>
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Internal Medicine Journal 2005; 35: 563–566
TRACTABLE AND INTRACTABLE PROBLEMS – AND A TROUBLING QUESTION

Over the last 20 years there have been concerted efforts to institutionalize advance directives by legal, administrative and educational means, and by means of policy and codes of practice. For example, all states in the USA now have legislation authorizing the use of advance directives, and a federal act requires all hospitals, nursing homes and Health Maintenance Organizations to develop written policies about advance directives; to educate their staff about them; to ask all patients on admission whether they have advance directives, and to inform them of their right to do so.7,8 In Australia, several states, including New South Wales, have published guidelines on ‘best practice’ in relation to the use of advance directives.9,10 Professional bodies have also produced codes of practice that offer guidance to members in drafting and implementing advance directives.11 At the same time, however, there is consistent evidence that advance directives have low uptake,12,13 and that where they are completed, they are ineffective in a range of important ways. They are often not referred to in the clinical setting,14 they do not bring surrogate decisions into line with patients’ wishes,15,16 they do not improve communication, nor do they change clinical practice surrounding resuscitation.17–19

We can understand why advance directives are so often ineffective or irrelevant by considering Mary’s case. Mary’s friends knew that her advance directive existed, they knew where to find it, they agreed with the refusal it contained, and it was relevant to the clinical situation that eventuated. Each of these facts represents a contingency which advance directives depend on, and if a single one is not satisfied, an advance directive may never be implemented.

Solutions can be found to many of these problems by putting suitable systems in place. Some problems are intractable, however. Consider, for example, what actually happened to Mary.

Mary’s case – continued

Despite her advance directive, Mary’s neurologist, who had not met her before her stroke, insisted on treating her pneumonia in order to keep her comfortable. Over the next 2 weeks she began to show some signs of recovery. She regained a few words and clearly recognized old friends, nodding and smiling at them with obvious pleasure.

Over the next month, she recovered enough speech to remake her will and to hold conversations for up to half an hour. She forgot the names of many familiar people and places, but she was rational, interested and funny about herself and others. She began to ask about going home, and to plan live-in care and rehabilitation. The ‘living will’ was never mentioned. Her right side remained completely without movement. She was unable even to feed herself. Yet she made it clear that she wanted to live, to go home, under any circumstances. She wanted antibiotics, speech therapy, physiotherapy, permanent care.

Mary’s neurologist made his decision in the context that presented to him rather than the context imagined by Mary 20 years before, and Mary survived long enough to demonstrate a radical change in intentions and life plans. She amended her legal will and her actions arguably invalidated her advance directive or ‘living will’. Thus, when someone dreads a type of disability so much that they refuse treatment in advance should it eventuate, we must always be open to the possibility that they will desire differently once the experience is upon them. This possibility remains even if they have good grounds for dreading it, as did Mary, and even if their refusal persists over time and is periodically reaffirmed. The intractable problem is that, where the disability precludes meaningful communication, we can never know if the patient has had a change of heart if and when it eventuates.1

Another intractable problem concerns the sheer difficulty of discussing dying, which confronts us with our own terminal suffering or that of others. Note how, following Mary’s partial recovery, neither she nor her carers resumed this discussion in any way. This raises the question of whether advance directives provide all parties to communication at the end of life with a pretext not to have such discussions. Once something is written down, encoded in a form, do people have a pretext to avoid it by treating the matter as ‘having been dealt with’? Is the question that lies at the heart of the issue: How can people ‘do’ those discussions well?

ADVANCE CARE PLANNING: TOWARDS A FUTURE RESEARCH AGENDA

Given all these concerns about advance directives, should we give up trying to respect a person’s wishes about treatment at the end of life, and hand the decisions back to doctors? This is not a solution for which we would argue. Rather, we think the central issue needs to be re-framed as planning for treatment and care in the event of future incapacity.12,18 Advance care planning refocuses attention away from a particular document to a broader, ongoing process which can be constantly revised in the light of changing clinical circumstances or changing subjective evaluations of disability and suffering. Such a process should aim to keep interaction open and ongoing, rather than aiming for closure in a written document. It should be open to a range of goals that is known to be important to patients at the end of life, such as reconciliation with estranged friends or relatives, and adding meaning to a life by sharing stories from the past.12,20 Making treatment decisions in advance to preserve individual autonomy may or may not figure among these goals, depending on the personal and cultural values at stake in each case.

The question of what the structure and process of advance care planning should be needs to be answered through careful research and evaluation. Furthermore, if the problem is how to do advance care planning well, the need for advance directives and the centrality of individual autonomy should not be assumed. Reframing the
problem forces us to ask new questions and evaluate existing solutions anew. What are the stages of advance care planning? What options should exist at different stages to accommodate different goals? Do written forms have a place in the process at all? If so, at which stage and for what purpose? How does documentation influence spoken interaction? Do advance directives reduce the possibilities for meaningful communication rather than facilitate patient involvement in decision-making? How do we train doctors to put advance care on the agenda for individual patients, and keep it there? These are the central research questions for advance care planning. They are tractable questions for both qualitative and quantitative research.

If advance directives are assumed to have a place in advance care planning, we may have cause to be wary. Even though advance directives increasingly look like failed social policy, they have three characteristics which may ensure that they keep being offered as a solution, no matter how the problem is re-framed. First, advance directives are easy to count, and they are therefore attractive as a measure in outcomes research. Second, researchers may have an interest in designing forms that entail intellectual property rights: if they stand to benefit financially when their forms are used, they may persist in proffering forms as a solution. Third, written forms suit the documentary reality of organizations.

Finally, although advance care planning is a concept worthy of attention, Mary’s case again serves to remind us that all practical, rational ‘solutions’ may be overwhelmed by contingency and uncertainty.

Mary’s case – concluded

While planning for live-in care at home, Mary suffered another cerebral bleed and died.

CONSENT

This case is an authentic one in which one of the authors was directly involved. Since both husband and wife are now dead, obtaining consent is impossible. We have therefore altered some details, including names, to protect the identities of those involved.

REFERENCES

1 HE v A Hospital NHS Trust (2003) 2 FLR 408.
2 R (on the application of Burke) v The General Medical Council (2004) EWHC 1879 (Admin).