

Adherence to advance directives in critical care decision making: vignette study

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Abstract

Objective To explore health professionals' decision making in a critical care scenario when there is an advance directive.

Design Qualitative study.

Setting Scotland.

Participants Interviewees (n = 12) comprising general practitioners, hospital specialists, and nurses, and six focus groups (n = 34 participants) comprising general practitioners, geriatricians (consultants and specialist registrars), hospital nurses, and hospice nurses.

Results When presented with an advance directive that applied to the same hypothetical scenario, health professionals came to divergent conclusions as to the "right thing to do." Arguments opposing treatment centred on the supremacy of autonomy as an ethical principle. Other arguments were that the decision to treat was consistent with the terms of the advance directive, or that, notwithstanding the advance directive, the patient's quality of life was sufficient to warrant treatment.

Conclusion Advance directives are open to widely varying interpretation. Some of this variability is related to the ambiguity of the directive's terminology whereas some is related to the willingness of health professionals to make subjective value judgments concerning quality of life.

Introduction

Decisions to withhold or withdraw life prolonging treatments are among the most difficult to make for patients and health professionals.¹ Although the need to integrate the perspectives of patients, relatives, and other carers into decision making poses new challenges for clinicians, it is not known to what extent this happens in practice.

Particular difficulties arise when a critically ill patient is cognitively impaired. The advance directive is a means of promoting patient autonomy—providing a written statement of treatment preferences made when the patient was in sound mind. One study, however, showed that in most cases advanced directives were not consulted by carers in critical care situations.²

No studies have specifically examined the effect of advance directives on health professionals' decision making, although there is work on their views and experiences.^{3,4} We elicited health professionals'

responses to a critical care vignette of a fictitious patient who had previously signed an advance directive (box 1). The vignette was constructed to highlight the ethical dilemmas that arise when implementing advance directives in the clinical setting.

Methods

Data were generated through a combination of individual interviews and focus groups. Our purposive sample was defined for three primary dimensions: the professional group, experience with advance directives, and attitude to advance directives.

The quota for the prospectively defined sample was met through a variety of established methods, including the use of "key informants." We conducted 12 interviews and six focus groups (see bmj.com for characteristics of participants). The focus groups comprised consultants and specialist registrars in medicine for elderly people, nurses, general practitioners, and hospice staff.

Participants were provided with the hypothetical advance directive (see box 1).⁵ They were then shown a critical care vignette relating to the patient, who had written the advance directive before developing dementia (box 2). They were asked what they believed was the "right thing to do."

All interviews and focus group discussions were recorded, transcribed verbatim, and analysed according to a modified grounded theory approach.⁶ Preliminary coding categories were derived from the topic guide but were refined to take account of the issues raised by participants, with earlier transcripts being systematically revisited in light of these new categories.⁷

Results

To treat or not to treat?

The vignette was designed to create dissonance between the ethics of beneficence and respecting autonomy. No participant said that they would withhold treatment in the absence of the advance directive.

This scenario created division of opinion. Six of the 12 interviewees (three nurses and three doctors) said that they would not treat the patient with antibiotics, whereas five (all doctors) said that they would. The position of one of the interviewees was unclear.

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Box 1: Hypothetical advance directive

After careful consideration and discussion with my medical advisers I have freely and in sound mind decided that it is my express wish that if I should develop:

- Severe degenerative brain disease (due to Alzheimer's disease, arterial disease, or other agency)
- Serious brain damage as a result of stroke, injury, or other illness
- Advanced terminal malignancy
- Severely incapacitating disease of nerve or muscle
- Any other condition of comparable gravity

and as a result suffer mental impairment such that I am unable to participate in decisions regarding my care, and two independent physicians conclude that to the best of their knowledge my underlying condition is irreversible, then the following points should be taken into consideration:

- In the event of cardiac arrest, regardless of the cause, I should not be given cardiopulmonary resuscitation
 - With the development of any life threatening medical situation I should not be given active treatment such as antibiotics, ventilation, surgery, or blood transfusion
 - Any futile treatment initiated out with terms of this directive should be withdrawn
 - If during an advanced illness I should become unable to swallow food, fluid, or medication then these should not be given to me by drip or feeding tube into intestines or vein
 - I wish to have ordinary humane nursing care and the use of medical interventions only to control distressing symptoms and not merely to prolong my existence
 - I consent to the use of analgesics and other measures to control distressing symptoms regardless of the consequences for my physical health
- I have discussed this document with my general practitioner. I reserve the right to revoke this directive at any time.

Signed:

Witness signature: I hereby witness the signing of this document by the above named in my presence. She is of sound mind, understands the implications of the document and, to the best of my knowledge, has been brought under no external pressure to sign it. I do not stand to gain from her death.

Signed:

Copies of this form are with my general practitioner, solicitor, next of kin, and hospital records

Opinion was also equally divided between and within focus groups.

Factors in decision making

Many thought the right thing to do was to get more information from as many sources as possible. Three of the four interviewees who mentioned the need to try and communicate directly with the patient were nurses. The following is a response to the initial question of the "right thing to do":

I think to discuss with [the patient] what her wishes are, to read the advance directive, to speak to both the daughters if possible and to speak to the nursing team, and to read her notes. (Female hospice nurse)

All 12 interviewees mentioned the need to engage the family in the discussion. This consideration highlights the limitations of the vignette based approach, where participants' decisions are constrained by limited information—the "it depends" response.⁸ The general practitioners were keen to draw on their knowledge of the patient in sound mind. Another issue was whether or not the patient would require intravenous antibiotics. Some would likely have stopped short of transfer to an acute hospital.

Notwithstanding this missing information, what reasoning did participants put forward to explain their decision making? Those who would treat the patient constructed two main types of argument. Firstly they argued that treatment is wholly consistent with the terms of the advance directive and secondly that to follow the directive would be to go against the best interests of the patient. Withholding treatment was justified primarily on the grounds of respecting autonomy. See bmj.com for a summary of reasons for and against treatment.

Arguments why treating is consistent with advance directive

The most commonly presented justification for treatment was that the patient's dementia did not constitute "severe degenerative brain disease." This was put forward by half the interviewees and one in four of the focus group participants. This is clearly a question of interpretation, with some participants arguing that a condition that renders the patient unable to read or converse should be judged severe, especially in light of its progressive nature. The next most common argument was that the use of antibiotics is justified as a means of symptom control (as opposed to a means of preventing death):

This comes under the idea of humane nursing and care ... because although pneumonia may sometimes be silent in that kind of situation, it quite often isn't. It can be quite unpleasant. (Female general practitioner)

In five interviews and two focus groups the presenting complaint was considered not necessarily life threatening. The patient might survive her untreated pneumonia and be left in a state of ongoing respiratory distress and worsening cognition—the very state that she wanted to avoid in signing the directive:

Very often you're treating not the condition as it is now but the condition as it will be if we don't. (Male geriatrician, retired)

Box 2: Hypothetical clinical vignette

The patient is 78 years old. She lives in a residential home. Up until retirement she worked as a secretary to the headmaster of a private school. She has a devoted daughter who visits twice a week and another daughter "down south" who comes up infrequently.

The patient lives with dementia. She can walk and feed herself and needs some help with dressing. She occasionally wanders at night. Her physical health is good in that she is not currently being treated for any medical condition, having had a thorough assessment at the hospital one year ago.

She recognises her daughter and is glad to see her, but her conversational repertoire is limited—the daughter does virtually all the talking during visits. She is unable to read—something that up until three years ago she did avidly. She is undemanding, popular with the staff, and does not seem to be distressed.

She made an advance statement aged 70 years at a time when she enjoyed good mental and physical health. This was given to the home when she arrived 18 months previously.

One night, after a home outing, she comes down with a high fever. The doctor is called and examination shows that she has a pneumonia. With antibiotic treatment she may make a full recovery, without it there is a significant chance she will die.

Arguments why advance directive should not be followed

The preceding arguments are couched as legitimate interpretations of the advance directive. However most of the arguments in favour of treating view the patient as having, despite her dementia, a reasonable quality of life that is intrinsically worth preserving regardless of the advance directive:

I'd give her penicillin, I really would, regardless of her living will. I think I can defend that. She is clearly not unhappy in any obvious sense. Her daughter who comes and visits her every week is probably giving her something, who can say? (Male general practitioner)

According to this argument, while acknowledging the existence of the advance directive, the carer has a duty to reflect on what the patient would really want to happen to her in this scenario, with the feeling that her current state is not the one she had in mind when drafting it. This is a matter of individual judgment. Participants were pressed to explain their view that the patient had a reasonable quality of life and gave a variety of reasons. Some participants warned against reliance on such interpretations:

The point is that that's your interpretation. Here we come back to the same problem, "quality of life is not bad." Who says so? The doctors. (Male anaesthetist)

Several of those who thought that the patient's quality of life warranted treatment, discussed how they would use the ambiguity of the advance directive to justify their treatment choices:

I feel in [the patient's] view this is probably the situation where she would want that [the advance directive] enacted. I think as a doctor I could let myself out of this by saying she is not severely demented at all, treat it and then we will ask questions afterwards. (Female specialist registrar)

Arguments for withholding antibiotics

The primary argument for withholding treatment was respect for autonomy. These protagonists argued that the patient had a severe and irreversible degenerative brain disease, was unable to participate in decisions about her care, had an acute life threatening illness of the type she was thinking of when she wrote her advance directive, and had specifically refused treatment with antibiotics in such a scenario:

Make her comfortable, I mean she made this statement eight years ago when she knew exactly what she wanted ... she can't read anymore, her intellect has gone, I would think that at 70 years old this is what she wouldn't want so ... keep her comfortable (Female ward manager)

To treat her, they argued, would be in direct contradiction of the patient's clearly expressed wishes. Furthermore, any argument for treatment based on a lay or professional carer's perception that she was "happily demented" could be seen as no more than the projection of one person's set of values on another. Even if her dementia were not far advanced, it inevitably would become so. It was the patient's wish to avoid interventions at this stage so that she might be spared the indignity of further decline into imbecility. Thus, to treat her was to consign her to a future she had hoped to avoid.

Legal implications of decision making in scenario

In the United Kingdom there is no statutory law relating to advance directives, although such laws do exist in several countries. UK case law has established guidance for the creation of advance directives, but the obligation of doctors to follow them has not yet been tested in the courts.⁹ Several participants were boldly dismissive of the legal status of the advance directive. Others expressed uncertainty. All those who would treat the patient thought they could justify their decisions with reference to the ambiguities. Although four participants cited the potential value of advance directives in offering legal protection to the doctor who went against a family by withholding treatment, only one participant was in favour of statutory legislation. The following is from a participant who was positive about advance directives:

I think that the medicine and the law are very uneasy bedfellows. I think that [legislation] would be a most retrograde step simply because the law is about certainties and medicine is very much about uncertainties. (Male general practitioner)

Discussion

Decisions made by health professionals about the "right thing to do" when confronted with a hypothetical advance directive applied to a hypothetical critical care vignette varied widely. Those who favoured treatment tended to see adherence to the advance directive as not being in the patient's best interests, whereas those who opposed treatment invoked respect for autonomy as the determining ethical principle. Those who favoured treatment were particularly swayed by subjective judgments on the quality of life of the "happily demented" patient.

Most of the participants came from greater Glasgow. Given the sampling methods, it is unlikely that these participants were representative of UK health professionals. However, the attitudes expressed were broadly consistent with those from a 1997 survey of general practitioners in the West of Scotland.¹⁰ The findings relate to a specially constructed advance directive and cannot be directly transferred to any of those currently in regular use.

We conclude that advance directives are open to different interpretations and that anyone creating one cannot assume that any particular outcome will result from its implementation. Outcome depends to a great extent on who deals with the advance directive. This is the sort of reasoning that lies behind the drive for legislation to make advance directives binding on health professions—a move recently rejected in the United Kingdom by the House of Lords.¹¹ However, given the ambiguous nature of terminology used in advance directives, it seems unlikely that successful prosecution could proceed, with the legal profession trying to interpret terms such as "life threatening," "irreversible," and "futile."

One weakness of advance directives of this sort is that they give little information about what in the patient's view constitutes a good quality of life. Advance directives will not lessen the responsibility of health professionals to weigh up a range of conflicting considerations, and medical education should seek to

What is already known on this topic

Advance directives are written statements made by patients about future treatment preferences if they are mentally incapable of expressing them

Little is known about how health professionals react to the presence of an advance directive in a critical care situation

What this study adds

Health professionals come to different conclusions about the “right thing to do” when applying the terms of an advance directive to a clinical scenario

Some health professionals are willing to over-rule the preferences stated on the grounds of beneficence

Variations in interpretation are explained in part by the ambiguity of advance directive terminology and the situations in which they are applied

This same ambiguity would make legislation, compelling doctors to adhere to advance directives, difficult to enforce

develop students' empathic skills, and scenarios such as this could be used for this purpose.¹²

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Ethical approval: At the time the study was carried out (November 1999 to February 2000) it was not a formal requirement to obtain ethical approval for non-interventional research with health professionals. All participants gave signed consent.

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Effect of the critical care outreach team on patient survival to discharge from hospital and readmission to critical care: non-randomised population based study

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Abstract

Objectives To determine the effect of the critical care outreach team on patient survival to discharge from hospital after discharge from critical care and readmission to critical care.

Design Non-randomised population based study.

Setting Tertiary referral teaching hospital with 1200 beds.

Participants Patients discharged from the critical care unit after their first or only admission for two study periods, 26 February 2000 to 25 February 2001 and 26 February 2001 to 25 February 2002.

Main outcome measures Survival to discharge from hospital after discharge from critical care and readmission to critical care.

Results The introduction of a critical care outreach team increased survival to discharge from hospital after discharge from critical care by 6.8% (risk ratio 1.08). Readmission to critical care decreased by 6.4% (0.48).

Conclusions The activity of the critical care outreach team seems to improve patient survival to discharge from hospital and may reduce the number of readmissions to critical care.

Introduction

The report *Comprehensive Critical Care* identified a strategy for change that has begun to transform the delivery of critical care services in England and Wales.¹ Many of the recommendations in the report are subsumed under the broad remit of critical care outreach teams. Perhaps the most important of these recommendations was the development of patient at risk teams and follow up services to complement critical care while improving the speed and quality of patient recovery to discharge from hospital. The need for this service was based on several reports, which indicated suboptimal management of both patients discharged from intensive care and patients at risk of

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