

Determining the decision-making capacity of a patient who refused food and water

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Abstract: A terminal patient expressed the wish to hasten her death and refused nutrition. The psychiatrist asked to render an opinion relevant to her competence employed questions in a semi-structured interview derived from a new instrument originally designed to determine competence to create 'Advance Directives'. Although the patient ultimately demonstrated her resolve by totally ceasing fluid intake, the complexity of the case – including the question of the stability of her choice – illustrates the need for specific patient safeguards.

Key words: bioethics; palliative care; dehydration; mental competency; terminally ill; euthanasia (passive)

Resumé: Un patient en phase terminale a exprimé le désir de hâter sa fin et a refusé de s'alimenter. Le psychiatre interrogé sur la lucidité de la patiente a utilisé pour cela un questionnaire semi-structuré tiré d'un outil initialement destiné à tester l'aptitude à 'formuler des directives évolutives'. Bien que la patiente ait finalement démontré sa résolution en cessant de s'hydrater, la complexité de ce cas, particulièrement autour du caractère définitif du choix de la patiente, illustre le besoin de garde-fou spécifique pour les patients.

Mots-clés: bioéthique; soins palliatifs; déshydratation; lucidité; phase terminale; euthanasie (passive)

Introduction

The Chairman of the British Medical Association's Medical Ethics Committee, Dr Michael Wilks, wrote in the foreword to *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision-making*¹ (herein called *The Guide*): 'Decisions to withhold or withdraw life-prolonging treatment are among the most difficult for patients and health professionals to make ... [When] artifi-

cial nutrition and hydration is not a benefit to the patient, [it] should not be provided or continued.'

The Guide also states: 'Competent patients sometimes decide that the stage has been reached beyond which, for them, continued treatment aimed at prolonging life, although possible, would be inappropriate.' (Section 1.2). More specifically: 'It is well established in law and ethics that competent adults have the right to refuse any medical treatment, even if that refusal results in their death' (Section 9.1). As food and water are medical treatments, it follows – both logically and legally – that competent patients may refuse food and water to hasten their deaths.

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The ability of a patient to decide on life or death thus turns on whether she or he is determined to be competent. Yet Schneiderman and Teetzel² noted: ‘We must acknowledge that there are no clear guidelines as to how a physician should determine whether a patient is incapable of directing his or her medical care’.

Brief tests of cognitive functioning such as the mini-mental status examination³ (MMSE) may fail to differentiate competent from incompetent patients;⁴ they also may underestimate the prevalence of impaired decision-making capacity in elderly nursing home residents.⁵

Citing a case referred to as *MB*,⁶ Section 13.2 of *The Guide*¹ notes that British courts recognize two ways an individual may lack decision-making capacity:

- the inability to retain and comprehend material information; and
- the inability to use this information to arrive at a decision.

Fazel *et al.*⁷ introduced an instrument to assess whether patients with mild dementia were competent to create advance directives which emphasized the abilities to understand, to appreciate and to derive a rational decision by asking only nine questions. As early Alzheimer’s patients do not suffer from a terminal illness, the interviewer reads the patient one or two hypothetical end-of-life scenarios. Then the interviewer asks the patient to choose between a potentially curative treatment vs a comfort-care alternative. Excerpted sections of the vignette help patients overcome short-term memory problems. Using a cutoff score of six out of 10 points yielded 96% sensitivity and 98% specificity compared to two psychiatrists’ global assessments of competence, among a group of well people contrasted with those suffering from mild dementia. The number of subjects in each group, however, was small.

To determine the decision-making capacity of the patient detailed in this report, no hypothetical vignette was used; instead she was specifically asked about the most relevant situation: her own terminal disease process and treatment alternatives.

History

One day after this 72-year-old woman was admitted to the 24-bed In-patient Care Center of the San Diego Hospice, she announced her desire to limit her nutrition to hasten her dying. She continued to drink diet soda, however. To rule out the possibility that she suffered from a treatable psychiatric illness impairing her judgement, her primary physician requested a psychiatric consultation.

The patient had lost weight after several serious falls; when seen, she weighed 79 pounds with a stated height of 5 foot 8 inches. Her skin was thin and broken down; haematomas covered about half of her body. Her primary physician had previously consulted with other palliative care physicians who felt that further curative/restorative treatment could not reverse the course of her multiple organ disease and general debilitation.

Her chief complaint was: ‘I no longer want to live because I can’t do anything. I must lie perfectly still – otherwise, the pain is excruciating when I’m touched, and when they move me, it’s unbearable’. She did not meet criteria for a Depressive Mood Disorder, or an Eating Disorder according to DSM-IV.⁸ She was neither despondent nor hopeless, and she enjoyed sharing memories about her late husband. She had no fear of gaining weight, and she fully recognized the medical seriousness of her low body weight.

The psychiatrist felt his duty included an attempt to persuade her not to hasten dying – first, to preserve life if possible; second, to test her resolve. As the patient reached a peak of enjoyment during the interview, he argued, ‘If you ate more, you might build up your body; then you would be able to do more, and life would again be worth living’. She agreed. But the next day, she refused to eat again, stating she still wanted to hasten her death.

On that same day, the psychiatrist interviewed her three adult children. All were certain the patient was not aware that she could live for perhaps months with hydration alone – given her low body weight and immobility. They wanted their mother to be so informed. Because of his previous attempt to persuade the patient to eat and live, the psychiatrist felt it best that the adult children (if willing), not he, inform the patient about the need to cease fluid intake if she did not want to prolong her dying. That would reduce the possibility that she would

misinterpret the process of informing with suggesting. During the discussion, the palliative care physician and psychiatrist were present, and neither observed any attempt on the part of the children to persuade their mother as they clarified her two options: 'continue to drink' vs 'stop drinking'. Then the psychiatrist interviewed the patient using the format of the Fazel *et al.*⁷ questions, as show in Table 1.

The patient's abbreviated answers indicate a perfect score of 10 out of 10; hence her decision-making capacity was judged intact.

Somewhat surprisingly, the next day the patient was still drinking small amounts of fluids – as the humanistic procedure, well summarized in Section 3.5 of *The Guide*,¹ was followed: 'Where nutrition and hydration are provided by ordinary means ... [they] should always be offered but should not be forced upon patients who resist or express a clear refusal'. When interviewed, the patient's responses revealed not that she had changed her resolve but that she had merely forgotten to stop drinking. As the psychiatrist began to remind her of her options, she interrupted to say, 'I remember now: I must stop drinking completely to hasten my dying'.

Table 1 Questions to determine decision-making capacity

The patient was able to:

1. Understand her immediate situation ('I'm so completely immobilized by pain that life is not worth living'), and her long-term medical problem ('I've lost too much weight to regain my health').
2. Express a choice regarding a treatment option ('I want to stop drinking').
3. Understand that there is another treatment option ('I could continue to drink').
4. Explain her reasoning for her choice ('Malnutrition alone would not hasten dying').
5. Appreciate the consequence of her choice ('I would die sooner').
6. Appreciate the impact of the choice: for her ('I'd suffer less'); and for her family ('They'd start mourning me sooner ... but then they'll get back to their own lives').
7. Appreciate the short-term effect of her choice ('I'll get uncomfortable from thirst').
8. Appreciate the long-term effect ('I'll die anyway, but this will hasten it').
9. Demonstrate stability by repeating her treatment choice ('I want to stop drinking').^a

^aNote: Fazel *et al.*'s scoring system⁷ allocates two points each for questions 1 and 6, but none for question 2.

Follow-up

The patient confirmed her resolve by subsequently ceasing all oral intake; a day later she lapsed into a coma; three days after that, she died.

Comment

Despite her fluctuation in memory, it was not considered necessary to re-evaluate the patient's decision-making capacity, especially since she subsequently continued to refuse all fluids, confirming her intent.

Discussion

Tailoring the Fazel instrument questions to the specific clinical situation and treatment alternatives formally meets the widely accepted general criteria for determining competency as set forth by Appelbaum and Grisso:⁹ competent patients must have 'skills [to] communicate a choice, understand relevant information, appreciate the current situation and its consequences, and manipulate information rationally'.

This patient's decision to hasten her death was quite different from a patient referred to as *W*, summarized in Section 16.1 of *The Guide*.¹ *W*, a 16-year-old suffering from anorexia nervosa, 'appeared capable of understanding the information given to her and what would be the consequence of not receiving treatment but refused to accept it'. The British court ruled her incompetent to refuse treatment, stating 'her refusal was ... symptomatic of her condition which involved a desire not to be treated'. *W* probably would have failed the Fazel instrument because her decision to refuse food was not rational. In contrast, the patient described in this paper met all criteria of Appelbaum and Grisso.⁹ Forcing a patient like 16-year-old *W* to receive nutrition and hydration might permit survival, and, with psychiatric treatment, the opportunity to lead a normal life. Forcing a patient, like this 72-year-old woman, to receive nutrition and hydration would have merely prolonged her suffering against her clearly expressed will. Yet, the crucial difference depended not on age but on decision-making capacity: *W* suffered from a mental

illness that impaired her judgement; the patient described in this paper had no impairment.

Ascertaining the stability of this patient's decision-making capacity and her specific treatment choice was important, especially if terminal patients exhibit fluctuations in their will to live, as suggested by Chochinov *et al.*,¹⁰ although not proved.¹¹ Terminal dehydration may be preferable to the practice of prescribing lethal doses of medications for patients' self-administration (even where legal), as the former requires a continual demonstration of commitment and thereby makes impulsive acts of suicide less likely. When this patient subsequently forgot to restrict fluids, the psychiatrist felt it unnecessary to repeat the competency evaluation as the patient not only recalled that option and appreciated its consequences, but most importantly she then behaviourally continued to restrict her fluids.

Courts in neither the USA nor the UK want the burden of hearing many end-of-life cases, despite Applebaum and Grisso's statement: 'competence is a legal concept and can be formally determined only in court'.⁹ When the psychiatrist's opinion regarding the decision-making capacity is effectively the last word, it is even more important to use a structured method to determine decision-making capacity; the questions Fazel *et al.*⁷ suggested may provide one such method. That instrument is currently being modified for non-psychiatric physicians to use, to help resolve a variety of end-of-life conflicts.

Singer *et al.*¹² identified five major areas of concern among terminal patients. In this paper the patient's most urgent concern was the most common area that Singer *et al.* identified: to avoid a drawn-out death. Her second concern (in Singer's words) was 'desiring the full involvement of loved ones in communication about dying'. Involving her children did seem to strengthen their relationships. Third, by refusing treatment, she expressed her 'voice in her end-of-life care'. But she did not voice concern about Singer's fourth area: the burden of providing physical care (which hospice was providing), or of witnessing her death (which she felt was inevitable), or of asking her family members to make life-sustaining treatment decisions (which she did herself). Fifth, the least common concern of Singer's patients was obtaining proper pain relief and symptom management. Because of unbearable pain, this patient had to remain completely immo-

Table 2 Checklist for patients who refuse life-prolonging treatment

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1. Has the primary physician fully informed the patient of the prognosis and options?
 2. Have all treatment alternatives been considered to relieve 'refractory' pain and other symptoms that could influence the patient's decision not to prolong life?
 3. Does the patient have a treatable psychiatric disorder (such as depression) that affects judgement?
 4. Is the patient influenced by inappropriate feelings of being a burden to his/her family?
 5. Is actual overt or covert pressure from the family influencing the patient's decision?
 6. Does the patient have decision-making capacity – as revealed by employing a method such as the instrument of Fazel *et al.* – to satisfy Applebaum and Grisso's criteria?⁹
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bile, which led her to feel she had no remaining quality of life.

Table 2 summarizes the basic issues that a psychiatrist should consider when evaluating patients who request withholding or withdrawing life-prolonging medical treatment.

Possessing decision-making capacity is only one factor a psychiatrist must evaluate when a patient refuses treatment to prolong life. Such decisions must also be truly voluntary rather than be subject to other influences. In this case, to evaluate the possibility that the patient was motivated to hasten her death by feeling she was a burden, or by pressure from her children, the psychiatrist interviewed the patient and children, separately and together. Although he considered and documented on the medical chart that these influences seemed minor compared to the patient's chief complaint, it is still appropriate to paraphrase Schneiderman and Teetzel:² We must acknowledge that there are no clear guidelines to suggest how psychiatrists might determine if a patient's decision to refuse life-prolonging treatment is voluntary. Clearly, further research in this area is needed.

Additional safeguards in the form of published clinical guidelines or newly enacted laws should be based on the following considerations.

If litigation occurs after death, what is written in the medical chart may be the only record of what transpired between physician and patient. By then it may be difficult, if not impossible, to be certain that it was the patient, and not the doctor, who decided to hasten dying. For physicians' as well as patients' protection, it can be dangerous to permit

only one physician to determine that a patient's reasoning to refuse life-prolonging treatment is sound. The requirement of two doctors' written opinions might have prevented such tragedies as may have occurred at the Kingsway Hospital in Derby, UK, where investigations are underway to determine if physicians unilaterally decided to hasten dying by dehydrating patients, which acts may eventually be judged as involuntary euthanasia.^{13–15}

In Oregon State, where physician-assisted suicide is legal, two physicians must concur, but neither is required by law to be a psychiatrist. This case history illustrates how complex an evaluation of a patient's refusal of life-prolonging treatment can be:

- (a) The patient's adult children became involved in the decision-making process by informing her that it was important to restrict fluids to accomplish her goal.
- (b) The psychiatrist had to change his stance: from trying to influence the patient's behaviour to live, to facilitating her autonomous decision to hasten her dying.
- (c) The patient's memory disturbance raised the question of instability of her choice, although behaviourally her decision eventually became quite clear.

Until the medical community has sufficient experience to publish agreed-upon clinical guidelines to reliably help physicians determine which cases are straightforward, it seems prudent to this author that one of the two consulting physicians be a psychiatrist. Psychiatric consultants may also provide benefit to the primary physicians; in this case, it helped assure the primary physician that the right action was taken. On the other hand, there is also a potential danger that psychiatrists, through their veto power, might impose their own values – either

consciously or unconsciously – upon the patient. One could imagine a psychiatrist offering a bogus diagnosis of 'rule-out' depression and recommending involuntary hydration and nourishment to 'improve' mental status before a subsequent evaluation. The ethical principles that hang in the balance here are adequate safeguards for patient safety (non-malevolence) vs honouring patients' rights to decide what happens to their bodies (autonomy). Table 3 summarizes the recommended safeguards that seem appropriate at this time.

Conclusions

What can be inferred from applying the British Medical Association's guidelines to a case involving an American patient and hospice? That the competing ethical principles of autonomy vs non-malevolence transcend political and legal differences. As long as a patient's judgement is unimpaired, most ethicists in both countries would agree she has the right to exercise her autonomy.

The BMA's goal, as set forth in *The Guide's* introduction,¹ is 'to provide a coherent and comprehensive set of principles which apply to all decisions to withhold or withdraw life-prolonging treatment. It is hoped that this general guidance will stimulate the development of local policies and guidelines as part of a wider network of safeguards for doctors and patients'. The author hopes that presenting this case will further this goal. As he grappled with considerations of right and wrong in this case, he personally appreciated the insights and support he received from an in-depth discussion with the Ethics Committee of the San Diego Hospice.

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Table 3 Recommended safeguards for patients who refuse life-prolonging treatment

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1. Two physicians agree in writing that the patient has decision-making capacity.
 2. One of the two physicians should be a psychiatrist.
 3. Institutions should develop a checklist to help ensure that clinicians consider all potentially influencing factors, such as ruling out family pressure and making sure all reasonable measures for palliative symptom control have been considered.
 4. Physicians should refer the case to an ethics committee if there is still conflict.
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