ETHICAL DEBATE

Are advance directives legally binding or simply the starting point for discussion on patients' best interests?

Following advance directives in emergencies throws up some complicated problems, as **Stephen Bonner and colleagues** found. We asked an emergency doctor, a medical defence adviser, and an ethicist what they would do in the circumstances

The ethical principle of respect for autonomy has progressively overtaken paternalism in the interface between medical profession and patients. For competent patients this translates into the concept of informed consent. In addition, the Mental Capacity Act 2005 enabled individuals to write an advance directive or appoint a lasting power of attorney to make their views on health care known should they lose capacity.[1] However, these rights are limited to planned refusal of specific medical treatments, and even this is vulnerable to challenge if the directive is not sufficiently specific.

The following case study explores the questions that arise with regard to an advance directive to refuse treatment in the context of a life threatening overdose.

Case history

A 62 year old woman, bed bound with severe arthritis and in constant pain despite strong opioid treatment, presented to the emergency department unconscious with an obstructed airway and absent gag reflex. A suicide note documented that she had taken an overdose up to 24 hours previously of chloral hydrate, diazepam, paracetamol-codeine combination, and alcohol. The note also clearly expressed the patient's distress at her longstanding pain and severe restriction of function and independence. Her general practitioner had called for the ambulance with the support of her husband, who presented medical staff in the emergency department with an advance directive signed by the patient (see bmj.com) stating that she did not want life sustaining medical treatment. Her husband emphasised that although the family would ideally want her advance directive followed, they would support any actions and treatment taken by the healthcare team in our interpretation of her directive and wished to remain independent of any decision making.

The urgent decision for staff was whether to initiate advanced life saving treatment, involving intubation and ventilation, against her stated wishes or administer simple non-interventional treatment such as oxygen and fluids and maintain comfort and dignity in accordance with her advance directive, with the likely outcome of death.

Further information from her husband revealed that the patient had completed her advance directive five years ago, having seen both parents die in intensive care after prolonged, undignified, and distressing illnesses 10 years previously. She was insistent that this was not what she wanted at the end of life and had expressed specifically to her family that she never wanted to be admitted to intensive care. She had filed five copies of her advance directive with her husband, sister, daughter, general practitioner, and lawyer and was consistent in this view throughout the intervening period.

She had a long history of rheumatoid arthritis, but her health had declined appreciably over the past five years, and the pain had confined her to a wheelchair during the past six months. Three weeks before admission she had had an acute deterioration with widespread joint pain and sciatica, which had been particularly debilitating. She had been reviewed by a rheumatologist and prescribed methotrexate, but her symptoms had not yet improved.

Medical decision making

Medical management of this patient without the variable of the advance directive would be immediate intubation and ventilation, provision of intensive care, and active management of her underlying medical condition and any associated depression once she was recovering from the acute illness.

The key question facing staff, with little time available, was whether the advance

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COMMENTARY It is often difficult to establish exactly what has been directed

Emergency medicine, as the name suggests, is a specialty of rapid decision making, and decisions often have to be made with limited information. Emergency physicians are adept at collecting, assimilating, and assessing the available history of a patient's condition together with relevant indicators of physical state to form a menu of possible actions. The patient's wishes are always part of this process. Sometimes, as has been suggested here, a first assessment might seem to show that only one action (in this case immediate intubation and ventilation) can prevent death, but experience shows this is rarely, if ever, true. If, in the brief time available to reflect, it seems that the only available choice really is to act now or to allow immediate death then most emergency physicians (including me) would act—on the grounds that it is always possible to withdraw treatment from a live patient but never possible to start treatment in a dead one.

What would the outcome of that reflective moment be in this case though? Well the first clue lies in the length of the history. It is unlikely that a patient who has survived 24 hours is in immediate danger of death. Furthermore, the nature of the overdose is such that, barring sudden and catastrophic ventricular dysrhythmia (which really would require an instant decision), general support is likely to buy time for wider consultation and for a thoughtful and better informed decision to be made.

Having decided to buy time, the next vexing issue is deciding what constitutes general support and what is apparently precluded by her advance directive. In this case of mixed overdose several treatments are available that may lighten the depressed conscious state and therefore help protect the airway without intubation. The effects of diazepam and codeine can be reversed with flumazenil and naloxone respectively. The patient may also be hypoglycaemic after paracetamol overdose, and this (unlike the implied underlying liver damage) can be easily reversed with intravenous glucose. Although the advance directive seems to preclude any medical intervention or treatment that will prolong or sustain life, this is only in a situation where the conditions mentioned in the schedule apply. There is sufficient doubt about the qualifying nature of the underlying condition in this case that I would feel justified in giving a trial of the two antidotes and measuring and correcting the blood glucose; managing the airway non-invasively in this way buys time more safely.

The aim of any treatment provided is to prevent deterioration while clarity about the patient's wishes is established as quickly as possible

In summary then, I would take a measured approach to a case like this. The law requires well documented and clear advance directives to be followed—the problem in the emergency department is that it is often difficult to establish exactly what has been directed.

In these circumstances the aim of any treatment provided is to prevent deterioration while clarity about the patient's wishes is established as quickly as possible. Even with this proportionate approach, deciding what treatments are appropriate can still be problematic, and the particular circumstances will have to be taken into account.

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COMMENTARY Certain criteria must be met to determine if an advance directive is legally binding

In an already challenging clinical situation the team is faced with a serious dilemma: to follow the advance directive refusing life sustaining treatment or to treat the patient against her previously expressed wishes.

The Mental Capacity Act 2005 enshrined in statute law the right of an adult with capacity to make an advance directive to refuse specific treatment at a point in the future when they lack capacity. Certain criteria must be met to determine if an advance directive is legally binding. It is these that the team must consider without delay.

Firstly, as this advance directive is refusing life sustaining treatment, it must be in writing, signed, and witnessed and include a clear written statement that it applies to the specific treatment, even if life is at risk.

Secondly, the advance directive must be valid at the time it is put into effect. If there is evidence to suggest the person has changed his or her mind—for example, if they have done something that goes against the advance directive—this would make the advance directive invalid.

Thirdly, the advance directive must be applicable to the current circumstances. If it does not specify the treatment that is now proposed, or if the circumstances envisaged at the time of writing have now changed, then the advance directive may not be applicable. Factors to consider include the length of time that has passed since the advance directive was made and changes in personal life that may affect the circumstances the person is now in.

If the healthcare professionals are satisfied that the advance directive is valid and applicable, it must be followed

An important question in this case is whether the advance directive made five years ago applies to the circumstances of the patient's present suicide attempt. Information contained within the suicide note should be taken into account, but to be binding as a refusal of treatment it will need to meet the same criteria as above. In addition, consideration should be given to the patient's capacity at the time of writing the suicide note.

If the healthcare professionals are satisfied that the advance decision is valid and applicable to the proposed treatment in the current circumstances, then it must be followed. It is as legally binding as a refusal by a competent adult, and a failure to follow it could lead to a claim for damages for battery or a criminal charge of assault.

If the doctors are not satisfied, based on the information available, that the advance directive is valid and applicable, they can provide treatment in the best interests of the patient. The advance directive must be considered as part of the assessment of the person's best interests. The doctors must be prepared to justify their decision, and careful documentation of the reasons behind their decision is essential.

In the emergency situation, when there may be some unavoidable delay while the advance directive is assessed, immediately necessary treatment to preserve life may be provided.

When there is genuine doubt about the validity or applicability of an advance directive, an application can be made through the trust's legal department to the Court of Protection for a determination. Urgent cases can be considered quickly, 24 hours a day under the court's emergency procedures.

There were some differences of opinion between members of the team in this case, which is not unusual. Ultimately, the decision rests with the healthcare professional who is in charge of the person's care when the treatment is required.

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COMMENTARY There is no evidence the patient was not competent when she made her advance statement

Confronted with a legally valid advance directive, medical staff in England and Wales are essentially bound to follow its terms if they are applicable to the circumstances since the passing of the Mental Capacity Act 2005. The act enshrines the concept of autonomy in statute, allowing individuals to choose to avoid a particular treatment that they would, for whatever reason, find unacceptable. In Scotland, there is no statute that gives legal effect to advance directives, but there is a general view that they should be followed. In this case, there is no evidence that the patient was not competent at the time she made her advance statement. Her decision was based on her observation of the deaths of her parents and her concern not to suffer in a similar way. Her determination to avoid this fate seems to be evidenced not only by making the directive but also by repetition of her wishes over the years and by the fact that she lodged a copy of the document with several people, leaving them in no doubt as to what she wanted.

When a condition is life threatening but treatable, it is obviously extremely distressing for healthcare professionals to allow the patient to die, but this is what the law requires, and liability could follow a deliberate failure to abide by the terms of an advance directive to reject treatment. On the other hand, no liability will follow the withholding or withdrawing of treatment if the healthcare professional "reasonably believes" that there is an existing advance directive that is valid and applicable.

The act intends to give the same validity to an advance directive as to a contemporaneous one and healthcare professionals should treat it in this way, however difficult that may be

Although the facts in this case seem quite straightforward, there may be others that are not so clear cut. What if there is doubt about the capacity of the individual to execute a valid directive? For example, could it be said that if someone was depressed at the time of taking the decision to reject treatment in the future or was suffering from a mental illness they were not capable of making a legally valid decision? The law does not assume an inevitable lack of competence in these situations. All adults are deemed to be competent, although this presumption can be rebutted by evidence to the contrary, and the act spells out that for incompetence to be established the person should be "unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."

Of course, healthcare professionals treating an unconscious patient in an emergency setting will have no easy way of ascertaining the person's state of mind when the decision was made. If in doubt, they would be well advised to consult the patient's family or general practitioner, and ultimately they may decide to seek a court decision about the validity of the directive. Where such doubt reasonably exists, the act is clear that there is no liability if life sustaining treatment is provided while awaiting the court's decision.

However, this should not be interpreted as allowing healthcare professionals to use the courts to avoid respecting the patient's competent prior wishes, just as a healthcare professional confronted with a contemporaneous refusal of treatment cannot impose it. The act intends to give the same validity to an advance directive as to a contemporaneous one and healthcare professionals should treat it in this way, however difficult that may be.

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directive generated a binding veto on this course of action. The foundations for both the directive and the suicide attempt seemed logical given her progressively debilitating medical condition, poor quality of life, and the fact that she had clearly and consistently expressed her views for many years about end of life care.

The advance directive was valid in the terms of the Mental Capacity Act in that it was in writing, witnessed, consistently expressed over many years, and supported by her family. Indeed, the act does not demand that a view is necessarily understandable or the medically "correct" course of action if it is a deeply held belief, which seemed true in this case.

The staff from emergency medicine and intensive care held a range of views about appropriate management. This was a reversible condition, yet treating her seemed to be against her longheld beliefs and wishes, and it was unclear what constituted acting in her best interests.

Staff were anxious that failure to administer potentially life saving treatment might constitute assisted suicide. What should the healthcare team do at this point?

Case management

Although the meaning of the patient's advance directive was clear, and some members of staff thought it should be complied with, the team decided to intubate and admit her to intensive care. There were five reasons for this decision:

- Any delay in attempting definitive resolution would result in death or serious morbidity

- Her clinical condition was not specifically covered by the conditions listed in the advance directive
- Staff could not be sure of the patient's state of mind at the time of taking the overdose, but if this was in response to pain or depression, alternative treatments could potentially improve her quality of life. She had sought treatment for her arthritis, and this constituted a willingness to seek and accept medical treatment that could be given if she recovered
- Her condition was likely to respond quickly to treatment rather than result in the protracted distressing death that her parents had experienced, and the appropriateness of ongoing management could be regularly reviewed in light of her advance directive
- The risks of adverse consequences in the form of further pain, dependence on medical intervention, or distress, from intensive care management after a simple overdose are small—that is, the risk of doing harm in a physical sense was low.

Subsequent progress

The patient remained unconscious and ventilated in the intensive care unit for three days. When she regained consciousness, it was apparent that she had had a stroke with a left hemiparesis. She was discharged to a rheumatology ward after five days, where treatment with methotrexate gave excellent symptomatic relief from her arthritis. She was diagnosed with depression and started on fluoxetine. She was discharged home after three months of hospital treatment, almost pain free and mobile with assistance.

At a review six months after discharge she was cheerful and able to walk with a stick, with only a mild residual left sided weakness and her pain well controlled. Although she acknowledged that her quality of life had improved greatly and was grateful to staff for attempting to act in her best interests, she still considered that she had a poor future quality of life and maintained that she would rather have had her wishes respected, retained her independence and dignity, and not survived. This position was confirmed in a subsequent letter. She also said that if assisted dying legislation had been in place, she would have explored this possibility, a position supported by her family.

She died in hospital 18 months later after a second stroke and with respiratory complications of methotrexate.

Discussion

This case shows the difficulties healthcare workers face when respect for autonomy apparently conflicts with the associated ethical principle of beneficence and when the absolute authority of an advance directive has to be defined, particularly in emergency situations and end of life decisions with an understandable sense of professional vulnerability whichever path is chosen.

Advance directives are an important and valid expression of patient autonomy, endorsed by the British Medical Association, the Standing Committee of European Doctors, the General Medical Council, and the Mental Capacity Act 2005.[2-4] The Medical Treatment (Advance Directives) Bill clarified that doctors who complied with an advance directive would not commit a criminal offence. The Law Commission stated that advanced refusal of treatment should carry as much weight as a refusal from a currently competent person,[5] a position also adopted within the civil courts.[6 7]

However, the same authorities state that doctors are not bound absolutely by advance directives. "It could be impossible to give advance directives in general greater legal force without depriving patients of the benefit of . . . new treatments and procedures."[8]

This is relevant in this case, as the patient had clearly sought medical help for her arthritis and accepted previously unexplored treatment, which should over time have modified the refractory pain that was a key trigger for the suicide attempt.

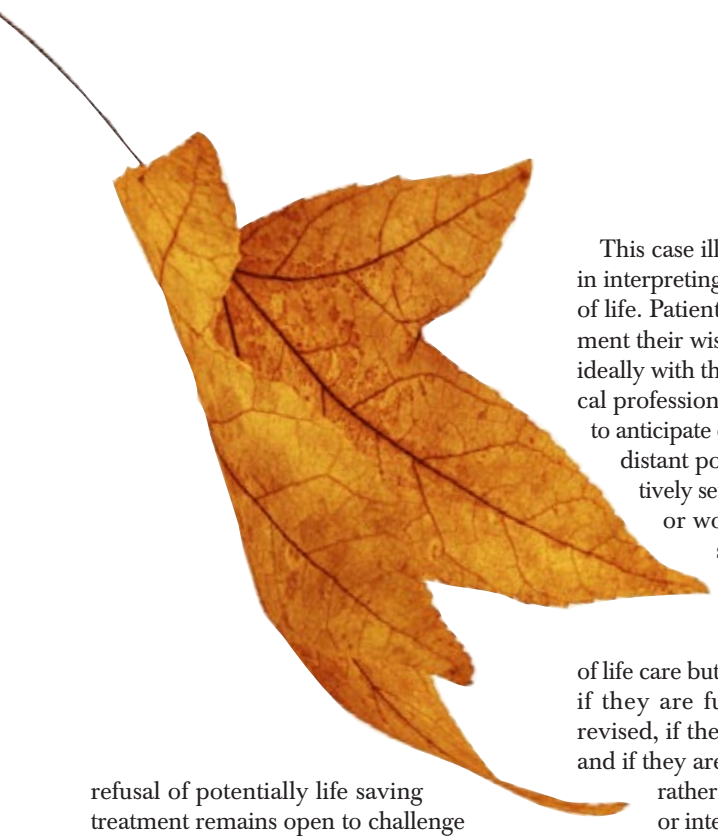
An additional relevant circumstance in which compliance with an advance directive would not be supported is if it was used to justify an illegal act, such as euthanasia or assisted suicide. A medical defence society opinion was that she should be treated rather than risk an accusation of abetting a suicide, punishable under the Suicide Act 1961. This creates an interesting paradox with the case of Ms B, a competent, tetraplegic, ventilator dependent patient, where the courts held that it was unlawful to refuse to comply with her wishes to stop ventilatory support in the full knowledge that death was an inevitable consequence.[6]

In both this and our case the reason for refusing treatment was an unacceptable quality of life.

The validity of our patient's advance directive could also be questioned because the specific circumstances of overdose were not mentioned. Although she had repeatedly informed her relatives that she did not want to be admitted to intensive care, a verbal advance directive, this was based on her parents' experiences, not taking into account the good prognosis from her overdose. We thought that this justified treatment despite the advance directive.

If the patient had presented critically ill—for example, from pneumonia—she probably would not have been admitted to intensive care because her condition would have been similar to those specified in the directive—that is, requiring invasive distressing treatment and with relatively poor prognosis. Specificity is required to make any directive binding but could carry unwanted consequences. If certain elements of life sustaining treatment are refused, the overall package of care becomes artificially restrained and creates the very imbalance of harm versus benefit that patients are seeking to avoid. For example, if a patient had specifically refused a tracheostomy but could not be weaned from ventilation without, would staff be committed to repeated and distressing failed trials of extubation simply because the patient had not understood what a tracheostomy entailed or that the alternatives were worse? How can we evaluate informed consent in a previously written advance directive?

The role of the next of kin creates an additional layer of complexity. Professional bodies recommend liaison with next of kin to determine a person's values and beliefs and specify a need for their assent when carrying out medical interventions.[9 10] However, next of kin have no formal authority under English law, and although the Mental Capacity Act allows a competent person to appoint a lasting power of attorney with specific responsibility for medical matters,



refusal of potentially life saving treatment remains open to challenge as against best interests. The act supports adoption of the least restrictive option—that is, preserving life. Differences of opinion between healthcare staff and appointed attorneys attempting to restrict life sustaining medical treatment seem inevitable.

Another problem is that a person's values may change over time, and it is unclear when an advance directive becomes historical if not updated or revised. Advance directives are based on then current understanding of medical practice and outcomes and fail to accommodate subsequent advances.[11] There is evidence that patients understand this and prefer that treating clinicians retain considerable flexibility in the interpretation of instructions.[12] Although advance directives have been promoted in Texas for over 30 years, most people prefer to leave decisions about end of life treatment to someone else.[13]

This case illustrates some of the problems in interpreting advance directives at the end of life. Patients should be engaged to document their wishes in the event of incapacity, ideally with the combined input of the medical profession and next of kin, but attempts to anticipate every possible scenario at some distant point in the future and proscriptively set out which interventions would or would not be acceptable, to the standards necessary to make this binding, appear unfeasible. Advance directives form an opportunity to plan for end of life care but are more likely to be followed if they are fully informed, are regularly revised, if their limitations are understood, and if they are drafted to reflect motivations rather than specify clinical conditions or interventions.[14] Healthcare professionals have a duty to understand their responsibilities under the Mental Capacity Act and derive the validity and applicability of any advance directive that they receive, but clarification regarding the legal position of healthcare professionals failing to act to preserve life in accordance with an advance directive would be welcomed.

Our patient's directive did not help staff to treat her as she would have wished. She lived almost pain free for another 18 months with some reservations but no resentment over her management and unfortunately subsequently died in hospital in a manner which she had tried to avoid.

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Patient consent not needed (patient anonymised, dead, or hypothetical).

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ANSWERS TO ENDGAMES, p 1263. For long answers go to the Education channel on bmj.com

STATISTICAL QUESTION

Random allocation II
b

PICTURE QUIZ A case of diplopia and arm weakness

1 Ptosis, worse on the right, and failure of abduction of the left eye are the most apparent clinical signs.
2 The weakness affects several extraocular muscles, resulting in diplopia on lateral and up gaze. The proximal weakness is worse on exertion and towards the end of the day and better with rest. These findings suggest myasthenia gravis.
3 Investigations should include vital capacity measurements, assay for serum acetylcholine receptor antibodies, Tensilon (intravenous edrophonium) test, electromyography, and contrast enhanced computed tomography of the chest to exclude thymoma.
4 Management includes anticholinesterase drugs (pyridostigmine, prostigmine) for symptomatic relief, and steroids, together with azathioprine or other immunosuppressants.