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## Commentary

# Ethics roundtable debate: should a sedated dying patient be wakened to say goodbye to family?

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## Abstract

Intensivists have the potential to maintain vital signs almost indefinitely, but not necessarily the potential to make moribund patients whole. Current ethical and legal mandates push patient autonomy to the forefront of care plans. When patients are incapable of expressing their preferences, surrogates are given proxy. It is unclear how these preferences extend to the very brink of inevitable death. Some say that patients should have the opportunity and authority to direct their death spiral. Others say it would be impossible for them to do so because an inevitable death spiral cannot be effectively palliated. Humane principles dictate they be spared the unrelenting discomfort surrounding death. The present case examines such a patient and the issues surrounding a unique end-of-life decision.

**Keywords** ethics, intensive care, palliative care, terminal care, withholding treatment

## Introduction

### Brian Woodcock

The ability of modern medicine to maintain the human body by artificial means has progressed dramatically. Even in the face of complete failure of respiratory, cardiac, and renal systems, artificial organ replacements can maintain life to a point beyond that where any feasible recovery is possible. With artificial ventilation, ventricular assist devices, and extracorporeal membrane oxygenation, it can be extremely difficult to die in a medical center with access to these advanced modalities of life support. Problems can arise when the patient reaches a point where technology is maintaining 'life' but there is no way for life to continue without the technology. Withdrawal of this support can raise more difficult questions than during institution of support. The case we are presenting concerns the dilemma of whether a patient would want to awaken before life support is withdrawn and he/she is allowed to die. And in this circumstance, who should make that decision?

## The case

A 57-year-old patient suffered intraoperative complications and failed to wean from cardiopulmonary bypass during a coronary artery bypass graft operation. Inotropic drugs and intra-aortic balloon counterpulsation failed to restore an adequate circulation. The patient was transferred to the intensive care unit (ICU) on multiple life support systems, including mechanical ventilation, and left and right ventricular assist devices.

Cardiac transplantation is not possible for this patient for logistical reasons. The biventricular assist devices cannot be continued indefinitely. Placement of a permanent implantable left ventricular assist device is not feasible. The alternative is likely to be withdrawal of support, which will result in rapid death.

In the ICU the patient is heavily sedated with propofol, but otherwise presumably neurologically intact. Would you want

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ICU = intensive care unit.

to wake the patient up first so he could be informed what is happening? Would you give him a chance to say goodbyes to family? Should the intensivist ask the family to decide?

The feelings of the medical team are diverse, opinions vary as to whether an individual would want to wake up before death. Would it be cruel to wake him up, just to tell him that he is going to die? He may have gone into the operation knowing that this was a high-risk procedure but had the reassurance of thinking 'If I wake up, I'll be OK, if I'm going to die, I'll never know about it'. In those circumstances the patient would not be expecting to waken to the certainty of imminent death. An alternative feeling in the medical team was that, given the opportunity, many people would want to know what was happening and possibly complete the process of saying goodbye to loved ones.

### **A trouble shared is a trouble halved**

**Anna Batchelor**

The case scenario presented involves three sets of people each with needs and desires: the patient, the relatives, and the carers.

Considering the patient first, he has no choice to make about continuing care as there are no viable options; however, he does have a right to know what is happening and to make a choice about communicating with his family. We are not told what his presurgery views were – would he wish to be able to communicate in this situation or not? Is it possible for this patient to have his pain, distress, and anxiety relieved at the same time as withdrawing sedation to allow a meaningful return of consciousness? The worst endpoint would be a confused, agitated patient in pain failing to effectively communicate.

The relatives are our concern too; they will leave the hospital with memories of their loved one and the quality of care offered them. Some people will be able to communicate effectively their goodbyes and love to the patient, others will find this stressful. We need to know from the family what the patient is likely to have wanted in this situation. Had he already said his goodbyes 'just in case' or had he avoided such discussions? Is he going to be any better prepared for such discussions surrounded by machinery and strangers? Is he someone who liked to be in control of himself and his surroundings and would welcome the opportunity?

The carers have to examine their own reactions and not impose their own views on the family. Nurses particularly being in close contact with the patient may feel strongly that one course of action is preferable.

These matters should be resolved by team discussions involving all the carers, and possibly a minister of religion if that is relevant for the patient. Is it possible to achieve the desired scenario of an awake, communicative, undistressed

patient? Would the patient want this? If so, who will care for the patient during this episode.

Discussions with the family should involve a small number of carers all saying the same thing. The relatives must clearly understand that no further active medical treatment is possible and that the patient will die. It is necessary to explore with them the issues raised and find out whether they feel the patient would wish to be awake, and whether they wish this to be attempted. The family should feel that they are involved in the decision-making process and asked for their views but not that they are left to decide; yet again, this is a team decision. Who will be present? Is this an opportunity for the whole family to show they care or an intimate occasion for one or two key people? This in itself can lead to conflict. It should be clearly understood that the patient remains our main focus and it may not be possible to achieve an awake, comfortable patient. We will not allow him to be in pain or distress, and treatment for this along with the presence of an endotracheal tube will limit his ability to communicate.

### **No spiritual care without consent**

**Leslie Jenal**

To wake this patient either to inform him of his impending death or to provide an opportunity for closure violates classic principles of medicine: nonmaleficence, autonomy, and justice [1].

Under the facts of the case, this patient can no longer exercise any meaningful consent as to his treatment because nothing, in fact, can be done for him. Waking the patient to inform him of his prognosis therefore cannot give him autonomy in any meaningful sense. In fact, informing him of his inexorable death is very probably an act of harm if he is likely to suffer from death anxiety. Most people, even those who have had a chance to prepare, suffer from death anxiety, regardless of the depth of their religious faith and belief in an afterlife [2,3]. Justice demands that our patient's needs, and only our patient's needs, inform our actions. In this case, a decision to wake the patient would possibly have more to do with the physician projecting his own need to know the cause of death onto the patient [4,5].

The decision whether to wake this patient for purposes of closure concerns less his medical treatment than his spirituality and, under the facts of this case, can have no bearing on his physical health at all. Spirituality is defined here according to its function as that which brings significance and meaningfulness to a person's life. The principle of autonomy applies because meaningful consent is required for spiritual care as for other types of treatment. The patient cannot consent and probably no surrogate decision-maker under an advance directive concerning his physical health will have any power over spiritual care decisions. We should not therefore provide spiritual care if we do not have a reasonable belief that the patient would have consented [6].

In this case, the presumption should be that we do not wake the patient because we cannot guess whether he has a spiritual task to complete.

Of course, the patient's family may assist us in determining what the patient would want, but the burden of proof is on the family in this circumstance. The principle of justice demands that we concern ourselves with the patient's needs, and not his family's needs. First-degree relatives who have been in close contact with the patient in recent weeks should be consulted. We must be careful also to recognize that not all families operate like our own families, like other families we have observed, or like the families we would like to have.

Finally, we must consider procedural justice; that is, we must decide with full knowledge of how we, as individuals, make the decisions that we make. Decisions that impact a patient's spirituality require a very acute sense of the boundary between the decision-maker's needs and feelings, and the patient's needs and desires. Good decision-making requires self-reflection, knowing ourselves, and knowing how we make the decisions that we make.

## **My responsibility is to the patient not the family**

**Farhad Kapadia**

This example presents a dilemma one faces frequently in an ICU. A sedated patient on multiple supports has reached the point of no return. The family is informed and enquires whether the patient can be aroused so that they may communicate with the patient.

An encephalopathy is sometimes part of the multisystem involvement. We can inform the family that withdrawing sedation could lead to distress but there is little chance that the patient will be lucid enough to communicate. This invariably leads to a rapid family consensus that no such attempt be made.

Another situation that is more difficult is one in which the patient is likely to be completely lucid off sedation, but there is a glimmer of hope that the illness may not be terminal. As part of the intensive care therapy, sedation is stopped for a few hours of the day and the level of consciousness established. The family invariably communicates with the patient in these brief periods.

The real problem occurs in situations similar to the patient presented. First, it is presumed that the patient has no chance of independent survival. Second, the patient will probably be fully awake and comprehending when sedation is stopped. Finally, the patient was probably not forewarned that such a situation could arise.

In such a situation, to date, I have not agreed to stop sedation. My reasons are as follows. First, my initial

responsibility is to the patient and not to the family. Also, I do not know to what sort of distress withdrawal of support will lead. I would not feel confident that I could offer reasonable assurance that there would be minimal pain, minimal gagging, minimal coughing, minimal bucking, and minimal respiratory distress. Finally, even if I could assure an awake and comfortable patient with judicious drug therapy, I would be unwilling to decrease sedation as I have no idea what thoughts would go through the patient's mind. I would worry that these thoughts may lead to severe mental distress and perhaps even to terror of impending death.

I would explain these reasons to the family and inform them that I am unwilling to stop sedation.

There are two settings in which it is conceivable that I would agree to sedative withdrawal for terminal communication. First, if there was some sort of prior documentation stating the patient's desire to communicate with his family terminally, even in the environment of an ICU. Second, if I knew the patient and family before the critical illness, either as their primary care physician or socially, and I really believed that the patient would have desired to communicate terminally with the family. To date, I have not encountered either of these two settings.

## **First, do no harm**

**Stephen Streat**

Does the patient have a 'right' to be awakened? One can only speculate what the potential effects on the patient of such awakening might be, but it is impossible to see this as being anything other than 'very bad news'. I am strongly of the view that simply because the possibility of awakening exists, it does not lead to the concept of a 'right' to experience it. On the contrary, the patient has an overwhelming right to be treated with compassion and dignity, and it is these considerations that lead me to believe that allowing the patient to awaken and be informed of the immediate prognosis is a bad thing.

Possible benefits to the patient such as revising a will are small or absent. What about final farewells to loved ones? Again, I believe that the well-informed patient will have taken this opportunity after presentation of the risks of the planned procedure. I believe that people tend to live their dying much as they have lived their lives. If an opportunity to communicate love and possible farewell was not embraced and fully utilized when it was possible under optimal circumstances, it is unlikely to be taken or be of great benefit under conditions of considerable distress. There is also the possibility that the patient might wish to participate in a religious ceremony, or perhaps receive last rites. I am not strongly persuaded by this view but could entertain the possibility of discussing this aspect with the patient's family with a view to determining the strength and centrality of the patient's religious faith. It should also be mentioned that the patient need not be awake to receive 'last rites' from most, if not all, religions.

The reality is that, after awakening, the patient will probably have some postoperative pain and also experience the discomfort produced by the presence of an endotracheal tube. Communication is imperfect under these circumstances, and this imperfection is often a source of additional distress to intubated patients recovering from critical illness, let alone a patient receiving a hopeless prognosis. Perception of reality may be incomplete, like a bad dream, and the patient may be frightened and unable to respond with lucidity. It is difficult to imagine a patient being grateful for such news, delivered under such circumstances; indeed, I am inclined to view it as cruel.

We do well to realize that in everyday life we make choices based not only on the possibility of benefit, but also on the risk of unacceptably bad consequences – a circumstance that Gillett [7] has eloquently described (in consideration of the possible outcomes of severe brain injury) as “the risk of unacceptable badness”. I argue that in this circumstance (with the possible exception of the patient with unusually strong religious faith, who might appreciate a final religious rite), the risk of allowing the patient to awaken is unacceptable in the light of the weak (or absent) arguments for possible benefits that might accrue.

It is my considered opinion that this patient should not be awakened during the dying process.

## Wrap-up: some concluding thoughts

### Leslie Whetstine

This case raises two questions: ought the healthcare team awaken a terminally ill patient before life-sustaining treatment is withdrawn, and who ought to make this decision? All of the discussants agree on the substantive question, that this patient should not be aroused. Some controversy exists however, as to who should be the appropriate decision-maker. The consensus is that this encumbered patient would probably suffer unmanageable physical and emotional distress upon arousal [8]. The discussants' primary objective is the patient's comfort, and the burdens of arousal appear to outweigh any projected benefit [9].

Kapadia and Streat fear that even if adequate pain management were possible the psychological distress would be inhumane, culminating in a nightmarish altered perception of reality. Streat rejects the notion that simply because arousal may be possible, the patient has a right to it. Jenal argues that this is no longer a medical issue, but a spiritual care decision that should not be imposed upon the patient in the absence of a substantial consent. Jenal correctly points out that the facts of the case leave no autonomy to exercise.

Batchelor, however, suggests that while there may be no available medical options, the patient might have a right to know what is happening and to make choices about familial communication. In an ideal situation Batchelor is most

correct, but to respect autonomy in a literal sense would actually require the team to awaken the patient to ask him whether he wanted to be awakened. Clearly this type of reductionism should be avoided.

As a practical matter, Batchelor favors a joint approach to decision-making involving the medical team and family but is clear that the patient's comfort is her primary goal. Thus, if arousal would cause discomfort, it appears she would not comply. Streat does not suggest he would consult with the family, while Kapadia would only awaken the patient if there were advance directives or if he had an ongoing relationship with the patient. Jenal endorses joint decision-making but puts the burden of proof on the family, which seems to be the appropriate standard in this case.

The principles of beneficence and nonmaleficence [10] are clear for this patient. We have an obligation to do well and prevent harm when possible. Given the clinical doubts that arousal could be well palliated, the family must convince the team that the benefits thereof outweigh the detriments. It would seem unlikely that a family would be able to prove such a case. In the event they could prove a convincing case, their decision should be respected since the authority of surrogacy is the established norm, at least in the United States. If not, the physicians are ethically correct to tread the path leading to the greatest patient comfort under the circumstances

## The outcome of the case

### Brian Woodcock

The outcome in this case was that the decision never had to be made. The patient developed signs of a stroke, probably due to embolus from thrombus in his left ventricle. Sedation was discontinued and the patient had severe neurological signs with absent brain stem reflexes. Support was withdrawn and the patient never awoke.

## Competing interests

None declared.

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