Waking the Dying

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Many critically ill persons are unable to participate in medical decision making, due, at least in part, to medications administered to provide sedation and analgesia. Such patients may retain the ability to participate to some degree in medical decisions if these medications can be reduced or eliminated. Decisions regarding the withdrawal of support, in particular, highlight the ethical complexities surrounding the participation of the critically ill patient. An appeal to the principle of autonomy would seem to demand that in all such cases attempts must be made to involve the patient; however, under certain circumstances arousing a dying patient to inform them of their imminent demise runs counter to the principle of beneficence in health care. A casuistic approach to this apparent dilemma identifies the ethically relevant aspects of such cases and allows for the development of specific criteria for judging the appropriateness of attempting to involve a critically ill patient directly in decision making. Patient comfort, prognosis, and prior preferences carry significant ethical weight. In cases in which a sedated, critically ill person cannot be aroused without causing significant pain and suffering, has a very poor prognosis, and in which prior unambiguous directives or current family/surrogate consensus exists that withdrawal of support would be preferred by the patient, the author argues that no ethical obligation to attempt to involve the patient in medical decisions exists.

Key words: decision making; end of life; medical ethics; terminally ill; withdrawal of life support

Several factors may prevent patients in the ICU from participating directly in medical decision making. Severity of illness or specific neurologic injury may preclude any possibility of involvement by the patient. Often, however, the patient’s decision-making capacity is compromised by medical therapy designed to provide comfort in the form of anxiolysis, amnesia, and/or analgesia. In such situations, patients may be medically rendered incapacitated to participate in discussions regarding care. If medication was minimized or withheld, however, it might be possible for the patient to again participate in some fashion in medical decision making. Physician’s caring for such a patient, then, are faced with a question of whether to attempt to involve that person in medical decision making or, as an alternative, to rely on surrogate decision makers or physician judgement alone for decisions. Although this question rightly applies to any medical decision under such circumstances, from permission for simple procedures to decisions regarding withdrawal of support, it is the latter that has the most profound ethical implications.
To put the question succinctly, must a physician attempt to remove sedation and/or analgesia from a critically ill patient in an attempt to have that patient participate in, or at least be made aware of, a decision regarding withdrawal of support? Although physician attitudes on this issue appear to vary widely, I will argue here that the most appropriate answer is not absolute and does not depend on an appeal to ethical principles alone, but on an understanding of the particulars of each case. Specific criteria will be proposed and defended that, when met, would allow for support to be withdrawn from sedated individuals who might otherwise retain the capacity to participate in medical decision making.

**Beyond Autonomy and Beneficence**

One approach to the question of whether a sedated, dying patient should be aroused to participate in medical decision making is to frame the issue as a conflict between preeminent principles of medical ethics, the respect for autonomy, and beneficence/nonmaleficence. Deciding which of these principles takes precedence attempts to answer the question in absolute terms. Respect for individual autonomy has become the guiding principle of medical ethics over the last several decades. The President’s Commission for the Study of Ethical Problems in Medicine stated that excluding a competent patient from medical decision making regarding supportive care is “unjustifiable since it demeans the patient by barring self-determination and allows other to shorten the patient’s life...” Although the Commission does not directly address the issue, a strong notion of autonomy would seem to require that patients who are incapacitated by medication have that medication lessened or discontinued in an attempt to restore capacity and allow for direct participation in their medical care.

Certainly a counter argument based on beneficence can be made by arguing that autonomy is overvalued when it conflicts with common notions of compassion and caring. Forcing emotional, psychological, and physical discomfort on a patient in the name of respect for autonomy may, at times, seem cruel rather than respectful. Furthermore, the ability of a seriously ill patient, even when receiving no sedation, to exercise judgment in a truly autonomous fashion is suspect. Still, relying on the beneficence of caregivers alone is itself problematic in such situations. Simply allowing physicians to decide on the grounds of beneficence when not to involve a patient in medical decision making raises the legitimate concern of “hard” paternalism, with the attendant threat to patient autonomy.

Rather than depend on an appeal to apparently conflicting ethical principles in an attempt to resolve this particular ethical dilemma, a careful casuistic analysis provides an alternative approach that can yield practical insights into the problem and specific guidelines for clinical practice. Instead of starting with the exposition and defense of principles and then attempting to apply them to a particular problem, the alternative casuistic approach starts with the facts of the case at hand. From these grounds, the issue pertinent to the debate can be elucidated, invoking specific maxims and inviting comparisons to similar situations. Reasoning about the case, then, is done primarily by analogy with paradigmatic cases rather than deductively. The conclusion reached is provisional, holding only if the case at hand is similar enough to those prior cases on which it is based. Challenges, or rebuttals, will take the form of describing the ways in which the current case is different from those precedents. If the differences are great enough, the conclusion may be altered. This description of the case method above is greatly simplified, but many physicians have had some contact with it already, as this approach has been influential in the development of clinical medical ethics. Two paradigmatic cases are offered here, an analysis of which will elucidate the ethically relevant features of such cases and can be used to develop criteria by which other particular cases can be evaluated.

**Paradigmatic Cases**

**Case 1**

A man with severe COPD without other comorbidities who has been previously intubated again requires mechanical ventilation for an exacerbation. Although initially sedated for intubation, he is likely to be able to be managed without significant sedation. During previous hospitalizations requiring mechanical ventilation, effective communication through writing has been possible. There is a realistic possibility of eventually weaning from mechanical ventilation and the quality of life afterward should be similar to that preceding the exacerbation, which although limited, has been acceptable to the patient. No advance directive has been completed by the patient and no family is available, although a friend states the patient has said he would “never want to be kept alive on a machine.”

In this case, a considered judgment suggests that withdrawal of support while the patient is sedated without an attempt to involve the patient is ethically untenable. This patient clearly has maintained the capacity for autonomous decision making, previous preferences are ambiguous, and no compelling reasons exist for him not to be allowed and encouraged to participate in medical decision making.
Case 2

A man with metastatic lung cancer is intubated for acute-on-chronic respiratory decline. No clearly reversible process, such as pneumonia, is identified to explain the respiratory failure. The patient has had significant pain, treated with narcotics, from metastasis but has been interacting with his family. He had agreed to intubation when he decompensated with the hope that he would eventually be weaned. The family states that although he has dealt realistically with his illness in order to put his affairs in order and has said his good-byes to loved ones, he has remained quite fearful of the actual process of dying. He has made his preferences regarding protracted intensive care known to his family and has written a standard living will, both indicating that he did not want supportive therapy in a situation in which he was not to survive to leave the ICU. Family members all believe that he would want to be allowed to die under the current circumstances.

In this case, withdrawal of support without the cessation of sedation and attempts to involve the patient directly seems ethically appropriate and consistent with our considered judgments regarding compassionate end-of-life care. The prognosis is grim, both emotional and physical pain are likely to result from the discontinuation of sedation/analgesics, and the patient’s previous preferences are known and confirmed by his family.

No appeal to principles helps distinguish between the different sentiments that these cases evoke. In both, respect for autonomy would seem to dictate that sedation and analgesia be discontinued or lessened to assess the decision-making capacity of the patient and to allow for the possibility of active patient participation in end-of-life discussions. The details of the cases, however, carry normative weight; analyzing the distinctions between the two cases can help elucidate a set of conditions or criteria that may be used to determine when efforts should be made to allow a sedated, critically ill patient to participate in end-of-life decision making and whether such an attempt is not appropriate. The ethically relevant differences between the two cases presented above center on prognosis, prior patient preferences, and potential physical and/or emotional discomfort for the patient.

Criteria Allowing for the Ethical Withdrawal of Support From Sedated Patients

Cessation or Lightening of Sedation and/or Analgesia Will Produce Significant Physical and/or Emotional Discomfort for the Patient

When considering whether support may be withdrawn from a sedated, seriously ill patient without first attempting to involve that patient in the medical discussion, the examples above demonstrate the relevance of particulars regarding prognosis, prior preferences, and the comfort of the patient. This latter concern is logically prior to the others; that is, the first question a caregiver must ask is whether any harm will come from lightening or discontinuing sedation and/or analgesia in a particular case. If not, it would appear that making any medical decisions through a surrogate without trying to involve the patient would be normatively prohibited. An empirical study suggests that the short-term risks of lightening sedation are minimal, although in these studies sedation was not decreased enough to allow for communication with patients but rather just to the point that patients could follow simple commands or “until they became uncomfortable or agitated.”

In certain situations, such as case 2 above, significant emotional and physical discomfort for the patient will result if sedation/analgesia is significantly reduced or discontinued. In most clinical scenarios, however, there likely will be uncertainty regarding the effects of such maneuvers on individual patients. Where there is uncertainty, respect for persons would seem to require that a good faith attempt be made to lighten the sedation, with careful assessment of the patient’s comfort and, eventually, ability to interact with caregivers and family in a meaningful fashion. Physicians and family must be careful not to simply assume that discomfort will be the result of a withdrawal of sedation. In particular, the concern about the emotional distress that the patient will experience due to the discussion of medical condition, prognosis, and options is never, in itself, sufficient to preclude an attempt to wake the patient. If a patient can be maintained with minimal or no sedation and clinical illness does not otherwise impair decision-making capacity, then the patient should be allowed to participate in medical decision making. But if significant discomfort occurs during controlled decreases in sedation, or if significant physical and emotional suffering is certain to follow from such a reduction, then other factors need to be considered prior to deciding to withdraw support without continued attempts to involve the patient directly.

Prognosis for Survival and/or Quality of Life Is Very Poor

The importance of prognosis is evident in comparing the two paradigmatic cases. In case 1, there is a reasonable likelihood that the patient can be liberated from mechanical ventilation and return to a quality of life that was previously deemed acceptable.
by the patient. In case 2, no such possibility realistically exists. An extremely poor prognosis implies a lack of significant benefit of supportive care. From an ethical standpoint, poor prognosis is not requisite for allowing competent individuals to refuse even life-sustaining care. That is, a competent individual enjoys an ethical and legal right to refuse any medical intervention, even if that choice will result in a greatly premature death. Incorporating poor prognosis into the criteria allowing for withdrawal in sedated, critically ill patients provides for a level of protection for those persons and minimizes the likelihood that withdrawal of support would result in a loss of life of significant time and quality.

A specific prognostic cutoff (e.g., <5% likelihood of survival) need not be invoked for this criterion, and it would be expected that the likely quality of life if the patient survived would enter into the calculation of prognosis. That is, a low likelihood of survival coupled with a high likelihood of significantly impaired quality of life even if the patient survives represents a worse prognosis than the low likelihood of survival alone.

Note that this recognition of poor prognosis does not involve an invocation of medical futility, a concept that has been particularly difficult to incorporate into clinical practice.12,13 That is, withdrawal of support may be appropriate in certain situations that would not fulfill any of the criteria for medical futility.14

**Surrogates/Family Members in Agreement That Patient Would Not Wish for Continued Support Under Such Circumstances, or Clear, Unambiguous Written Directives Expressing Patient Preferences**

The rise of patient autonomy in medical ethics and jurisprudence has necessitated the development of tools and methods that attempt to allow persons to project their autonomous choices into a future when they will no longer maintain the ability to make contemporaneous, autonomous choices. Instructive directives, such as “living wills,” represent one such tool. Another is the designation of proxy decision makers who are charged to make decisions in the same manner that the patient would if able to participate directly in the process (the substituted judgment standard). Both of these approaches offer some indication of a patient’s previous wishes and might be seen by some as sufficient to allow for withdrawal of support without further involvement of the patient when there is ample prior evidence that the patient would not have wanted such care. But is important to recognize that previous statements and surrogate assertions do not have the same moral weight as a contemporaneous decision of a competent patient. One cannot ethically or legally invoke an advance directive when the patient can still participate in the decision-making process.

Instructive directives are rarely directly applicable in clinical medicine,15 as they are generally vague and demand interpretation by others.16 Proxy decision makers often err in their assessment of what level of care a patient would want under certain circumstances,17,18 meaning the choices made by surrogates should not be accepted as straightforward method of asserting patient autonomy. Rather, physicians need to remain aware that surrogates will not always speak for patients and be willing to search for other evidence of patient preferences when appropriate.19 The limitations of these tools designed to extend autonomy mean that expressions of prior preferences are never in themselves sufficient to allow for the withdrawal of support from critically ill patients without an attempt to assess decision-making capacity. But, when combined with a poor prognosis and discomfort associated lessening sedation, evidence that such a patient would not want continued aggressive care provides an additional and necessary warrant in support of withdrawal. The requirement of consensus among family members also provides an element of protection for patients. If uncertainty exists among family members, a good faith effort to involve the patient becomes necessary. Clear and unambiguous advance directives would serve the same function as family consensus, that is, providing sufficient evidence of a patient’s previous wishes to allow for withdrawal; but, as noted above, the likelihood of any instructive directive being sufficiently clear and unambiguous is low.

In summary, if all three of these criteria are met in a particular case, it is ethically defensible to withdraw supportive care from an individual without an attempt to directly involve that patient in the decision-making process. If any of the three criteria are not met, then an attempt to awaken the patient and have him/her participate in the medical decision making is ethically mandated.

**ANTICIPATED OBJECTIONS**

The criteria outlined above define a class of clinical cases in which withdrawal of support from sedated, critically ill individuals without any attempt to engage the individual in decision making may be ethically defensible. This coincides with our considered judgment that, at times, insisting on attempts to involve an individual patient in end-of-life discussions may conflict with common notions of compassion and caring. Objections to this argument would
be expected to take one of two forms. First, those who endorse an absolutist view of the value of individual autonomy will not accept that any circumstance allows physicians and families to make such an important decision for an individual unless it is demonstrably clear that the individual lacks decision-making capacity. In order to maintain this strong autonomy position, however, one must reject the possibility that there is ever a case, regardless of the amount of pain, the certainty of death, and the consensus of loved ones, in which support should be withdrawn without attempting to involve the patient. The idea of arousing an uncomfortable and dying patient, over the objections of his loved ones, only to inform him that he is dying seems a cruel example of putting principle over compassion, righteousness over care. Such a strong notion of autonomy would also have to be defended in all other aspects of medical care, disallowing the concept of medical futility and reducing the practice of medicine to the provision of any intervention demanded by patient clients.

Perhaps more difficult to dismiss are counter-arguments that invoke the slippery slope faced by allowing the unilateral withdrawal of support from those who might retain decision-making capacity. Here the prohibition against such an act stems not from an absolute adherence to the principle of autonomy but from the practical concern that once we allow for withdrawal in some such circumstances, soon supportive care will be withdrawn from other patients who do not meet the strict criteria outlined above. That is, once we cease demanding that any potentially competent severely ill person be assessed for decision-making capacity, we will allow for the withholding of support from an ever-increasing number of such patients, with an uneven application and softening of the criteria over time. The response to such criticisms is both practical and ethical. Practically, it appears that physicians already withdraw support in some situations in which patients might retain decision-making capacity, and without the benefit of specific rules to justify the act. A recent Swiss study revealed that physicians were evenly split when surveyed about whether they would wake a patient with a terminal diagnosis to allow her to participate in decision making. Rather than start us down a slippery slope, an open discussion and the explicit delineation and defense of the circumstances under which withdrawal of support in a sedated patient is justified will likely prevent the practice from being unevenly and furtively applied. Ethically, the necessity that all three criteria be met narrowly defines the class of sedated, critically ill patients in which withdrawal is allowable without attempting to involve the patient. This test, when rigorously applied, would necessitate waking the patient if that could be done without causing significant discomfort, or if the prognosis is anything but poor, or if there is not unanimity on the part of the family/surrogates. These explicit limitations provide protection against inappropriate withdrawal of support in this vulnerable patient population.

Implementation and Conclusion

If this ethical defense of the practice of withdrawing support in a carefully and narrowly defined subset of sedated, critically ill persons is compelling, then it will fall on physicians and hospitals to develop policies outlining the process. It would be expected and appropriate that institutions would build additional patient protections into these policies. For instance, a determination of whether a particular patient met all three criteria might need to be agreed on by two or more physicians. Alternatively, external oversight, from either an ethics committee or consultant, might be mandated. Requiring consistency of surrogate or family assessments over time would also add a layer of protection. It will be important to ensure that such policies serve to protect vulnerable patients, but are not so burdensome as to functionally preclude withdrawal when appropriate.

Nor does the recognition that there is not an ethical obligation to attempt to involve the patient in medical decision making mean that no reason exists to lighten sedation. In some instances, a family might request that sedation be reduced enough to allow the patient to be minimally responsive in order for some final communication to take place. Such requests should be honored whenever possible as long as patient comfort can be maintained.

Recognizing that support may be ethically withdrawn in some sedated, critically ill persons emphasizes the importance of compassion and empathy in the ICU. Simplistic appeals to moral principles of autonomy or beneficence fail to adequately address the moral complexity of these cases. A case-centered, casuistic approach has helped identify the ethically relevant elements of these cases. In cases in which a sedated critically ill person cannot be aroused without causing significant pain and suffering, has a very poor prognosis, and where prior unambiguous directives or current family/surrogate consensus exists that withdrawal of support would be preferred by the patient, no ethical obligation to attempt to involve the patient in medical decisions exists. In the end, balancing our respect for patient autonomy with our obligation to provide compassionate care requires us to move beyond ethical principles to examine the unique clinical circumstances of each individual patient.


REFERENCES

1 Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. Am J Respir Crit Care Med 1997; 155:15–20
3 Luce J, Raffin T. Withholding and withdrawal of life support from critically ill patients. Chest 1988; 94:621–626
7 Chevrolet J. Beneficence today, or autonomy (maybe) tomorrow? Hastings Cent Rep 2000; 30:19
15 Block AJ. Living wills are overrated [editorial]. Chest 1993; 104:1645–1646
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