Commentary

Treating the Brain Dead for the Benefit of the Family

John Hardwig

Our patient-centered ethics stands in the way of a more humane treatment of the families of patients. In fact, it leads us to abandon the patients' families at critical moments in their lives—for example, when they have just lost a loved one. If we maintain an exclusively patient-centered ethics, physicians and hospitals rightly conclude that their job is over as soon as the patient is dead. We see that obviously "there is nothing more that we can do for the patient." We then tend to abandon the family with little more than a perfunctory announcement that the patient has died.

But if there is nothing more we can do for the patient, it does not follow that there is nothing more we can do. The family can be helped to come to terms with the death of their loved one. Someone can take the time to sit and talk and listen to members of the family. Obviously, not all families will want to talk with an outsider, however empathetic, at such a time. But many families need help and would welcome the concern and care. I believe someone should be there for those families.

Traditionally, clergy helped families struggle with such losses. But many families do not belong to a church, and those who do often are uncomfortable talking to members of the clergy about subjects like this. Moreover, the family's minister, priest, or rabbi is usually not at the hospital at the moment of real crisis. There are complicated questions surrounding the issue of whether physicians should be the ones to take on the responsibility of such conversa-
tion. But if we are serious about benefiting the family, someone should be there for them. In response to the concern that such care for patients' families would be costly, one reply is that it would frequently be much less expensive—as well as more effective—than the aggressive medical treatment for dying patients that we so often substitute for genuinely responding to the needs of the family. If we could free ourselves from our one-dimensional focus on the patient and from our purely biomedical conception of care, the experience for those having a loved one die in a hospital could be much, much better than it usually is.

I am not convinced that extending the treatment of a brain-dead patient is the best care that can be provided for the family in most cases. However, if more treatment for the deceased is to be given to benefit the family, I think that Felicia Miedema's approach is, generally, the correct one. Her critique of the physicians' handling of the case she reports is generally sound. Still, I can imagine cases in which the physicians' treatment plan would genuinely benefit the family, and Miedema does not really explain why their treatment is not also legitimate. In any case, I believe the issues involved in cases like this one are a good deal more complex than Miedema allows.

In order to get to the issue Miedema wishes to discuss—the justification of treatment of the brain dead for the benefit of the family—we must make an important assumption. We need to assume that the physicians involved in the case she reports believe that the patient is truly dead. If they do not, the physicians may well see themselves as simply trying to benefit their patient—trying to give him every chance to make it. A neurologist and a neurosurgeon who do not accept brain death seem implausible. But the view that the physicians are trying to benefit the family, rather than the patient, does not account for the blood transfusions. As Miedema points out, blood transfusions do nothing to benefit the family. Surely the physicians must realize this, too. So, the hypothesis that they treated this patient as they did because they do not (fully) accept brain death becomes a plausible one.

The case reported by Miedema thus raises a whole array of issues about what a physician who does not believe in brain death should do. Miedema acknowledges this issue. She cites a study by Youngner and colleagues documenting ambivalence about the concept of brain death among health-care professionals, and she says that "the language used by the health-care professionals caring for this patient... may indicate that the caregivers' personal concepts of death influenced the care the patient received." Miedema herself seems to have some doubts about brain death. But her awareness of the issue of physician ambivalence about brain death plays no role in her analysis. Discussion of the obligations of health-care professionals who do not accept brain death is needed, but would take us away from Miedema's argument. So, instead of discussing that issue, I will assume that the physicians in the case she reports do believe that their patient is dead and that they are prolonging treatment of him in order to benefit his family.

Both Miedema and (we are assuming) the physicians involved in this case think it justified to continue to treat a dead person in order to benefit the family. Miedema differs from these physicians on two central issues: 1) what the family should be told, and 2) how long a brain-dead person can justifiably be "maintained" in order to benefit the family. Miedema also disagrees with the physicians about what treatments can justifiably be provided, but that disagreement may well grow out of the disagreement about how

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long treatment may continue. Let us consider the two central issues dividing Miedema and the physicians in order.

The physicians believe that withholding the information that the patient is dead will benefit the family. But Miedema insists that “health-care professionals are obligated to fully reveal the medical facts in understandable terms to the families of brain-dead patients.” The physicians calculate that the family would benefit from a few days to cushion the sudden, completely unexpected shock of the patient’s death and to get used to the idea that their loved one might die. Miedema thinks this attempt to benefit the family is never justified, but she fails to explain why not. Is her position that no family would benefit from being “let down slowly”? Or is it that withholding information about the patient’s death is unjustifiable even if it would benefit the family?

 Granted, withholding that information involves deception, obviates genuine informed consent, and delays the grieving process. Treatment without informed consent or refusal of treatment by a proxy (that is, by a family member) is also illegal. These are serious objections, indeed, but they do not answer the question of whether some families would benefit from the temporary deception.

My own view is that the familiar arguments against physicians’ paternalism toward dying patients would serve to support Miedema’s rejection of physicians’ paternalism toward patients’ families. In fact, paternalism toward the families is even less justified than paternalism toward patients, primarily because physicians know the families even less well than they know their patients. Physicians are seldom in a position to predict reliably which families would benefit from withholding information about the diagnosis of brain death and which would not. This is especially true in a case like this that involves neurologists and neurosurgeons, rather than a long-standing family physician or friend of the family.

Moreover, the wife and the rest of this patient’s family may well have been harmed by the physicians’ paternalistic attempt to benefit them. Miedema points out that the deception delays the necessary grieving process. But neither this delay nor the lack of informed consent is, I think, the main objection to this attempt at beneficent paternalism. The days of uncertainty provided by withholding the diagnosis of brain death are not—as the physicians probably assumed—simply a comforting time in which the family’s hopes can gradually fade and they can ease into a recognition that their loved one has died.

Rather, by telling the wife that her husband is “deeply comatose” or “severely brain damaged,” the physicians could well have unleashed a whole array of nightmares about her husband’s future (and her own) that she need not have worried about at all. What if he lingers for years and years in a “deeply comatose” state? Would he want to live on like that? What will she do then? His life insurance will not pay, their medical insurance will not cover his expenses, her income will not meet the payments on their home, and so forth. What if he recovers consciousness, but only as a shadow of his former self? What if his personality and intelligence are gone? What if she ends up married to a man who no longer even recognizes her... or himself? Should she discontinue treatment now in order to avoid these grim possibilities? Or, is that not giving him a full chance to recover or just to live?

So, though I can imagine that some families might genuinely benefit from temporarily withholding the diagnosis of brain death, I think such deception is unjustified because physicians cannot reliably tell which families would benefit and also because of the real horror that may be evoked by telling a family simply that their loved one is “deeply comatose” or “brain damaged.” Miedema is surely right. The physicians are obligated to convey the diagnosis to the family in a case like this, even if they are attempting to benefit the family.

There is, however, another set of questions about treatment of the deceased in order to benefit the family. Miedema is prepared to sanction treatment of dead persons for a short time period, “agreed upon by the family and the medical team.” She must then face two related questions: 1) What if there is no agreement between physicians and family on a short time period because the family simply does not accept brain death? 2) Why should we not be prepared to allow treatment of dead people to be continued for weeks, months, even years? If we are really trying to benefit the family, perhaps treatment could or should be extended until family members are really comfortable with the fact that their loved one has died and are ready to resume their lives without him.

Miedema no doubt wants to continue treating a dead person partly in order to spare the family the agony and anger of having to live with the conviction that their loved one was killed in the intensive care unit (ICU) when the doctors turned off the machines. Accordingly, Miedema is prepared to grant the family “a brief delay of several hours” to come to terms with the idea of brain death and the accuracy of this diagnosis of brain death. In the case she reports, the wife was perhaps able to come to grips with the concept of brain death in the course of one conference. But what if the family cannot come to accept brain death within several hours? The suffering imposed on a family who does not believe in brain death will not be significantly mitigated if a physician waits for several hours before killing (in the family’s view) their loved one.

Such lack of acceptance of brain death on the part of patients’ families is often dismissed as irrational denial, but this is not necessarily so. Even health-care professionals have ambivalence about brain death, despite years of training and experience dealing with it. So, why would a family’s uncertainty about brain death never justify a longer period of treatment? In fact, the physicians in this case might have been prepared to prolong treatment, if the wife of the patient had wanted that. This hypothesis, too, would make sense of
the hemodynamic support and the blood transfusions.

Perhaps Miedema holds that, as a matter of fact, prolonging treatment for more than "several hours" is never beneficial to the family, all things considered. But is that true? In any case, if we are prepared to continue treating dead people for the benefit of their loved ones, we will need an argument to show why such treatment cannot justifiably be extended for more than a few hours. Miedema has not developed that argument.

Once these questions about what truly benefits the family have been dealt with, Miedema faces the deeper challenge of whether it is justifiable to abandon a patient-centered ethics for an ethics of benefiting the family. I agree with Miedema that it is. But rejecting a patient-centered ethics faces a number of serious objections. It involves a rejection of the Hippocratic Oath and most other traditional codes of medicine; it flies in the face of an impressive consensus of contemporary theories of medical ethics; and it is, presently, illegal. Miedema's failure to acknowledge the radical departure from prevalent ethical and legal theory that her article represents is a serious weakness.

We can begin to understand the difficulties facing treatments designed to benefit the family by focusing on the interests of the patient. Miedema repeatedly states that further medical treatment can provide no benefit for the patient. But does further treatment harm him? There is some philosophical debate about whether it is possible to harm a dead person. But each of us can imagine things that we would not want done to our bodies after we are dead, and as a matter of practice, we do continue to respect the autonomy of dead persons (for example, in executing wills, funeral arrangements, and so on). Miedema herself says that invasive procedures on a brain-dead person are not justified, even though the patient feels nothing and can be aware of nothing. Why not? Presumably because they would harm the dead person.

According to Miedema, the principle of respect for persons argues against invasive therapies. But does respect for persons not argue against all treatment after death? Who would want to remain hooked up to machines after having died? Some might, but most would not. Miedema cites Yarborough's analysis. But Yarborough provides an important condition requiring respect for the dignity of the patient: the physicians must know that the patient would want to accept futile care in order to benefit the family. Miedema's conclusion includes no such condition.

It is one thing to justify treatment that provides no benefit to the patient, and quite another to justify treatment and harms the patient. Does Miedema want to go that far? If not, she must argue that no harm is done to a brain-dead person—including no affront to the person's dignity—by being treated in an ICU for "a short period" after death. I am not sure that this argument can be made in the case she reports. I suspect that it cannot be made in many cases in which the family needs our help.

Rather than try to make that case, I argue that it is sometimes morally permissible, even obligatory, to sacrifice the interests of one's patient to the greater interests of the patient's family. But this is a very unorthodox position. Accordingly, when I consult with physicians about treatment decisions, I feel obligated to tell them that mine is a minority view held by only a tiny fraction of medical ethicists and also that medical practice based on my position is currently illegal.

The law—and almost all medical ethicists and physicians—insist upon an exclusively patient-centered ethics. There is virtual unanimity within medical ethics that treatment must serve the interests of the patient, at least within limits posed by the just distribution of scarce medical resources. A patient-centered ethics means that the interests of the patient cannot be sacrificed to promote the interests of others—not the interests of society, the interests of other patients, not the interests of the family, and certainly not the interests of the hospital staff or the physician.

Treatment plans like that employed by the physicians in the case, or those sanctioned by Miedema, are illegal because the courts have also insisted on patient-centered standards for providing and withdrawing treatment. Suppose legal action were taken in a case like this. Battery, for example, might be alleged for "maintaining" the patient after death in the ICU. (Can you "battery" a dead person?) The physicians could not successfully defend themselves by claiming that they had to sacrifice the interests of the patient in order to pursue the interests of the family. For a court would undoubtedly insist that physicians are legally bound to do what is best for their patient and for no one else.

Nor could the physicians defend themselves by claiming, as Miedema tentatively suggests, that once the patient is brain dead, the family becomes the "patient." For the members of the family simply are not patients. None of them can legally become a patient unless they declare themselves to be. Adults can become patients without their consent only if they are incompetent or dangerous to themselves or others. Declaring people to be patients without their consent and then treating them without their knowledge creates an extremely dangerous precedent. We should not, either morally or legally, accept the overly simple slogan, "the patient is the family." Family members are not patients, and the appropriate care for them is usually compassion and understanding, not medical treatment of any kind. (If it is medical care that the wife needs, the treatment she requires is counselling, psychotherapy, or perhaps only a mild tranquilizer, and not continued use of a respirator on her husband's corpse.) So, if the interests of the patient are sacrificed by the physicians or by Miedema, they are sacrificed in order to achieve nonmedical care for nonpatients. I think that this is often perfectly appropriate, though it might not have been necessary in this case.
Legally, however, neither the treatment delivered by the physicians nor the treatment justified by Miedema is acceptable. No family-centered ethics of patient care will survive legal scrutiny. I believe this is so because our laws governing medical treatment decisions have been erected on a faulty moral theory. But that is the law.

Most medical ethicists believe that a family-centered medical ethics cannot be morally justified, either. For patient-centered medical ethics, the case reported by Miedema is an open-and-shut case. Further medical treatment cannot benefit the dead, it may well harm the dead, and there is no evidence to suggest that it would have been desired by the deceased. Under these conditions, family members ethically cannot authorize any further treatment, for they must act as proxies for the patient rather than request the care they want the patient to receive. Unless there is evidence that the patient would have wanted treatment continued, no further treatment can be justified in the case of a brain-dead person. Miedema’s analysis would be rejected for the same reasons.

Any family-centered medical ethics thus faces a host of objections that Miedema does not fully acknowledge. Bodily autonomy and other forms of patient autonomy are undermined, patient dignity is challenged, and the ethics of fiduciary responsibility of healthcare professionals to their patients is subverted. Obviously, this is not the place to attempt to respond to any of these objections. So perhaps the only conclusion is that Miedema’s conclusion is much harder to reach than she allows. I think she is on the right track, but we have a long way to go.

NOTES
2 For example, Miedema speaks of treatment after brain-death criteria have been met as “life-
sustaining treatment,” and that is a very odd way to talk about treatment of a corpse. She also says that “recovery from this condition [brain death] has never been reported,” and that, too, is odd. Presumably, brain death is not like AIDS or sclerosis of the liver—something we might some day find a cure for.
3 Obviously, there could also be deep divisions within the family. Though these are very important and provide another reason for trying to help the family through such crises, I, like Miedema, will not consider disagreements within the family.
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