

THE LAW, DEATH, AND MEDICAL ETHICS

Grasping the nettle—what to do when patients withdraw their consent for treatment: (a clinical perspective on the case of Ms B)

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Withdrawal of active treatment is common in medical practice, especially in critical care medicine. Usually, however, it involves patients who are unable to take part in the decision making process. As the case of Ms B shows, doctors are sometimes reluctant to withdraw active treatment when the patient is awake and requesting such a course of action. In theory, having a competent patient should facilitate clinical decision making, so where does the problem arise? It is argued that latent medical paternalism may come to the surface when doctors are asked by patients to follow a course of action which is in conflict with their own perspective.

doctors. The first is that patient autonomy should be respected throughout the time a patient remains under their care. The second is that a patient's right to refuse treatment may be exercised at any time in the treatment process, not simply at its initiation. The latter right is routinely written into consent forms for clinical research, but is not always acknowledged in day-to-day clinical practice.

Let us look first at refusal of consent. Some years ago (not in the UK) a patient was admitted to a critical care unit with intraabdominal bleeding. He was a Jehovah's Witness, but his wife was not. The patient refused blood products, while his wife pleaded for them. The surgeon spoke with both of them preoperatively. What was said to the patient is unknown, but the wife was told that once the patient was unconscious, blood products could be "slipped in". This proposed course of action was considered to be ethically unacceptable by the critical care staff and the anaesthetist, and a vigorous debate followed. Honesty is obviously one important issue here, but another is the right of competent patients to refuse treatment for whatever reason. In this case, as with Ms B, there was a clash of value systems, with the surgeon's approach being clearly paternalistic. He simply assumed that his medical judgment (that transfusion was necessary) could override the patient's wishes, even though those wishes were based on a deeply held value system. Both ethics and law encourage doctors to recommend appropriate treatment options to their patients, but in the end, both agree that medical opinion cannot overrule the expressed wishes of a competent patient who chooses to refuse any or all treatment.

Situations like this should no longer arise since experience and case law have now combined to securely establish the patient's right to refuse treatment at the outset. The subsequent withdrawal of consent once treatment has been initiated is, however, a more infrequent, but a more difficult problem.

In the practice of critical care medicine, patients are routinely admitted after life-saving measures have been instituted in an emergency without full (or indeed, any) consent being obtained from the patient. Generally the patient recovers, everyone is happy, and there are no ethical issues to debate. Alternatively (and quite commonly), the patient does not improve, remains "incompetent" and goes on to die, either from the disease process itself, or because active treatment is withdrawn after discussion with the relatives. The ethical principles that underpin this

In recent years medical paternalism has given way to patient autonomy. This does not mean that patients can dictate to doctors, but it does mean that patients should be treated with respect and dignity. This in turn requires (at a minimum) the active involvement of patients in the decision making process and recognition that patients can refuse treatment for whatever reason, or none. Against this background, it is perhaps surprising that it was necessary for Ms B to go to court to seek a resolution of her difficulties with her critical care physicians. After all, critical care physicians should be used to making "end-of-life" decisions (withdrawal of active treatment is the commonest mode of death in a modern critical care unit), so what made this case so different? Clearly there was a clash of values about the continuation (or discontinuation) of artificial ventilation, but that was simply the fulcrum of the underlying ethical debate.

Although patient autonomy is dominant in current ethical discussions, medical paternalism is not extinct. Indeed it cannot become so, for the exercise of paternalism is essential to the practice of medicine. After all, we are the medical experts, and we are required to recommend what is medically best for the patient. It is therefore arguable that some measure of paternalism is involved in most treatment decisions. This covert paternalism is not necessarily bad, provided it is recognised for what it is, and is used appropriately to guide and support patient autonomy rather than to override it.

Unfortunately paternalism can quickly become overt rather than covert, particularly if the patient's values conflict with those of the doctor. In such cases, two principles are paramount for

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process are well known and will not be further considered here. We should note in passing, however, the role of covert medical paternalism in this procedure. In England, family members cannot make decisions on behalf of an “incompetent” relative. Even if the family could legally consent to withdrawal of active treatment, it is generally agreed that relatives should not be burdened with actually making end-of-life decisions for their loved ones. Rather, the role of the family is, after appropriate explanation and discussion, to accept (or reject) the recommendation of the medical team that it is now time to move to “comfort” care. This approach to the withdrawal of active treatment demands the exercise of covert paternalism: the medical team must decide the “best interests” of the incompetent patient, the medical team must decide when the burdens of treatment outweigh the benefits, and it is the medical team, not the family, on whom the burden of responsibility lies for the decision to stop active treatment.

But another outcome is possible. Here, the patient’s life is saved, but when they recover consciousness they find themselves, not simply disabled, but totally dependent on others for everything, including breathing. Some patients can come to terms with this—but some cannot. The latter group of patients are the ones who may ask for the withdrawal of life-support systems. In other words, they wish to revoke the implied consent that was assumed when emergency treatment was initiated. Although such patients are few and far between they do cause much heart searching—and Ms B was just such a patient.

It is always difficult to contemplate withdrawal of life support when much effort has been invested in, and a relationship has been established with, the (now competent) patient. The ethical principles are, however, clear. Patients are free to refuse treatment, and it would be unreasonable to argue that this right can only be exercised before treatment actually begins. The right of refusal implies a similar right of withdrawal of consent at any time and either initial refusal or subsequent withdrawal of consent may result in the death of the patient. As doctors, respect for patient autonomy requires us to accept that possibility and to acknowledge that there are some outcomes that some patients will consider to be worse than death. In such situations medical paternalism must not mislead us into believing that we really do know what is best for the patient, nor into overruling them if they continue to reject our medical advice. Difficult though it is, the competent patient is the only one qualified and authorised to make decisions about his or her “best interests” or “quality of life”.

Autonomy aside, other ethical arguments are wholly on the side of patients such as Ms B. The utilitarian approach would favour withdrawal of life support, since this is not only what the patient wants but would free up valuable resources. Beneficence and non-maleficence lead to the same conclusion—what could be more harmful than being imprisoned on a ventilator against one’s will and powerless to do anything except plead for release? Justice, too, is on the patient’s side. Is it “just” to overrule the wishes (and the fully informed wishes, at that) of a competent but helpless patient? And surely distributive justice would suggest it was inappropriate to use restricted critical care resources to continue treatment against the patient’s wishes and with no hope of recovery?

It is not simply paternalism that prevents some doctors from withdrawing life support in such cases. There is also the fear of exposing themselves to charges of euthanasia (particularly if appropriate sedation is provided beforehand). However, withdrawal of active treatment and euthanasia are quite different, if only because the latter requires an active intervention to end someone’s life when death would not normally occur without such intervention. It is worth noting that Ms B did not seek death, rather she recognised and accepted it as the only possible alternative to continued life support—a treatment which she considered too burdensome. Without medical intervention her death would have occurred months before—artificial ventilation would no doubt have continued to delay her death (and would have continued to do so indefinitely), this delay was at the expense of a quality of life that Ms B found intolerable. When medical care cannot produce the desired outcome, and the burden of treatment outweighs the benefits, it *is* ethical to stop treatment, even though the outcome may be the certain death of the patient.

Finally, it is always appropriate for doctors to relieve distress. Therefore, to contemplate withdrawal of ventilation without premeditation in a patient such as Ms B would be inappropriate. On the other hand, doses of sedatives do not have to be so large that the doctor could be open to a charge of homicide. With care, it is always possible to sedate a patient adequately but not excessively.

Thankfully, cases such as Ms B are rare (I have had direct involvement with only two in my 25 year critical care career). However, such patients need us to respect their autonomy, and to support them in and through the extremely distressing and difficult decisions they must make, even if that means withdrawing life-sustaining treatments. That is the nettle we must grasp. The alternative is to relapse into paternalism, and to put ourselves in conflict with both law and ethics.