
Editorial 2

Deciding about resuscitation

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This edition of the journal includes, with an introduction and three commentaries, a recent joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, on decisions relating to cardiopulmonary resuscitation (CPR).¹ The statement was produced in response both to a professional need to decide when attempting CPR is and is not ethically appropriate, or indeed lawful (especially in the light of incorporation of the European Convention on Human Rights into UK law), and also to public concern that such decisions have not always been made in concordance with the wishes of patients or people close to them. The guidelines it sets out reflect a broad consensus of current medicolegal views in the UK, include a variety of helpful and practical recommendations, and can be seen, in many respects, as a model of their kind. As a model of actual decision making however, they raise some problems. Model helps us understand the reality they represent by simplifying it, but in the process of simplification, aspects of the reality represented which do not fit in with the model may be left out or downplayed. Three such aspects identified by our commentators concern patient autonomy, quality of life judgments, and the role of families in decision making.

Patient autonomy

In his commentary, Robin Gill argues that while “many of us cherish” the right to be properly informed before decisions about our treatment are made, such information “may become a burden for others when they are at their most vulnerable”. Being told about CPR, with the implication that a “do not attempt resuscitation” (DNAR) order is at least possible, may provoke “angst about death” in these vulnerable patients. The guidelines state that a competent patient’s wish not to discuss resuscitation should be respected. But they also state that if, subsequently, a DNAR order is made, health professionals “must be able to justify their actions”, and the patient’s “clear desire to avoid such discussion ... must be documented in the health records and the reason given”. Yet how, Gill asks, are health professionals “to establish this ‘clear desire’ without those very patients being involved in a discussion about at least the initial stages of the subject (death and CPR) which causes them such angst?”²

This problem is not confined to these guidelines or to CPR. Draft guidance on withholding and withdrawing life-prolonging treatments generally, sent out for public consultation earlier this year by the UK General Medical Council, recognises that discussing such subjects with patients “may be difficult and distressing”; and it states that where “patients clearly indicate that they do not wish to know or discuss the details, you should not force this information on them”. But it warns that “this does not mean that discussion should be avoided”; and in an appendix specifically on CPR, it adds that “failing to involve the patient or, where appropriate, the patient’s family or other carers before reaching a decision often causes more distress than tackling the issue sensitively”.³ On a different but related topic, the Bristol Royal Infirmary Inquiry, commending proposed information for relatives on postmortem examination organ removal and retention for being “detailed and specific”, recognises that while this will be helpful to some parents, it will be painful to others, “already reeling from the loss of their child”. “We cannot square this particular circle”, the inquiry states. “There is a price to be paid for being informed. We can only seek reassurance in the knowledge that those trained in the area of bereavement understand these difficulties.”⁴

The inquiry’s appeal for reassurance, and the GMC’s “often”, are sufficiently equivocal to suggest that something important is being left out or downplayed. Is this simply a reluctance to face up to the fact that “our” cherished right to autonomy must be paid for by others who are more vulnerable than we are? Or is there something about the notion of patient autonomy itself, which makes current model guidelines fit uneasily with the reality they claim to represent?

Autonomy or self rule, as the rejection of heteronomy or being ruled by others, is something we rightly cherish. It is much more than mere consumer choice (in which we are often more subtly ruled by others than we care to admit), and exercising autonomy responsibly is a major human achievement. But rule by oneself is possible only over those areas of oneself, one’s thoughts and activities, one’s possessions and projects, which admit such rule. There are other areas—those bound up with creativity, love, and suffering, for example—where self rule, if it is not to be lost altogether, has to be shared, with an unruly unconscious, with other persons, with necessity.

When a DNAR order becomes a real possibility in their case, many patients' autonomy of action is already compromised by their lack of knowledge and power to act effectively on their own behalf. But then, if asked their views on CPR, their autonomy of thought and will also may become compromised by the very nature of the choice they are confronted with. To the doctor, this is a choice whether or not resuscitation should be attempted. To the patient, "To be or not to be: that is the question"; and the patient does not need to be a Hamlet to find "the native hue of resolution ... sickled o'er with the pale cast of thought". Even in nonterminal illness, patients may find such decisions impossible to make. Alfred Tauber, for example, describes his own experience of this. He was unable to pass a kidney stone and because he was a physician, his urologist

"perhaps was less adamant in his advice, and his counsel was ambiguous. I was to decide, alone. As an adult I had never before this required medical attention. This was my first mature experience as a patient. I was immobilised. I could not make the decision. I kept thinking that maybe one more day was all I needed. I knew the risks of surgery, the postoperative recovery, etc, and still I procrastinated. My doctor left me to anguish and I sought counsel elsewhere, but no one would tell me what to do. They probably didn't take me seriously—the guy who always made decisions couldn't decide whether he was in enough discomfort to have surgery? Silly. They figured if the pain was severe enough I would submit myself to the knife. Finally, during the sixth pain episode, my urologist made the decision. I was whisked into the operating room. 'Well, Fred, it's time. You've had enough.' I nodded numbly."⁵

The difficulty, and for many the impossibility, of exercising autonomy of thought and will in such circumstances, is to some extent met by the guidelines' advice that "ideally" such decisions should be "made in advance as part of overall care planning for that patient and, as such ... discussed with the patient along with other aspects of future care". In advance, perhaps, the patient can be sufficiently detached to make an autonomous decision. But the very possibility of detachment calls in question whether what the patient is being detached about, is the real substance of the choice that, when actually confronted with its full implications, he or she may find mind-numbing. The advance decision, taken in detachment, may have been autonomous, but whether it is the relevant decision remains in doubt.

Living wills

This problem, of course, is familiar in the discussion of living wills, and in that context it may be asserted that the clearly stated past wishes of a then competent person must be respected, as much with regard to his or her future treatment as with regard to the disposition of his or her property. But the problem with this response, especially with CPR or DNAR orders in view, is that property and

treatment are not analogous. The patient *has* property, but *is* what the effect of the treatment decision determines. (This fundamental distinction between having and being⁶ is supported by and arguably the origin of, the common law's refusal to regard even a dead body as property.) Conceptually as well as in practice therefore, individual patient autonomy with respect to such reflexive life-or-death decisions seems incoherent. This need not mean that the notion of patient autonomy as such is simply what Alfred Tauber calls "a conceit".⁷ In nonlife-threatening conditions treatable by medicine, surgery or midwifery, informed patients may well be able to make autonomous choices regarding the nature or timing of different treatments. But the problem is whether and how far it is possible, either in principle or in practice, to extend this exercise of autonomy into conditions that are life-threatening.

Mutual trust

Part of the problem here is that when individual autonomy may not be possible and heteronomy has been rejected, there may appear to be no other obvious and realistic option. Ideally, the distinction between autonomy and heteronomy would no longer be relevant in a relationship of mutual trust, in which when or even whether to discuss CPR would be determined by the parties' knowledge of one another and sensitivity to one another's cues. Even in a deeply trusting relationship, of course, cues can be misread, and some patients might still secretly want to know more, or less, than they heard from their doctors. But in the ideally trusting relationship, this would be more than compensated for, as far as the patient is concerned, by the confidence that when the outcome had to be left in the doctor's hands, the doctor would know what he or she was doing, and would do his or her best for the patient.

A relationship of this kind, arguably, is as near to the ideal as is possible for fallible human beings. From the patient's point of view it would not be heteronomy but help. But a background assumption against which current guidelines about resuscitation are constructed appears to be that such an ideal cannot be realised, either because doctors are insufficiently trustworthy or virtuous to meet the demands of such a relationship, or because the organisational and practical constraints of a modern health service make this impossible for even the most trustworthy and virtuous doctors. For these reasons, any attempt to create such a relationship, inevitably would end up as the kind of medical paternalism society is no longer prepared to accept, and against which patient autonomy needs to be defended, by seeking, through the production of guidelines, to ensure that all patients are fully informed about possible treatment options, up to and including CPR.

But does ensuring that patients are fully informed actually defend their autonomy? If it really is not possible for many patients to exercise the autonomy that guidelines are designed to defend, the production of guidelines must raise the question, *cui bono*? If the answer to that is

“doctors”, this casts only further doubt on whether doctors are trustworthy. Confronted by this downward spiral of distrust, it is at least worth asking how well this apparent background assumption corresponds with actual decision making within the constraints of a modern health service.

Certainly there is ample evidence in the UK to support the claim that many patients and their families have not been consulted about treatment decisions, including CPR and DNAR orders, about which some of them would have wished to be consulted. It is less clear however, in a culture rapidly changing as a result of media exposure and litigation, how many patients and their families are now being consulted about treatment choices whose full implications they have not been trained to understand, and which some of them at least would prefer doctors to take on their behalf. Nor, in the midst of this, is it clear what proportion of doctor-patient relationships have come closer to the ideal suggested above than to either of these heteronomous or autonomous alternatives. Since it is simply a fact of life that more bad news tends to be reported than good news, it is at least possible, and perhaps probable, that relationships which come closer to the ideal than to the alternatives are more common than the background assumption of public opinion implies.

Quality of life judgments

Reflection on issues discussed in the commentaries by Helen Watt and Steven Luttrell may lend some support to this conclusion. Helen Watt argues that benefits and harms are not dependent, for their existence, on being consciously experienced; and that if the contrary is assumed in quality of life decisions, this may have serious implications for the protection, for example, of profoundly mentally disabled patients from lethal experiments which do not necessarily affect their mental life.⁸ This may seem an extreme example of the dangerous wider consequences of legitimising the view that prolonging an unconscious patient's life is of no benefit to the patient. But it is clear that many people, including disabled people or their spokespersons, are concerned that allowing such value judgments any role in medical decision making could negatively affect professional and public perceptions of the value of disabled lives generally.

But what part do such value judgments actually play in treatment decisions for unconscious patients at or near the end of life? Some part, for some doctors and nurses, no doubt. But a significant further side to the story is supplied by the deep reluctance of health care professionals generally to accept and act on the repeated official reassurance that there is no morally relevant (or in British case law, legal) distinction between withholding and withdrawing life-prolonging treatment. This reluctance is commonly explained by saying that while withdrawing is ethically equivalent to withholding, it is psychologically different. Part of the psychological difference may be that a decision to start life-prolonging treatment, not least because it may have to be made

relatively quickly, is not difficult for health professionals to represent to themselves as a purely clinical decision. Withholding treatment can then be represented as not starting treatment that is clinically inappropriate. But deciding whether to withdraw treatment which is sustaining life, and could prolong it for an indefinite time without apparent discomfort to the patient, is more difficult for health professionals to represent to themselves as a purely clinical, rather than a moral, or value, judgment. At this point they may prefer to “let nature take its course”, and then respond to that with further clinical decisions. One morally significant reason why health professionals are so reluctant to accept the moral equivalence of withdrawing and withholding treatment, therefore, may be that they do not want to be drawn into making such moral or value judgments about a patient's continued existence. What the pervasiveness of this apparently illogical reluctance strongly suggests, in other words, (and provided that such patients continue to be cared for as well as treated) is an attitude of respect (Kant's *Achtung!*) for the person of the patient who has been entrusted, or who earlier entrusted him or herself, to these health professionals.

The role of families

In his commentary, Steven Luttrell questions the impression given by the guidelines that the role of relatives and friends is “merely to reflect the wishes” of a no-longer competent patient. “Surely”, he writes, “their views as to what is in the best interests of the patient are also relevant and should be taken into consideration”.⁹ As a practising geriatrician, Luttrell no doubt is aware that when, as now is increasingly the case, relatives and friends are consulted, their views, if not fairly clearly against the patient's clinical best interests, are usually taken very much into consideration, and in many cases the decision, although legally the clinician's, in practice is a joint one. Such an approach seems morally justified. If the relatives and friends are indeed the others who have been closest to the patient, and if their views are not against the patient's clinical or financial interests or otherwise known wishes, it is difficult to see what qualifies the doctor as any better judge than they are of the patient's best interests generally. The doctor, because of the caveats just mentioned, has a duty to ensure that the relatives and friends are the appropriate people to make such a judgment, and also that they are realistically informed of the clinical realities. But when this has been established, their judgment that the patient would not have wished the treatment to be continued, combined with their own wish that it should not be continued, and the assent to this of the health professionals caring for the patient, is probably the closest one can come to a moral justification for withdrawing the treatment.

Persons are not only legal persons: they are the persons they have and will become through their relationships with other persons. This is equally true of patients, their relatives and friends, doctors

and other health professionals, all of whom make decisions not in isolation from but in interaction with other persons. This aspect of real-life decision making is difficult to accommodate within guidelines designed to defend patient but also professional autonomy, apparently on the assumption that a relationship of mutual trust between patients and professionals is no longer possible. Part of the problem however, now that old-fashioned medical paternalism has been rejected, may be the failure of current public and professional rhetoric to acknowledge that it is possible only to approximate to either autonomy-based or mutual-trust-based alternatives. Current public and professional rhetoric tends to give the impression that autonomy-based decision making is achievable. Perhaps, when the inherent limitations of this model have been more fully appreciated in practice, a more realistic and favourable appreciation of the merits of approximating, however distantly, to a mutual-trust-based model may become possible.

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