

About Decision-Making at the End of Life: A Singaporean Perspective

This is a complex and tragic case which demonstrates very clearly that the situation constituted a true ethical dilemma. There is no room for negotiating around the issues or for turning them into technical problems; the case makes it clear that whatever decisions are made, there will be compromise of moral principles. The main concern is that of the patient's best interests.

In Andrew's case, it is more difficult to arrive at an ethical position on the role of the family in deciding what would be in his best interests than it is in cases of withholding or withdrawal of treatment. This is in part because the family is involved in the care at home, care which is becoming increasingly difficult and ultimately impossible. Also the option of terminal sedation is not a straightforward route as it contravenes Andrew's wish to remain lucid. To further compound matters, as Krishna points out, Andrew's own wishes are conflicting because being alert and being comfortable are mutually exclusive in his case. So the healthcare professionals have a very difficult decision to take and, as this case illustrates, it is, in the end, the healthcare professionals who have to take the decision.

This case draws particular attention to the family not least because it is a complex family including two wives, deceased and current, and with children from both marriages. The evident internal disagreement highlights the fact that the family is not as coherent and warm as a social unit as it sounds when invoked in the abstract. When we consider the views of the family, remembering that in some legal contexts, they are only really of interest insofar as they give the healthcare professionals some insights into the wishes of the patient who is incapable of conveying his own wishes. The individual patient is the main concern when we make ethical decisions in healthcare and it is sometimes

difficult to focus on this when the family is so vocal and, in this case, discordant. Different cultures of course have different approaches to this question of primacy of interest.

It is interesting to note that in this case, it was the healthcare professionals who had to take the decision to re-admit Andrew to hospital when his symptoms worsened. Ultimately, the onus is on the medical member of the team, who is responsible for taking the decisions which are going to be in the best interests of the patient.

There are difficulties on ethical grounds with the family's wishes being overruled, because the physician's first duty is to the patient. Nevertheless, we have to recognise that the experience of working through these decisions in the context of very upsetting circumstances is by no means trivial. The involvement of the family is of course important as family members can be thought of as part of the care team insofar as they are providing care and equally importantly providing information and insights concerning the patient's wishes. This is always assuming that the family has discussed these matters. In cases where the family has not previously discussed the various options available in situations where continuing to live is unacceptable to the patient, the family voice might be said to lose some of its force in terms of supplying the patient's view.

All of this points to the needs and wishes of the patient being paramount. In turn, this means that patient consent is important. Herein lies the problem in the context of terminal sedation. In the case Krishna describes, the family has differing views on the issues and indeed are following rather different agendas. George, Andrew's eldest son, in particular, was unable to bring about consensus on the question of sedation. George's overriding concern seemed to be to act in such a way as to square his own conscience, rather than to find the best outcome for his father.

The medical profession is concerned with the legality and moral acceptability of the treatments adopted. A part of the moral argument is to act in the patient's best interests and so we are back to this central issue raised by the case.

Consider the four options of last resort as described by Quill (2008) where there is *unacceptable suffering*. These are: *intensive pain and symptoms; forgo life support sustaining therapy; voluntarily stop eating and drinking and sedation to unconsciousness*. The first two options, Quill notes, are uncontroversial and are accepted by both medicine and law. It has to be remembered that recourse to the last option, sedation to unconsciousness is usually in conjunction with cessation of provision of nutrition and fluids and when death is imminent. Also, with respect to "sedation to unconsciousness", Quill says that this option

is “distinct from the proportionate use of sedatives to treat severe anxiety and delirium, which is a relatively common part of terminal care. Instead, it is an explicit decision to render the patient unconscious so that he or she can escape otherwise severe and intractable suffering”. Quill notes sedation to unconsciousness is generally accepted as a means of relieving “severe, intractable suffering in imminently dying patients, but as one gets further away from these circumstances, agreement about its permissibility falls off sharply”. We need to remember that it is a small number of patients that fit the criteria for this fourth option of last resort.

There are problems with the idea of terminal sedation. Engström *et al.* (2007) note, in their systematic review of palliative sedation, that there are differences between the attitudes of healthcare professionals towards palliative sedation and those of the public. Professionals such as Engström *et al.* have positive attitudes towards palliative sedation, whereas the public thinks of palliative sedation in the same category as euthanasia and physician-assisted suicide.

The closeness of the idea of palliative sedation to euthanasia and physician-assisted suicide makes, in the minds of many, the possibility of palliative sedation untenable. If, however, we adopt an approach which says that if life cannot be tolerated by the person living it, then it is the duty of the healthcare professionals to act in order to alleviate the suffering. This is where the best interests principle comes in with prime importance given to “value of the life for the person who must live it”, as opposed to “the value the person’s life has for other persons” (Beauchamp and Childress 2001: 103).

One of the driving forces in the debates around both terminal sedation and physician-assisted death is the acceptability of a treatment to medicine and the medical profession. The question of whether something as controversial as terminal sedation is adopted as a treatment of last resort depends in large part upon the context within which it is considered. The work of van Bruchem-van de Scheur *et al.* (2008) demonstrates that it cannot be assumed that nurses are prepared to accept as a part of routine nursing work the involvement in euthanasia. They found that Dutch nurses were unwilling to be involved either in reviewing cases or being party to the practicalities and technical care associated with euthanasia. This suggests that for terminal sedation to be accepted, even though there is compelling clinical and compassionate reasoning to offer this masking of intolerable symptoms at the end of life, there is some way to go before it can be brought into the canon of accepted medical practice. For such a controversial treatment to stand a chance of acceptance, it has to be brought alongside conventional medical practice.

One way of thinking about what might be capable of finding acceptance in mainstream medical practice is to make a distinction between different

contexts in which these options of last resort are considered. We might think of those practices which can be regarded as “Hippocratic”, that is, those which come within the realms of good ethical practice. And, in stark contrast, consider those practices where the ending of life has more in common with another social institution, namely the criminal justice system. This is a very different context in which death is brought about by a single lethal injection. A short-hand label here might be “death row”.

Euthanasia and physician-assisted suicide fall outside of the “Hippocratic” context and the idea of ending life with one lethal dose certainly falls into some other category which has more in common with “death row” practices than those of mainstream medicine. Quill comments upon the differences between ending life by a single injection and by terminal sedation and the fact that the unease surrounding the instant death is avoided with the more gradual approach of terminal sedation. Bringing about an instant death has more of a “death row” context about it, whereas terminal sedation has at least “Hippocratic” leanings.

The language used in these debates is important. Battin (2008), in a paper entitled “Terminal Sedation: Pulling the Sheet Over Our Eyes”, is responding to Quill’s paper in which he set out the case for legislation for physician-assisted death. Battin notes that terminal sedation is also referred to as palliative sedation and that this only serves to confuse the situation. Arguing against terminal sedation, she says that the term “palliative sedation” is, as she puts it, “a new euphemism ... now often used instead of the more distressing ‘terminal sedation’”. Battin argues that avoiding the word “terminal” leads to confusion because there is no suggestion that death is involved and so the most important feature of this practice is obscured and terminal sedation is confused with “palliative care” (Battin 2008). This, she argues, throws consent into question.

The context and language used when terminal sedation is discussed plays a part in making it acceptable to mainstream medicine. Take, for example, Quill’s four options of last resort and the inclusion of voluntary stopping of eating and drinking [VSED] as a separate option. VSED can more usefully be linked to palliative and terminal care within the mainstream practices of end-of-life care, rather than stand out as such a stark category of its own, with leanings towards physician-assisted death, as opposed to physician-supported dying. In other words, shifting contexts from near “death row” to “Hippocratic” helps to locate terminal sedation within the mainstream of accepted medical practice.

We can see from Andrew’s case that consent and the desire to act in the patient’s best interests are key concerns. It is also the case that to a great extent, legal concerns dominate these developments in end-of-life care. This in turn tends to make medicine’s approach to the idea of terminal sedation and

physician-assisted death rather defensive. To an educated public with an eye to patients' rights, the reluctance of medicine to contemplate terminal sedation and even physician-assisted dying to having a legitimate place in end-of-life care may seem not only defensive but perhaps also somewhat grudging.

All this leads me to wonder whether the four options put forward by Quill (2008) are such discrete entities as they appear to be. Sedation is part of the VSED option when the doctor supports the patient through the difficulties of stopping eating and drinking. Sedation is clearly a part of the sedation to unconsciousness option, and in any case can be said to be part of good Hippocratic terminal care. A gradual reconsidering of what end-of-life care might reasonably entail would seem to be one way forward.

Untrammelled by legal preoccupations and the focus upon the intention of physicians (again a legal preoccupation), the four options of last resort could be seen to amount to good Hippocratic practice. I am not suggesting that we can ignore the law, just that when it is allowed to drive the debate, it unsettles clinical judgement and in a way distorts our view of what good medical practice should look like.

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References

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