

# Should children's autonomy be respected by telling them of their imminent death?

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## Different questions than the one originally posed need to be asked

Vince and Petros describe the heart-rending situation of an adolescent boy who has been diagnosed with terminal respiratory failure and for whom no further beneficial medical treatments are available. All of the members of the healthcare team and the boy's parents are in agreement that mechanical ventilation should be withdrawn with the expectation that the child will die shortly thereafter. Conflicting views arose, however, as to whether the boy's sedation should be lifted so that he could be informed of his impending death. The authors lay out the opposing arguments, for and against informing the child of his impending death, in some detail. Rather than specifically critiquing those arguments, I would like to comment on several ancillary issues that were not explored in the paper and, in doing so, point to some ways in which end of life decision making processes could perhaps be improved in the future.

### ADVANCE CARE PLANNING

The analysis of this case highlights the potential value of ongoing and early introduction of discussions around death and dying with chronically and terminally ill persons, even when the person is a child (using age appropriate language and descriptions). In the paper, we are given relatively few hints about the boy's understanding of the nature of his disease (although the authors do indicate that there had been no previous discussions with him about the gravity of his condition). It is unclear what conversations took place with him during the course of his illness, and, in particular, during his current hospitalisation and just before his reintubation and accompanying sedation. Did he consent/assent to these treatments? Did the consent discussion include a range of possible outcomes? Were the benefits and burdens of the treatment clearly described? Similarly, we do not know much about the child himself. Was this boy inquisitive about his illness? Was this child one who liked

to be involved in his care? Did he like to make decisions for himself or did he routinely defer to his parents? What were his values? What in his life was most important to him? How well did he cope with pain and respiratory distress? How did he respond to bad news in the past? An exploration of the responses to these questions would have helped those involved to better understand what the boy's wishes might have been relative to the current situation.

### BENEFITS/BURDENS

An analysis of the benefits and burdens of alternative courses of actions is an integral part of any ethical decision making process. Although the authors discuss some of the benefits and burdens associated with informing the child of his impending death, there are some potential burdens and benefits that are not mentioned, which, I believe, are of central importance. The primary burden to the child is described in terms of psychological burden, in that it would be "cruel" to wake him simply to tell him he is dying. There are, however, accompanying physical burdens that are extremely important to consider and that ought to be factored into the benefit/burden analysis. Presumably the sedation is being used to control pain and discomfort and is considered medically necessary (or at a minimum, medically appropriate). Thus removing the sedation would perhaps be experienced as a significant burden to the child by contributing to his physical pain and suffering. On the other hand, one of the possible benefits of awakening the child would be to allow him to say goodbye to family members and friends and to make known any last wishes (something as simple as indicating that he would like a favourite possession to be given to a certain friend). Indeed, I see this as the most compelling benefit for awakening the child (although perhaps not strong enough to outweigh the possible burdens).

Framing the decision to continue sedation and not to awaken the child as prioritising the parents' fears over the ethical rights of the patient is, I believe, an inadequate representation of the situation. The parents' fears may be better represented by the ethical principle of non-maleficence (minimising harm). Thus, I think the conflict in this situation is better framed as one between two competing and important principles, non-maleficence and autonomy, both of which have the child, not the parents, as the centre of focus. The heart of the ethical dilemma lies in determining which principle ought to be privileged in this situation.

### CONCEPT OF CHOICE

Considerable emphasis is placed on the concept of autonomy and having the ability to exercise one's choices as the principle that most clearly supports awakening the child to inform him of his impending death. It is unclear, however, what choices would be practically available to the child. It is stated in the paper that all those involved had concluded that withdrawal of treatment was the appropriate (and only?) course of action. If the child was awoken, was he going to be given a choice in this matter? Was he going to be asked to consent to the withdrawal of treatment (and if he refused to consent would that decision have been respected)? If, as the authors suggest, there was only one option in terms of care, it is difficult to argue for disclosure of his imminent death on the grounds of respect for his autonomy and his ability to exercise choices around the timing and means of his death.

As the authors correctly point out, one must be capable in order to fully exercise his/her autonomy. They identify several factors that might impede the child's capability if his sedation were to be lifted—for example, effects of hypoxia and age. Most would agree that if an individual is heavily sedated, he/she is not presently capable and is unable to take part in the decision making process. Every day in intensive care units around the world, substitute decision makers make decisions on behalf of sedated (but potentially capable) patients. Thus, in some ways, whether the child was capable before he was sedated or might have had the potential to be capable following removal of sedation, may not be particularly relevant questions. In the current situation, sedated and intubated, the child is not able to be part of the decision making process. Generally in such situations, a substituted judgment or best interests model for decision making is recommended and in some

jurisdictions legally mandated. In the absence of any previously expressed wishes that suggest that the child would have wanted to be informed of his impending death, one would strive to make the decision based on what was in his best interests. Those who know the child best, in this case the parents, are usually in the best position to make this assessment. In the case as described, there is nothing to suggest that the parents have anything but the best

interests of their child in mind. Deciding not to inform the child of his impending death need not necessarily be considered a paternalistic action, but failing to consider the child's previously expressed wishes and values would be.

Lastly, I want to suggest that an analogous situation could occur with an adult patient and that the same set of questions and ethical concerns would arise. I would like to thank the authors for bringing this case forward for

discussion. It highlights and raises our awareness of a number of ethical concerns and once again compels us to engage in end of life conversations with patients and their families sooner rather than later.

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