Regrettably, the image contains the text of a published article in the Journal of Medical Ethics. The content discussed in the article involves clinical ethics, specifically addressing the question of whether children's autonomy should be respected by telling them of their imminent death. The article is by T Vince and A Petros, and it discusses the ethical considerations in deciding how to inform a child of their terminal condition, taking into account their developmental stage and capacity for understanding.

The article introduces the case of a 14-year-old boy who was admitted to the paediatric intensive care unit (PICU) with acute on chronic respiratory failure and was mechanically ventilated. He was known to have obliterative bronchiolitis secondary to an episode of Stevens-Johnson syndrome. He had a history of IgG2 subclass deficiency and phenylketonuria but was developmentally normal. He had severely impaired lung function with both forced expiratory volume (FEV1) and forced vital capacity (FVC) at around 20% of that predicted for his age and was receiving home oxygen. He was being considered for lung transplantation.

Throughout the admission, he was difficult to ventilate but five days after admission, he was extubated. He was, however, unable to maintain adequate spontaneous ventilation and rapidly deteriorated, requiring reintubation under sedation and ventilation. It soon became apparent that, rather than just an acute deterioration of respiratory function following a chest infection, this was the presentation of terminal respiratory failure. A multidisciplinary discussion involving the respiratory, transplant, and intensive care teams and the boy's parents took place to review the management options. The lung disease was felt to be irreversible and of such severity and progression as to be rapidly terminal. It was agreed by all that lung transplantation was not a viable option as transplantation in children ill enough to need mechanical ventilation had previously been uniformly unsuccessful. It was also unanimously agreed that the child was deemed competent and capable of understanding his terminal situation, the medical team had an ethical duty to inform him of their discussions and decisions and to involve him in the process of his own death. By not doing so, the child would be deprived of his autonomy and rights to be involved in discussions surrounding his imminent death.

This case provoked considerable debate amongst those caring for the child. The patient's parents felt that the child should be kept comfortable and adequately sedated and have treatment withdrawn; to wake up the child would be to deprive him of his autonomy and his right to be involved in discussions surrounding his imminent death. The contrasting view was that he should be kept comfortable and adequately sedated and have treatment withdrawn; to wake up the child and inform him of his imminent death would be cruel and unnecessary. This was recognized as a paternalistic approach but felt to be in the child's best interests and was the viewpoint supported by the parents.

It was argued that if the child was deemed competent and capable of understanding his terminal situation, the medical team had an ethical duty to inform him of their discussions and decisions and to involve him in the process of his own death. By not doing so, it would be violating his personhood, autonomy, and human rights. An individual has “personhood” if he is able to value his own existence and has hopes and desires for his future life. An individual’s right to life emanates from that personhood rather than his innate biological form. With personhood comes the benefit of autonomy, in that we place a high moral value on the ability and freedom to make choices consistent with our hopes and desires. In the article, the ethical decision of informing the child of his terminal condition is described, taking into account both the child's developmental stage and his capacity for understanding.

**Abbreviations:** PICU, paediatric intensive care unit

**CLINICAL ETHICS**

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

T Vince, A Petros

Respect for an individual’s autonomy determines that doctors should inform patients if their illness is terminal. This becomes complicated when the terminal diagnosis is recent and death is imminent. The authors examine the admission to paediatric intensive care of an adolescent with terminal respiratory failure. While fully ventilated, the patient was kept sedated and comfortable but when breathing spontaneously he was capable of non-verbal communication and understanding. Once resedated and reintubated, intense debate ensued over whether to wake the patient to tell him he was going to die. The authors discuss the ethical arguments that surrounded their decision.

A 14 year old boy was admitted to the paediatric intensive care unit (PICU) with acute on chronic respiratory failure and was mechanically ventilated. He was known to have obliterative bronchiolitis secondary to an episode of Stevens-Johnson syndrome. He also had a past history of IgG2 subclass deficiency and phenylketonuria but was developmentally normal. He had severely impaired lung function with both forced expiratory volume (FEV1) and forced vital capacity (FVC) at around 20% of that predicted for his age and was receiving home oxygen. He was being considered for lung transplantation.

Throughout the admission he was difficult to ventilate but five days after admission he was extubated. He was, however, unable to maintain adequate spontaneous ventilation and rapidly deteriorated, requiring reintubation under sedation and ventilation. It soon became apparent that, rather than just an acute deterioration of respiratory function following a chest infection, this was the presentation of terminal respiratory failure. A multidisciplinary discussion involving the respiratory, transplant, and intensive care teams and the boy’s parents took place to review the management options. The lung disease was felt to be irreversible and of such severity and progression as to be rapidly terminal. It was agreed by all that lung transplantation was not a viable option as transplantation in children ill enough to need mechanical ventilation had previously been uniformly unsuccessful. It was also unanimously agreed that the child was deemed competent and capable of understanding his terminal situation, the medical team had an ethical duty to inform him of their discussions and decisions and to involve him in the process of his own death. By not doing so, it would be violating his personhood, autonomy, and human rights. An individual has “personhood” if he is able to value his own existence and has hopes and desires for his future life. An individual’s right to life emanates from that personhood rather than his innate biological form. With personhood comes the benefit of autonomy, in that we place a high moral value on the ability and freedom to make choices consistent with our hopes and desires. In the article, the ethical decision of informing the child of his terminal condition is described, taking into account both the child's developmental stage and his capacity for understanding.

**DISCUSSION**

This case provoked considerable debate amongst those caring for the child. The patient’s parents felt that the child should be kept comfortable and adequately sedated and have treatment withdrawn; to wake up the child and inform him of his imminent death would be cruel and unnecessary. This was recognized as a paternalistic approach but felt to be in the child’s best interests and was the viewpoint supported by the parents.

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determination. Thus, recognition of the child’s personhood was integral to respect for his life. Clearly, before his admission the boy was functioning normally at school and, for all purposes, was a person. By ensuring the boy remained comfortable and allowing him to die peacefully, without the stress of being awoken only to discuss his imminent death, the team was exercising an extreme degree of paternalism, which denied his autonomy and his right to self determination.

Before this admission, the boy had been living a normal but restricted life and on PICU, while intubated and mechanically ventilated but with sedation lifted, he had demonstrated good non-verbal communications. As such, there was no reason to believe that he would not have been able to understand the gravity of his condition. Nonetheless, it was suggested that he was too young to cope with the knowledge of his death. Yet it is well recognised that children with chronic illnesses, as young as 10 years old, can be aware they are dying and can benefit from participating in decisions surrounding death such as funeral arrangements.3 In retrospect, this case highlights the need for early and ongoing discussions about death with children with chronic illnesses. In this case, the child was aware of the chronic nature of his condition and the probable need for lung transplantation in the future. Discussions about death had not been previously broached with him, however, as they had not seemed pertinent to his primary physicians. Furthermore, on this admission, his acute deterioration was more rapid and severe than expected and it was unclear how he would have coped with this type of discussion in his current condition. Nevertheless, some members of the team felt he should be allowed the option. Indeed, if the outcome of withdrawal of therapy is the death of a person who is able to understand then should not consent be sought irrespective of age? Allmark would argue that this paternalistic approach to withdrawal of treatment, for fear of causing distress, denies a child his personhood and is unacceptable.4

During the boy’s admission, and while ventilated, the advice of the specialist teams was that if he was unable to breathe spontaneously and was dependent upon mechanical support, his chances of successful lung transplantation were extremely poor. The PICU team relayed this opinion to the family, but until the child required reintubation this was merely a probability rather than fact. Thus the future management plans were dependent upon how he would have coped with this type of discussion in his current condition. Nevertheless, some members of the team felt he should be allowed the option. Indeed, if the outcome of withdrawal of therapy is the death of a person who is able to understand then should not consent be sought irrespective of age? Allmark would argue that this paternalistic approach to withdrawal of treatment, for fear of causing distress, denies a child his personhood and is unacceptable.4

The alternative reason to awaken him, to allow him to “put his affairs in order,” bears consideration. As the outcome is inevitable, it may be postulated that the child had no real choices except in controlling some elements of the manner of his death. The opportunity to say goodbye may be vital for the child and may prove helpful for the family at the time of their son’s death and afterwards. Perhaps, for these reasons alone, awakening the child may be beneficial.

Ethical dilemmas concerning end of life decisions are an almost daily occurrence on the PICU. In recent years, more children die on the PICU as a result of withdrawal or limitation of life sustaining treatment than of unsuccessful attempts at resuscitation.12 Limitation of intensive care support is almost invariably agreed between staff and families.13 Sklansky, however, described withholding and withdrawing life sustaining treatment as passive euthanasia since death occurs due to the absence of a treatment that would otherwise have prolonged an unbearable existence.14 Medical and legal authorities accept this because it is considered to be in the patient’s best interests.15 In our case, there was a significant degree of medical paternalism and parental judgment exercised in concurring over withdrawal of therapy, which might have led Sklansky to describe it as paternalistic euthanasia. Concerns about competence because of residual sedation and respiratory failure, and the
potential distress the patient might suffer meant that obtaining consent was abandoned. Under these circumstances, a surrogate party must act in the person’s best interests. In most situations on PICU, this will be the child’s family as they have shared beliefs and values and are best placed to know the patient. It is unclear, however, how well a third party can act as a proxy. Meyer et al report that many parents feel they have little or no control in the process of their child’s death and, in retrospect, up to 25% would change things. In addition, parents are sometimes unable to act in the child’s best interests because of emotional stress or conflicts of interests. Furthermore, several studies indicate that families do not accurately predict the resuscitation directives of their sick relative and may, therefore, instruct doctors differently from how the patient would have wished. Healthcare professionals can be helpful, as they tend to be more experienced and objective about the child’s medical condition. Like parents, healthcare professionals consider the patient’s quality of life, potential for recovery, and pain relief in their decision making. Doctors are not, however, ethically obliged to provide any treatment they consider the patient’s quality of life, potential for recovery, and pain relief in their decision making.20 Hence, a paternalistic approach, albeit motivated by beneficence and non-maleficence, runs the risk of imposing on the family the physician’s own values and interpretations of the child’s best interests.14 19 21 22 Moreover, studies comparing staff and patient estimates of quality of life following spinal cord injury clearly demonstrate that healthcare professionals are more pessimistic than the patient’s perception of, or indeed, the actual subsequent quality of life.23 When disagreement occurs or differences cannot be resolved, it is often very helpful to seek the advice of the local clinical ethics committee27 28 as was done in this case. There is no doubt that the decision would have been harder to uphold if the parents had held differing opinions about what ought to be done, or had not been firm in their view of how their child should be cared for in the terminal stages of his illness.

In the end, the team decided to withdraw intensive care support without informing the child. It was felt that the manner in which the child died would be much more significant for the family than for the various sections of the medical team. The parents were adamant that they did not want to risk any chance that their son might be distressed if awoken. By acquiescing with the parents’ wishes, the medical team allowed them some control in their son’s death. The actions of the healthcare team and the parents may be described as paternalistic, but based on the ethical principle of non-maleficence, the healthcare team acted in what they perceived to be the best interests of the child. In doing so, they prioritised their own and the parents’ non-maleficent decisions over the patient’s right to autonomy. This may well have been the right thing to do. It may also be argued that the nature and acute circumstances of his illness never truly allowed the child to determine his future. The question remains, however, whether an individual’s best interests can truly be respected if he is denied the opportunity to exercise his autonomy.

Authors’ affiliations
T Vince, A Petros, Paediatric Intensive Care Unit, Great Ormond Street Hospital, London, WC1N 3JH, UK
Correspondence to: T Vince, Paediatric Intensive Care Unit, Great Ormond Street Hospital, London, WC1N 3JH, UK; VinceT1@gosh.nhs.uk
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REFERENCES
4 Gillon R. Ethics needs principles—four can encompass the rest—and respect for autonomy should be “first among equals”. J Med Ethics 2003;29:307–12.
9 Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402 (HL).