CLINICAL ETHICS

Neuromuscular blockers—a means of palliation?

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Revised version received 17 January 2002 Accepted for publication 18 January 2002 As we die, our respiratory pattern is altered and we seem to gasp and struggle for each breath. Such gasping is commonly seen as a clear sign of dyspnoea and suffering by families and loved ones, however, it is unclear whether it is perceived at all by the dying person. Narcotics and sedatives do not seem to affect these gasping respirations. In this issue of the *Journal of Medical Ethics*, we are asked to consider whether the last gasp of a dying patient could be or, perhaps, even *should* be avoided by administering neuromuscular blockers to palliate dying patients. For many reasons, such as our current failure to alleviate pain and distress, stories of inadequate analgesia and sedation in critically ill paralysed patients and the inability to know the intent—whether to palliate or to euthanise—it would seem that administering neuromuscular blockers should not be ethically permissible.

n this issue of the journal, Perkin and Resnik¹ ask us to reflect on the complex ethical issues surrounding the palliation of dyspnoea at the end of life. In their thoughtprovoking article, they ask us to consider whether the last gasp of a dying patient could be, or perhaps even *should* be, avoided. They suggest that while we are uncertain how much dying patients actually perceive, the gasping phase of the dying process is difficult to palliate since narcotics and sedatives do not alter this respiratory pattern, characterised by seemingly excessive respiratory muscle contractions which themselves are a recognised factor in the perception of dyspnoea. Furthermore, such gasping often distressingly colours family members and loved ones' last memories of the dying person. Since the only way of alleviating the gasping is by administering neuromuscular blockers to achieve respiratory muscle paralysis, Perkin and Resnik1 propose that these drugs be given to the dying patient once he/she enters the gasping phase, not with an intent to kill (euthanise) him/her but with an intent to palliate them.

The administration of neuromuscular blockers at the end of life is an ongoing source of controversy in the end of life care literature.¹⁻⁵ Critically ill patients, whether they be adult or paediatric, are paralysed when they cannot be adequately oxygenated on a ventilator even with heavy sedation and the intensive care unit (ICU) team has no choice but to achieve complete control over their respiratory function in order to attempt to save their life. Debate has raged over what intensivists should do when a decision has been reached to withdraw life support from such a paralysed patient since without the ventilator they would not be able to breathe on their own. For many adult intensivists, to withdraw a ventilator from a paralysed patient—the resulting inability to breathe being the immediate cause of death-is indistinguishable from euthanasia. Some propose reversing or waiting for the neuromuscular blockers to wear off before initiating the ventilator withdrawal to ensure the patient has an opportunity to breathe and, since paralysis eliminates signs of distress such as facial grimacing, to permit better palliation of pain, dyspnoea, and distress.²⁻⁴ The difficulty is that sometimes in the presence of multisystem organ failure, metabolites can accumulate and therefore the effects of these drugs cannot always be easily or quickly reversed. The resulting delay in withdrawing the ventilator, especially when the prognosis for survival is non-existent, can be a source of significant distress

for the family and health care providers. In this situation, most intensivists would accept withdrawing the ventilator without waiting for the effects of the drugs to wear off.²⁴ Certainly adult intensivists have, for the most part, opposed the initiation of neuromuscular blockers when withdrawing ventilatory support since the resulting paralysis and inability to breathe—by being the immediate cause of death—is felt to indicate an intent to kill (euthanasise) and not to palliate the dying patient.²⁴

In paediatrics, the attitudes towards neuromuscular blocker use at the end of life have been even more ambiguous. As with the debate seen in the adult critical care literature, some paediatric health care providers argue that their primary responsibility is to the child and that therefore the withdrawal of ventilatory support should only occur once the neuromuscular blockers have worn off, for the reasons already alluded to; others suggest that any resulting delay in ventilator withdrawal while neuromuscular blockers wear off or are reversed would lead to such emotional and psychological distress for the parents that the burdens of waiting for the effects to wear off outweigh the benefits.⁵ On the other hand, quite differently from their adult critical care colleagues, some actually suggest that the drugs can be continued if already in use, so that parents do not perceive any signs of distress or dyspnoea in their dying child.4

In their article Perkin and Resnik¹ propose another perspective, not previously elucidated: that the intent of the physician administering neuromuscular blockers is not to kill but to palliate. They argue that since we are not sure how much a dying patient actually perceives, and since large doses of analgesics and sedatives do not alleviate gasping, the physician should use neuromuscular blockers to paralyse respiratory muscles and alleviate dyspnoea-once appropriate doses of narcotics/ benzodiazepines have been given. This is indeed an interesting viewpoint. Before consideration is given to using neuromuscular blockers, one must first ask what is an appropriate amount of analgesics and sedatives. Research has revealed that the management of pain and suffering at the end of life is not well taught and sources of distress are too often not alleviated.² Health care providers' perceptions of what constitutes an appropriate amount of analgesia vary widely for a given situation.² Such perceptions of adequate amounts of drug can indeed be questioned by ICU survivors, who describe severe pain while their caregivers felt adequate pain relief had

been achieved.² We seem to have strayed so far from the teaching: "a patient's pain is what he/she says it is", that one can honestly question whether we as health care providers truly have any idea how much pain and discomfort our patients tolerate.

Gasping respirations, while upsetting to the family and health care team, are perhaps akin to other alterations in respiratory pattern seen after strokes-for example, Cheyne Stokes respirations, which, while they might signify neurological injury or altered physiology are not necessarily perceived as dyspnoea by the patient. Such respiratory patterns-when the result of neurological injury-are not treated as signs of dyspnoea by health care providers, yet such patterns look equally uncomfortable. Moreover, if a patient is paralysed to prevent gasping and we are uncertain how much they perceive, how do we know that we have not worsened their suffering since they may then be aware of their inability to breathe or move despite still having a desire and a drive to do so? After reading the chilling stories of ICU survivors who recall what it was like to be awake and paralysed, are we willing to take this chance with even one dying person?

If we accept that dying patients perceive gasping as severely distressing, when would we be prepared to initiate such paralysis? If gasping is perceived as severe dyspnoea by the dying, perhaps we should not even wait for gasping to begin but simply initiate paralysis when a decision has been reached to withdraw life-sustaining treatments. Certainly we accept that good palliative care means that analgesics and sedatives can be administered in anticipation of suffering.²⁴ If neuromuscular blockers are accepted as a means of palliation, should we not also be prepared to give them in anticipation of suffering? Or would this really indicate an intent to kill (euthanise)? As health care providers can we claim that an ethical difference truly exists?

Perkin and Resnik¹ rightly state that the principle of double effect is used to permit the administration of analgesics and sedatives in order to alleviate the dying patient's distress even though such administration could foreseeably hasten his/her death.⁶⁻¹² While the current literature would seem to refute that such hastening actually occurs,¹² arguably, the administration of narcotics and sedatives may shorten time to death. Recently, the principle of double effect was given legal sanction in an United States Supreme Court decision prohibiting physician assisted suicide: if the intent in administering analgesics and sedatives is clearly to palliate, physicians do not need to fear being charged with murder or assisting suicide.^{2 11}

Since much of their article supporting the use of neuromuscular blockers to palliate dyspnoea hinges on the principle of double effect, it is worth exploring this principle in more detail. The principle of double effect arises from Catholic deontological theory in which some acts, either of commission or omission, are absolutely forbidden.^{7 & 12} However, situations in which it is impossible to avoid all moral harms arise.^{7 & 12} The principle of double effect was developed to set limits on such absolutism in situations in which no matter what action is taken or not taken, moral harms cannot be avoided. $^{\scriptscriptstyle 6-8\ 12}$ In these circumstances, acts-for example, administering analgesics, and through them causing a state of affairs-for example, death, ordinarily prohibited, can be ethically accepted, although the resulting state of affairs (death) remains essentially undesired.7812 In other words, we can refuse to kill intentionally-for example, euthanasia but we cannot avoid all foreseeable harms—for example, hastening death in cases of moral impossibility—that is, in situations in which death is a certainty which we cannot prevent or avoid no matter what action we take. Even when death is certain, however, directly causing death remains unacceptable and is considered murder no matter how short the person's life expectancy.

The most important criticism of the principle of double effect is to do with whether a real ethical difference exists between what is intended and what is merely foreseen. Some argue, as do Perkin and Resnik, that the difference is merely one of degree: "the difference between 'hastening death' and 'causing death' is at best a matter of degree not a matter of kind".1 It is worth exploring this notion since this distinction is a source of considerable discomfort for health care providers, especially since this line of reasoning has been used before to diminish the differences between palliative care and euthanasia by those who support physician assisted death9causing confusion and resulting in further decreases in the quality of end of life care. In ethics, intentions are important since through them we express our virtues, shape our character, and show respect for the intrinsic value and wellbeing of others^{6 12} For clarity, let's distinguish intentions from motives. Intents are different from motives-motives can be thought of as "ulterior" intents-for example, in euthanasia, the motive is compassion. While they are less important from a legal point of view, in ethics, motives are as important as intents since our motives also reveal our true character and determine virtue.6 12 While what one intends, one generally acts to bring about,^{1 6-8 12} we do not always act on an intention (in Perkin and Resnik's1 article this would be referred to as a "want") and particular acts are not always clear indications of intent.^{6-8 12}

What is often misunderstood is that the principle of double effect does draw a distinction between what is intended and what is only foreseen.^{7-9 12} While the principle does hold us morally responsible for both what we intend and for what we only foresee,^{7 8 12} since both are voluntarily brought about, it makes a distinction based on the fact that one does not act for the sake of what is foreseen—in other words, one does not administer analgesics to cause death.^{7 12} Moreover, some question whether bringing about these "side effects" (hastening death) is fully voluntary: do the "side effects" instead represent important considerations in spite of which one acts?^{7 8 12} So, if one accepts that neuromuscular blockers are the only way of palliating dyspnoea and the intent is not to cause death, using the principle of double effect to justify the foreseeable hastening of death would seem to hold merit.

To the extent that it is impossible to know what someone intends versus what he/she only foresees, however, the border between palliative care and euthanasia, may never be completely clear.^{7-9 12} The intent of a health care provider who administers neuromuscular blocking agents to eliminate gasping respirations is easily questioned in today's world, since the health care provider is a member of a profession which seems to have devalued, and perhaps even lost, virtue.12 Even if it is accepted that gasping respirations are a source of distress for the dying, and that neuromuscular blockers are needed to alleviate this distress, how can we distinguish the physician who uses neuromuscular blockers to palliate from the one who uses them to cause death? Or to use Perkin and Resnik's example: how can we know that smothering the dying patient is different from paralysing him?¹ Their notion of assessing regret and remedy would be difficult to apply since neuromuscular blockers and the resulting inability to breathe will cause death with absolute certainty.1

In Perkin and Resnik's¹ two case descriptions, the family recall as a last terrible memory the gasping of their dying children. No one among us should be unmoved by the families' recollections. However, questions remain: were the families prepared for what was going to happen? Did the intensivists explain how the breathing pattern of their children would change as the ventilator was withdrawn—how pain and any signs of distress would be treated? Health care providers are very ill-prepared to facilitate decision making at the end of life, never mind to communicate about death and dying. Such open discussions of what to expect during the dying process rarely occur and families and loved ones are left unsure and frightened about what they will see happen to their loved one at a time of overwhelming grief. Gentle explanation of how life-sustaining treatments will be withdrawn, what they will see, how they can help alleviate distress, and how they can be with their loved one during his/her last few moments is needed to help ease their suffering. Families should be encouraged to ask questions and express their fears. The families described by Perkin and Resnik¹ are haunted from watching the gasping of their dying children. The death of a loved one is devastating and our last memories, perhaps especially if we are present while a loved one dies, are always painful. We need to ask ourselves whether, if we prevent or eliminate gasping by using neuromuscular blockers-even if we accept that this is being done with the intent to palliate-we would not be equally haunted by images of the syringe being inserted? Would these painful images of the last moments sear our minds, as memories of our own anguish and suffering over the loss of someone precious always do?

Perkin and Resnik¹ have given us a new perspective to ponder as we seek to improve the quality of end of life care. Can we accept that neuromuscular blockers are needed to palliate gasping respirations? We do not know that such gasps are perceived as uncomfortable by dying patients and, for many reasons, it would seem that administering neuromuscular blockers should not be ethically permissible.

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