A request for hospice admission from hospital to withdraw ventilation

C Gannon

A request to admit a hospital inpatient with motor neurone disease to the hospice generated unusual unease. Significantly, withdrawal of ventilation had already been planned. The presumption that ventilation would be withdrawn after transfer presented a dilemma. Should the hospice accept the admission? If so, should the hospice staff stop the ventilation, and then when and how? Debate centred on the continuity of best interests and the logistics of withdrawing ventilation. The factors making the request contentious identified competing interests within hospice admission decision making that could detrimentally impact on patient care.

A fundamental aspect of palliative care is distinguishing which interventions appear in our patients’ best interests. But endorsing the subsequent withholding or withdrawing of life-prolonging treatment still remains difficult. Although guidance exists to inform such decisions, it is uncommon in the hospice setting, leaving staff unease. Withholding parenteral nutrition in a patient’s final hours or days is a daily occurrence and seldom emotive for hospice staff. Despite ethical parallels, withdrawing ventilation raised additional concerns. Debate centred on the continuity of professional decisions and the logistics of withdrawing ventilation.

Arguably, all patients have treatment withheld or withdrawn at some point, particularly in the hospice setting. But typically, the underpinning decisions are not contentious and not explicit. Reassuringly, an unequivocal lack of efficacy, patient refusal, or treatment failures will be the usual mechanism—where nothing is “denied” from patients.

However, if the intricacies of deciding “best interests” around stopping treatment are unfamiliar, seemingly controversial scenarios may generate unwarranted professional unease. Withholding parenteral nutrition in a patient’s final hours or days is a daily occurrence and seldom emotive for hospice staff. Despite ethical parallels, withdrawing ventilation generates more concern because:

- as a specific act it requires an unavoidably open decision
- it is likely to be associated with a short interval from withdrawal to death (effectively irreversible and where the prime intention can be mistaken to be ending life)
- it is uncommon in the hospice setting, leaving staff uneasy.

Intuitively, these factors increase the level of confidence required in making decisions to withdraw ventilation, and increase the burden of the act for staff. However, despite relevance on a personal level, the legitimacy of any professional bearing is less clear.

CASE HISTORY

A 69 year old woman with endstage motor neurone disease had worsening respiratory failure despite continuous non-invasive positive pressure ventilation (NIPPV). She was in a tertiary hospital and had reportedly received specialist palliative care hospital support but was not known to our service. NIPPV was to be withdrawn on the day of the referral to the hospice, with transfer requested for the next day, to meet the patient’s wish for a hospice death. This appeared optimistic, carrying the risk of dying before or in transit. To maintain continuity and minimise distress, we advised remaining in hospital for terminal care or transferring to the hospice on NIPPV with the presumption that it would still be withdrawn. Hospice transfer was chosen.

DISCUSSION

Accepting a transfer from hospital with the presumption that NIPPV would be withdrawn presented a dilemma for the hospice. Should we stop NIPPV as planned, if so when and how? The appropriateness of many hospice admissions from hospital is agreed with limited information, where “continuity of care” requires a leap of faith. However, inheriting the decision to withdraw NIPPV caused disproportionate concern, lowering our willingness to transfer. A conflict between continuity of care and our professional obligation arose. Was our prevailing duty to admit and follow the established plan to withdraw NIPPV (withdrawal had only been delayed to allow transfer) or to reassess best interests once admitted? Would the level of concern have been different if she had been better known to our service, even if not recently (that is, pre-dating the decision to withdraw NIPPV) or only known to our community team (remaining equally unfamiliar to the relevant inpatient staff)? Interestingly, if she had arrived off NIPPV as initially requested, would we have restarted it, until we were sure it should stop too? Also, although not our usual practice, it was argued that we should reassess the patient in hospital, despite this delaying transfer, being labour intensive, and only providing a “snapshot” for clinical judgment. Moreover, revisiting best interests could only benefit the patient if the original decision to withdraw NIPPV had been “incorrect”. Seemingly, resistance to this patient’s admission reflected an inconsistent distrust in better-placed colleagues, medical defensiveness, or a reaction to external constraints on our professional autonomy.

Concerns were also raised around when to turn off the ventilator. Clearly, if there was any doubt once the patient became our responsibility, reassessment of best interests would be necessary. However, if no clinical concerns were present, would a delay still be wise to avoid any appearance of hasty actions? If so, how long as an inpatient is reassuring? Variable responses of hours to several days were tabled. Despite inherent discomfort, if the patient had insisted that her NIPPV was stopped on arrival, we would have been obliged to stop it in the patient’s best interests and acknowledging the right to refuse treatment (assuming mental capacity). Yet a delay was argued as necessary because it could benefit relatives and inpatient staff. This
ability to override the patient’s rights appeared unusually explicit and at odds with the hospice’s patient centred and autonomy respecting philosophy. Despite remaining contentious, and risking a battery charge, such action does parallel rationing, where the greater good takes precedence over an individual’s best interests.

Deciding who should turn the ventilator off remained emotive, seemingly requiring specific guidelines, and seen by some as a medical and not a nursing role. Yet these caveats had not been sought for taking down parenteral fluids, which differed from common issues. However, as outlined, perceptions cannot be ignored, even if they are of uncertain substance. A firing squad using blanks and only one live bullet is a useful analogy. By introducing uncertainty, no-one carries the executioner’s burden, however, the outcome remains the same and the chance of individual responsibility persists. Thus, though not required professionally, we accepted individual decisions of conscience would remain pivotal in identifying staff willing to withdraw NIPPV.

Numerous factors made this request contentious. Although well motivated and possibly unavoidable, our concerns appeared predominantly personal, historical, and political. Yet these concerns nearly delayed the patient’s transfer, impinging on best interests. Ideally, healthcare decision making should not be influenced by how difficult, expensive, or emotive the subsequent interventions may be, for anyone other than the patient. Deciding whether to continue or withdraw potentially life-prolonging treatment is primarily the patient’s dilemma and not the healthcare professional’s choice. While competing interests within staff, units, and society will inevitably impact on an individual’s care, any discrepancy needs to be explicit to increase confidence within

our decision making. And where disagreement persists between informed competent patients and their healthcare professionals it is the courts that make the final ruling.

On admission, this patient retained capacity communicating with “yes” and “no”. Her immediate concern was our plan to stop parenteral fluids, which needed considerable but not unfamiliar discussion. Withdrawing NIPPV had not been raised before transfer, so NIPPV discussions were deferred. She died the following day, notably on NIPPV. Thus our concerns proved academic. While any professional mistrust was vindicated, importantly there was no still need to make withdrawal of NIPPV into a special case. Our response to the emotive nature of withdrawing NIPPV appeared counterproductive and could have left us legally vulnerable.

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Correspondence to: Dr C Gannon, The Princess Alice Hospice, West End Lane, Esher, Surrey, KT10 8NA, UK; craiggannon@pah.org.uk

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