Clarifying the data on double effect

In the first edition of *Palliative Medicine* this year, we published Seale’s paper on end of life decisions made by UK medical practitioners.¹ This paper sparked much interest in the media.²,³ This is unsurprising given the contemporaneous publicity surrounding cases of so-called ‘death tourism’ and the revival of the Lord Joffe Bill.⁴,⁵ Correspondents extrapolated the small percentage of deaths in the UK, reported as involving end of life decisions, to estimate the number of deaths that occur in the UK secondary to voluntary euthanasia, involuntary or non-voluntary euthanasia, withdrawal or withholding of treatment (non-treatment decisions) and situations where alleviation of symptoms might have shortened life.

The questionnaire used in the Seale paper was translated from a Dutch questionnaire, which has been used for similar surveys in Australia, New Zealand, and Europe. The data generated are important, however, in asking doctors to state whether they or a colleague intensified the alleviation of pain or symptoms ‘taking into account the probability or certainty’ or ‘partly with the intention’ of hastening the end of life, the questionnaire makes some questionable assumptions.¹ We know that surveys of practice and attitudes in relation to end of life decisions are notoriously problematic,⁶ and experience of teaching medical students and qualified doctors about medico-legal and ethical issues at the end of life also suggests there is much misunderstanding in this area. Against this background, the questionnaire may encourage misleading responses to these particular questions.

It is well documented that professionals have poor knowledge and inappropriate attitudes about the use of opioids at the end of life, believing, for instance, that addiction and tolerance are inevitable, respiratory depression limits dose escalation and that opioids shorten life. The literature suggests these attitudes and beliefs lead to inadequate prescribing of opioids for patients in pain at the end of life, resulting in sub-optimal symptom control.⁷ It is possible these attitudes and beliefs also exist in doctors who, nevertheless, prescribe opioids for patients at the end of life because they wish to control their pain. The work of Bilsen et al. suggests doctors ‘intensify the alleviation of pain and suffering’ considering the ‘possibility or certainty that this would hasten the patient’s death or with the explicit intention of hastening the patient’s death’ in 19–26% of deaths, depending on the European country surveyed.⁸ This implies that doctors believe they are hastening death, though the majority of these patients are taking only moderate doses of opioids (<300 mg oral morphine equivalent per day).

The doctrine of double effect is largely irrelevant in everyday practice. The doctrine states that a doctor can use measures (usually opioids) to alleviate symptoms at the end of life which might, as a secondary effect, shorten life, provided the doctor’s intention is the good outcome (symptom relief) rather than the bad (death). Critics of the doctrine argue only the doctor can ever know his or her intention, however common sense suggests intent could usually be judged by the drug, dose and route of administration chosen in relation to the patient’s circumstances and previous opioid requirement. Sykes and Thorns have reviewed the use of both opioids and sedatives in end of life care and conclude there is no evidence that their use ‘in palliative care requires the doctrine of double effect as a defence’.⁹

The problem with some questionnaires used in studies of end of life decisions is thus that the questions are based on the assumption that alleviation of symptoms may hasten death and are asked of doctors who believe it does. A close reading of the legal cases, along with experience of teaching and discussing these issues with clinicians and medical students, suggests there are three groups of doctors.¹⁰ The first, probably representing a tiny minority of the profession, intensifies symptom control significantly or uses other measures with the intention of hastening death, ie, practices euthanasia illegally. A second group of doctors are knowledgeable about care at the end of life and know that they very rarely, if ever, hasten death by achieving symptom control. The third group of doctors manages patients’ symptoms at the end of life appropriately, albeit believing, and reporting, they are hastening death.

We propose this model explains the apparently high level of deaths involving end of life decisions reported, particularly hastening of death due to alleviation of pain and symptom control measures. Doctors who fall within the first and third groups are certainly a source of concern and we have yet to ascertain how best to educate and support them in providing palliative care of the highest standard for patients. However, it is also a
concern that the inherent assumptions which are evident in studies of end of life decisions and which, for example, can be seen in the questionnaire used by Seale and other authors, may generate misleading data which will obfuscate rather than inform the public and professional debate.

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References