

TERMINAL SEDATION – GOOD MEDICINE? GOOD ETHICS? GOOD LAW?

SHEILA A.M. MCLEAN*

The use of sedation at the end of life is becoming increasingly common, yet its ethics and lawfulness have not been as widely discussed as might have been expected. In this article, the primary focus is on what is known as ‘terminal sedation’, with particular reference to the use of sedation without the provision of assisted nutrition and hydration (‘ANH’). It is argued that, where ANH is not contraindicated by patient wellbeing itself, close scrutiny of the practice is required. There are both ethical and legal reasons why a move towards appropriate regulation is appropriate. The urgency of doing this is evidenced by the variety in practices throughout the world, with some commentators suggesting that the decision whether or not to instigate terminal sedation may be influenced by more than clinical indications for its use (in which case, it may be perilously close to a form of euthanasia). Indeed, it may be argued that there is little that differentiates terminal sedation from a form of euthanasia. Moreover, the relatively common exclusion of existential suffering as an indication for terminal sedation is questioned. Were this also to be accepted as a valid indicator for terminal sedation (without the provision of ANH) it becomes even more urgent that an adequate regulatory framework is developed and that the ethics of the practice are appropriately explored and clarified.

I INTRODUCTION

The purpose of this article is to address the implications – medical, legal and ethical – of the use of terminal sedation, particularly where it is combined with the removal or withholding of assisted nutrition and hydration (‘ANH’). My aim is to both evaluate the status of this increasingly common practice against principles that inform other end of life decisions, and to robustly analyse it for consistency and clarity.

The first task of any lawyer is to define her terms. In the case of terminal sedation however this can prove to be extremely difficult. As De Graeff and Dean note:

Sedation in palliative care has been named in various ways, for example, ‘sedation,’ ‘terminal sedation,’ ‘sedation for intractable distress in the imminently dying,’ ‘end-of-life sedation,’ ‘total sedation,’ ‘sedation in the terminal or final stages of life,’ ‘controlled sedation,’ ‘palliative sedation,’ and ‘palliative sedation therapy.’¹

*LLB (Glasgow University), MLitt (Glasgow University), PhD (Glasgow University), LLD (Edinburgh University), LLD (University of Abertay), Emeritus Professor of Law and Ethics in Medicine School of Law, University of Glasgow.

¹ Alexander De Graeff and Mervyn Dean, ‘Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards’ (2007) 10(1) *Journal of Palliative Medicine* 67, 69.

Van Delden argues for the use of ‘terminal’ sedation, ‘because it conveys the message that an end-of-life decision is involved, implying that the timing of death may be influenced.’² He makes the further point that:

One of the characteristics of this debate [about terminal sedation] is that it is a very confused one: people disagree about the meaning of the term, the appropriateness of it and, of course, about the conditions under which it (what?) would be morally justified....: as is often the case, a discussion about terms is a discussion about norms in disguise.³

Throughout this paper I will use the term ‘terminal sedation’ unless I am directly quoting from someone else. As Papavasiliou and colleagues note, while palliative sedation is also a commonly used term, terminal sedation ‘despite being heavily criticized, persevered in the literature probably because, once used, the concept of terminal was associated with the patient’s situation, that is, terminal cancer, not the objective of the treatment.’⁴ Whether this assertion represents fact or fancy will be considered further; in particular the desire to separate the outcome or objective from the use of the word ‘terminal’ requires further analysis.

According to Dean et al:

Palliative sedation therapy was first described in the early 1990s as an existing practice but little is known about its development. Many definitions have been put forward for various types of sedation used in palliative practice, but at the core they share the ideas that palliative sedation is: (1) the use of (a) pharmacological agent(s) to reduce consciousness; (2) reserved for treatment of intolerable and refractory symptoms; and (3) only considered in a patient who has been diagnosed with an advanced progressive illness.⁵

It is obviously the case that some medical decisions at the end of life – while overtly designed to treat or palliate – can ‘shorten survival’.⁶ For example, it has been claimed that in the Netherlands in 2010 ‘an end of life decision was taken in 57.8 per cent of all deaths.’⁷ It is plausible that such figures may be mirrored (perhaps even exceeded) in those jurisdictions where medicine is advanced and life expectancy increasing, particularly where assisted dying has been legalised. It is more difficult to estimate what proportion of deaths result from an actual decision in those jurisdictions where assisted dying remains illegal and no reporting criteria exist.

Terminal sedation becomes an option when the patient’s symptoms are refractory.⁸ According to De Graeff and Dean:

² Johannes J M van Delden, ‘Terminal Sedation: Source of a Restless Ethical Debate’ (2007) 33 *Journal of Medical Ethics* 187, 187.

³ Ibid.

⁴ Evangelia S Papavasiliou et al, ‘From Sedation to Continuous Sedation Until Death: How Has the Conceptual Basis of Sedation in End-of-Life Care Changed Over Time?’ (2013) 46 *Journal of Pain and Symptom Management* 691, 695-696.

⁵ Mervyn M Dean et al, ‘Framework for Continuous Palliative Sedation Therapy in Canada’ (2012) 15(8) *Journal of Palliative Medicine* 870, 870.

⁶ Sigrid Sterckx, Kasper Raus and Freddy Mortier, ‘Introduction’ in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 1, 4.

⁷ Ibid.

⁸ For discussion see, Clive Seale, ‘Continuous Deep Sedation in Medical Practice: A Descriptive Study’ (2010) 39 *Journal of Pain and Symptom Management* 44.

A symptom is regarded as being refractory (as opposed to difficult to treat) when the clinician perceives that further invasive or non-invasive interventions are (1) incapable of providing adequate relief, (2) associated with excessive and intolerable acute or chronic morbidity, and/or (3) unlikely to provide relief within a tolerable time frame. This implies a rigorous diagnostic approach, paying attention to the physical, psychological, social, and emotional dimensions of the symptom. It also implies that all available symptom-targeted medications, procedures, or interventions attempted have been ineffective or produced unacceptable side effects, or, if considered, were ruled out as too burdensome or risky for the patient, or have been refused by the patient.⁹

As Lanuke and colleagues remind us however, '[t]he incidence of refractory symptoms in palliative care patients is controversial and it is important to distinguish between difficult and refractory symptoms when addressing the needs of palliative care patients.'¹⁰ Careful medical decisions are, therefore required, subject of course, to ethical and legal analysis – of which more later. For the moment, it is interesting to note that the use of terminal sedation seems to be increasing. Indeed as Sterckx, Raus and Mortier write, 'dying after having been continuously sedated for some time is fast becoming one of the standard ways of dying.'¹¹

II SUMMARY OF USE

Seale notes that the use in the Netherlands of what he calls continuous deep sedation ('CDS') rose from 5.6 per cent of deaths in 2001 to 7.1 per cent in 2005. In Belgium the rates rose from 8.2 per cent of deaths in 2002 to 14.5 per cent in 2007.¹² According to his findings, 'CDS in the United Kingdom is more common in patients who are younger or dying of cancer.'¹³ Further research by Anquinet and colleagues¹⁴ found that '[i]n Flanders, BE [Belgium] in 2007, its incidence was estimated to be 15% of all deaths. In NL [the Netherlands] in 2005, this was 8%. In the U.K. in 2008, its prevalence was 17% of all deaths.'¹⁵ They also found that it lasted 'in most cases, for one week or less in all countries [Flanders (Belgium), Netherlands, UK] and both settings (hospital: 90% -93%; home: 91%-96%)'.¹⁶ Noting the variations in rates of use, the authors speculate that this may be a result of the difference in the laws regarding voluntary euthanasia and assisted suicide. Where assisted dying is legally permissible, they suggest that 'physicians and patients can "choose" between euthanasia and continuous deep sedation until death.'¹⁷ In the United Kingdom however, where no legalised assisted dying exists, 'the high rate may be a result of the fact that such sedation is perceived to be the only legal "last resort" option for a physician treating a terminal patient with refractory symptoms.'¹⁸

As in so many end of life predicaments, the Dutch have played a leading role and this is no less true in the case of terminal sedation. Dean et al report that national guidelines on its use were first drawn up in 2005 (these were amended in 2009). The medical profession was encouraged by the government to develop these guidelines, which require both the existence of refractory

⁹ De Graeff and Dean, above n 1, 70.

¹⁰ Kathryn Lanuke et al, 'Two Remarkable Dyspneic Men: When Should Terminal Sedation be Administered?' (2003) 6(2) *Journal of Palliative Medicine* 277, 279.

¹¹ Sterckx, Raus and Mortier, above n 6.

¹² Seale, above n 8, 45.

¹³ *Ibid* 51.

¹⁴ Livia Anquinet et al, 'The Practice of Continuous Deep Sedation until Death in Flanders (Belgium), The Netherlands, and the UK: A Comparative Study' (2012) 44 *Journal of Pain and Symptom Management* 33.

¹⁵ *Ibid* 35.

¹⁶ *Ibid* 38

¹⁷ *Ibid* 41.

¹⁸ *Ibid* 40.

symptoms and a life expectancy of less than two weeks.¹⁹ Guidelines developed by the European Association for Palliative Care also endorse the use of terminal sedation, noting that it requires ‘due caution and good clinical practice’.²⁰ In the United States the American Medical Association adopted guidelines which state that ‘palliative sedation should remain an option of last resort for patients with far advanced terminal disease whose suffering has proven refractory to all other usually effective palliative measures.’²¹

While some guidelines do exist, it is perhaps a worrying feature of the use of terminal sedation that significant differences emerge on a comparative analysis both as to its administration and indications for use. For example, while it would seem that terminal sedation is increasingly seen as responsible management in some European countries, in the United States this is less so, and even within the US there are differences of approach and variations in its use. Orentlicher, for example, claims that ‘patient access to palliative sedation may turn on the physician’s field of practice or other personal attributes.’²² He notes that ‘[p]hysicians often develop their practice patterns for idiosyncratic reasons, and that reality will influence the use of palliative sedation.’²³ Seale suggests that terminal sedation is ‘more likely to be reported by doctors who support the legalization of euthanasia or PAS and who are nonreligious. This suggests that the decision to provide CDS may be influenced by having attitudes that permit medical actions that shorten life.’²⁴ He also claims that ‘[t]he association between providing CDS and doctors’ attitudes toward assisted dying and religious beliefs...requires a better understanding of the ethical reasoning of doctors who decide to provide CDS in particular cases.’²⁵ Sadly, it is possible to conclude from these studies that while terminal sedation decisions should be about the needs of the patient, all too often they ‘depend to a large extent on the preferences of the patients’ physicians.’²⁶

At this point, it is worth further refining our terms. While terminal sedation may occur in a variety of forms, it is with continuous sedation without assisted nutrition and hydration (‘ANH’) that this paper is concerned. Unarguably, this is likely to be the most controversial form of terminal sedation since the deprivation of hydration in particular seems a different decision from the choice to remove consciousness. Seale reports that terminal sedation without the provision of ANH occurs in ‘39% of CDS cases in Belgium, and 56%-80% of CDS cases in the Netherlands. In the Netherlands, CDS is believed to have shortened life by more than a week in 27% of cases.’²⁷ It should be noted that the Dutch guidelines referred to above state that in the case of continuous sedation to death, no assisted hydration should be provided where the patient is unable or unwilling to take fluids. However, since *ex hypothesi* sedated patients will be unable to take fluids naturally, and their willingness to do so can no longer be

¹⁹ For discussion, see Dean et al, above n 5, 870.

²⁰ Nathan I Cherny, Lukas Radbruch and the Board of the European Association for Palliative Care, ‘European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care’ (2009) 23(7) *Palliative Medicine* 581, 581.

²¹ Ben A Rich, ‘Terminal Suffering and the Ethics of Palliative Sedation (2012) 21 *Cambridge Quarterly of Healthcare Ethics* 30, 32.

²² David Orentlicher, ‘Principle and Practice for Palliative Sedation: Gaps Between the Two’ in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 116, 122.

²³ *Ibid* 125.

²⁴ Seale, above n 8, 51.

²⁵ *Ibid* 52.

²⁶ Orentlicher, above n 22, 122.

²⁷ Seale, above n 8, 45.

ascertained, a general rule such as this is arguably unhelpful. Of course, should the provision of ANH in itself harm the patient, then good medical practice would mandate it being withheld.

It is also the case that the decision to sedate the patient and withhold ANH can be – and is – viewed differently by different commentators. While some argue that this practice amounts to one single decision (that is, the sedation and withholding of ANH are part of the same spectrum), for others they represent two separate decisions; the first designed to alleviate suffering, the second potentially to shorten life. Williams, for example, argues that ‘[w]hereas the goal of administering barbiturates to induce sleep to relieve suffering is good and beneficial to the patient, on no interpretation can the additional step of withdrawing artificial nutrition and hydration be considered a necessary condition of relieving pain.’²⁸ While it has been argued that there is little reason to assume that deprivation of ANH actually *does* shorten life, it must be conceded (a) that there is no evidence against this conclusion and that (b) if it is true, it is likely only to be true when terminal sedation is restricted to those situations where death is imminent.

Indeed, the withholding (or removal) of ANH is clearly implicated in the cause of death in the case, for example, of patients in a permanent vegetative state. Indeed, in the House of Lords (now the UK Supreme Court) case of *Airedale NHS Trust v Bland*,²⁹ this was explicitly accepted by at least two of the Law Lords. That withholding ANH *can* result in death therefore is equally true in the case of terminal sedation. As for the second point, while this may seem to be answered by guidelines that require a foreseeable, very limited, life expectancy, it remains to be asked why terminal sedation should be restricted to cases of imminent death? If it is indeed designed to alleviate refractory symptoms, then surely it should be available irrespective of the – presumed, but not provable – expectation of length of life?³⁰ Equally, on what basis can third parties – in this case, doctors – differentiate between kinds of suffering, each of which may be just as dreadful for the patient? However some guidelines, such as the US ones already referred to, specifically do not apply to cases of what has been called ‘existential suffering’, which is described as ‘the experience of agony or distress that results from living in an unbearable state of existence including, for example, death anxiety, isolation, and loss of control.’³¹ Further, the requirement that death is imminent may leave patients with refractory symptoms to suffer because their death is not deemed likely to occur within the usually very limited time period. Delbeke agrees, asserting that ‘[e]very patient has a right to adequate pain and symptom management and it should not be restricted to those with a limited life expectation.’³² In Belgium, for example, access to palliative care is a legal right of all patients – not just those whose death is imminent. Of course, there may be less than honourable reasons to maintain this position; the earlier that terminal sedation is initiated the more it resembles other actions that bring about the death of a patient, such as voluntary euthanasia.

The exclusion of ‘existential suffering’ can and should be questioned. As Sterckx, Raus and Mortier assert:

²⁸ Glenys Williams, ‘The Principle of Double Effect and Terminal Sedation’ (2001) 9(1) *Medical Law Review* 41, 51.

²⁹ *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

³⁰ For further discussion, see Victor Cellarius, ‘Terminal Sedation and the “Imminence Condition”’ (2008) 34 *Journal of Medical Ethics* 69.

³¹ Rich, above n 21.

³² Evelien Delbeke, ‘The Legal Permissibility of Continuous Deep Sedation at the End of Life: A Comparison of Laws and a Proposal’ in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 132, 139.

allowing a patient to die a good death may require bringing existential suffering within the reach of medical action. The extension of permissible indications for continuous sedation to existential suffering, however, is highly controversial. Existing professional guidelines contradict each other in this respect, in that some include existential suffering as an indication for continuous sedation at the end of life, while others do not.³³

Delbeke further argues that '[t]here is no reason why patients with refractory psychological suffering should be excluded from a right to adequate pain management.'³⁴ If this pain management results in an earlier death, with the patient's agreement, surely this would amount to good medical practice? The notion that medicine's sole or most noble aim is the preservation or prolongation of life, irrespective of quality, is surely one that has been discredited in certain situations. Of course, accepting the inclusion of existential suffering, or conceding that symptoms may be refractory even when life expectancy is not limited to a couple of weeks, means that the use of terminal sedation would more closely resemble other end of life decisions – a form of assisted dying – and this may sit uncomfortably with clinicians, politicians and some members of the public.

Here, we begin to see most clearly the ethical concerns that underpin the use of terminal sedation without ANH. In the next section, the ethical bases that are argued to support this practice, and the rationales given to present it as ethical practice, will be evaluated.

III ETHICAL CONSIDERATIONS

Hauser and Walsh claim that '[t]he ethical justification of palliative sedation is based upon the principles of double effect, autonomy and proportionality.'³⁵ If we accept Williams' point referred to earlier, then it would seem that in cases of terminal sedation without ANH, the proportionality issue can be resolved by concluding that removing or withholding ANH is disproportionate to the stated aims of terminal sedation. If the aim is *only* to avoid suffering, then the sedation itself is likely to be sufficient; it may be unnecessary to take the further step of withholding ANH.

The question of autonomy will be left until we deal with legal issues. This leaves for consideration here the principle of double effect. De Graeff and Dean explain the principle in this way:

The Principle of Double Effect is sometimes used as an ethical justification for the use of PST [palliative sedation therapy]. Briefly, this principle states that when a contemplated action (in this case sedation) has a good (relief of suffering) and a bad (possible foreshortening of life) effect it is permissible if (1) the action is either morally good or is morally neutral, (2) the foreseen yet undesired untoward result is not directly intended, (3) the good effect is not a direct result of the foreseen untoward effect, (4) the good effect is 'proportionate to' the untoward effect, and (5) there is no other way to achieve the desired ends without the untoward effect.³⁶

This principle, then, is broadly concerned with intention and causation, and is generally used to distinguish between legitimate and illegitimate practices; namely, the alleged difference

³³ Sterckx, Raus and Mortier, above n 6, 15.

³⁴ Delbeke, above n 32, 138.

³⁵ Katherine Hauser and Declan Walsh, 'Palliative Sedation: Welcome Guidance on a Controversial Issue' (2009) 23(7) *Palliative Medicine* 577, 577.

³⁶ De Graeff and Dean, above n 1, 77.

between terminal sedation and assisted dying. Taylor and McCann, for example, distinguish the two on the basis of intention, saying:

Unlike euthanasia or physician-assisted suicide, where the stated objective is the death of the patient (to relieve intractable symptoms), controlled sedation for refractory suffering has been accepted among hospice and palliative care physicians because its stated goal is the relief of suffering, not the death of the patient.³⁷

However, even a cursory consideration will suffice to show that inferring or identifying intention from declared motives is highly problematic. Indeed, some studies have demonstrated that mixed motives can and do arise in the practice of terminal sedation. De Graeff and Dean, for example, state that '[t]he use of sedation for the relief of symptoms at the end of life is open to abuse. There are data from several countries indicating that administration of sedating medication, ostensibly to relieve distress, but with the manifest intent of hastening death, is commonplace.'³⁸ The use of double effect, then, is inappropriate in such cases since the intention is as much to cause death as it is to alleviate suffering. Even where the intention is purely the alleviation of suffering, it can still be questioned whether or not double effect is appropriate where terminal sedation is combined with the failure to provide ANH. For Williams, the principle of double effect is 'wholly inapplicable' in this situation because

[w]hile it can be argued that 'sedation' eases the patient's pain and can be justified under the principle of double effect, withdrawing artificial nutrition and hydration 'does nothing to relieve the patient's suffering', and the inevitability of death following its withdrawal means that it does not satisfy all the conditions of the principle of double effect.³⁹

In fact, in such cases, as Holm argues, this:

[l]ooks very much like a slow form of euthanasia. The patient is put into a state where she is unable to take water and food, hydration and nutrition is not provided, and she will eventually die from dehydration, if the underlying disease does not kill her first. This means that in patients with very short and certain life expectancy, even continuous TS [terminal sedation] without continued hydration and nutrition may not count as euthanasia, because it is known that the patient will die from her underlying disease. It is, however, rare that we can predict life expectancy with certainty, and there will therefore almost always be the possibility that this kind of TS [terminal sedation] will turn out to be equivalent to euthanasia.⁴⁰

Holm concludes that however much clinicians may wish to separate the two, 'terminal sedation with withdrawal of hydration and nutrition has many ethically relevant similarities with [voluntary] euthanasia, and very few dissimilarities.'⁴¹ Further, Taylor and McCann argue that:

As in euthanasia, even if the patient were healthy, sedation would end the life of the patient if fluids and nutrients were not provided. This practice differs from voluntarily stopping eating

³⁷ Brigit R Taylor and Robert M McCann, 'Controlled Sedation for Physical and Existential Suffering?' (2005) 8(1) *Journal of Palliative Medicine* 144, 145.

³⁸ De Graeff and Dean, above n 1, 77.

³⁹ Williams, above n 28, 53.

⁴⁰ Søren Holm, 'Terminal Sedation and Euthanasia: The Virtue in Calling a Spade What It Is' in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal perspectives* (Cambridge University Press, 2013) 228, 231.

⁴¹ *Ibid* 239.

and drinking, because the patient is sedated and therefore does not have the chance to continuously reflect on or to change his/her decision.⁴²

Van Delden, on the other hand, reaches an apparently different conclusion, namely that ‘although in some cases terminal sedation and euthanasia are two morally equivalent ways of hastening death, in most cases they represent essentially different clinical situations.’⁴³ It may be surmised, however, that the situations where he finds congruence between the two may well be those under consideration here – the use of terminal sedation with no ANH. As Rich argues, ‘all current practice guidelines and policies provide that the decision on total sedation and the decision about nutrition and hydration must be separate and distinct, and the latter may not properly be a condition precedent for the former.’⁴⁴ Whether this is actually what occurs in practice, however, may be disputed.

It would seem then that the principle of double effect may not in fact provide sufficient justification to render ethically acceptable the practice of terminal sedation without the provision of ANH. For this reason, and while recognising that in some cases the principle may be appropriate, Billings and Churchill propose that ‘considering a variety of approaches will deepen our moral perceptions and provide greater wisdom than uncritical reliance on a single rule, however useful that rule may be.’⁴⁵ Developing alternative, convincing and broadly applicable approaches is, however, a major challenge. Nonetheless, the apparent convenience of the appeal to the principle of double effect needs to be re-evaluated. As Rich argues, ‘the almost reflexive manner in which the double effect finds its way into the ethics of end-of-life care belies its confusing origins and the persistent controversy over whether the doctrine can ever, and if so, under what circumstances, be consistently and coherently applied.’⁴⁶

IV LEGAL CONSIDERATIONS

It is generally accepted that any intervention, whether or not medically supported and clinically indicated, requires that the patient provides a valid consent. Without this, allegations of assault – or worse – might attach to the act in question. Consent, it is said, is the legal means that supports autonomy – the principle referred to above. While some have disputed the efficacy of consent in achieving actual protection of autonomy,⁴⁷ it remains the best tool available to the law to offer such protection, however limited it may be. Where terminal sedation *and* the removal or withholding of ANH are proposed, and given the foreseen, if not intended, outcome, obtaining a valid consent is arguably of even greater importance than in less serious decisions. Perhaps surprisingly, however, the Dutch guidelines already referred to seem equivocal as to the value of patient consent. Swart et al, for example note that ‘[w]hereas being aware of the preferences and wishes of the patient and the family can arguably facilitate the decision to start CPS, this may sometimes also complicate decision making’.⁴⁸ Rather, the guidelines are clear that this is a medical decision, where ‘[t]he preferences of patients and families and the patient’s

⁴² Taylor and McCann, above n 37, 145.

⁴³ van Delden, above n 2, 188.

⁴⁴ Rich, above n 21, 36.

⁴⁵ J Andrew Billings and Larry R Churchill, ‘Monolithic Moral Frameworks: How Are the Ethics of Palliative Sedation Discussed in the Clinical Literature?’ (2012) 15(6) *Journal of Palliative Medicine* 709, 712.

⁴⁶ Ben A Rich, ‘Causation and Intent: Persistent Conundrums in End-of-Life Care’ (2007) 16 *Cambridge Quarterly of Healthcare Ethics* 63, 69.

⁴⁷ See, for example, Sheila AM McLean, *Autonomy, Consent and the Law* (Routledge, 2010).

⁴⁸ Siebe J Swart et al, ‘Continuous Palliative Sedation: Not Only a Response to Physical Suffering’ (2014) 17(1) *Journal of Palliative Medicine* 27, 32.

life expectancy are weighed against the severity of refractory symptoms...⁴⁹ Just who would be better at making such a calculation than the patient him- or herself seems a relevant, albeit overlooked, question here. Orentlicher claims that, apart from the Netherlands where consent was sought in 96 per cent of cases, studies from other countries show that consent from patients was not sought in significant percentages of cases.⁵⁰ As consent can amount to a defence against a criminal charge in medical cases – for example, it is already accepted that physicians can engage in consented-to behaviour like surgery which would otherwise amount to an assault – it might be thought strange that consent was not sought.

It may, of course, be asked whether or not a patient may be so incapacitated by their suffering as to make it difficult, if not impossible, for them to make a valid decision. In such cases, proxy decision-makers may be sought, although the extent to which we can be sure that their choice would in fact be that of the patient may be questionable. Ideally, therefore, and where feasible, this would suggest that discussions about the future possibility of terminal sedation should be undertaken early with the patient, as should the separate question of whether or not ANH should be provided. While these are undoubtedly difficult conversations, if the patient is to be truly involved in decisions about their own life or death, and the way in which they die, then they must occur. As De Graeff and Dean note, '[s]uffering and distress are subjective criteria, so only the patients can determine the suffering to be intolerable.'⁵¹ In an echo of the point just made about the patient who is unable to offer a valid consent, they also caution that where a proxy decision-maker is involved '[t]he health care team should be confident that the proxy expresses the (presumed) wishes of the patient and not his or her own.'⁵²

From the physician's perspective, a further legal question will relate to the possibility that their actions (or omissions in the case of ANH) might amount to criminal behaviour. This will very much depend on what is seen as the cause of death. In the US Supreme Court judgement in *Vacco v Quill*,⁵³ the court's view was that the cause of death was the medication 'but that the purpose of the sedation [was] twofold, to ease suffering and to comply with the patient's wishes.'⁵⁴ In another Supreme Court decision – *Washington v Glucksberg*⁵⁵ — terminal sedation was described as 'one of three situations where "physicians are already involved in making decisions that hasten the death of terminally ill patients."⁵⁶

If so, then it is tempting to ask in what ways terminal sedation without ANH differs legally from other forms of assisted dying. This question has already been raised from an ethical point of view; what would the legal response be? Leaving aside the question of intention, which has already been discussed, the law's response when clinical decisions and practices are under question is often – in addition to the question of consent – first to address 'standard or reasonable medical practice' and then – sometimes at least – to consider whether the behaviour can be categorised as an act or an omission. Additionally, the concept or defence of necessity may be relevant.

Where doctors are able to argue that their behaviour was in accord with – in the UK at least – a responsible body of medical opinion, then no civil liability will follow. In the UK case of *R*

⁴⁹ Ibid 33.

⁵⁰ Orentlicher, above n 22.

⁵¹ De Graeff and Dean, above n 1.

⁵² Ibid.

⁵³ *Vacco v Quill*, 521 US 793 (1997).

⁵⁴ Williams, above n 28, 48.

⁵⁵ *Washington v Glucksberg* 521 US 702 (1997).

⁵⁶ Williams, above n 28, 48.

*v Arthur*⁵⁷ accepted medical practice was taken as evidence that no criminal act had been committed. However this case is of dubious precedential value.⁵⁸ It does however show the extent to which courts have been prepared to excuse decisions of considerable gravity, essentially by categorising the issues as clinical, rather than criminal. The mistake of categorising events in this way led to the dubious decision in the *Arthur* case and displays a lack of insight. In any case, as Battin has written ‘[d]istinguishing between different sorts of intentions on the basis of observed practice is not only impossible but morally indefensible.’⁵⁹ Delbeke notes that terminal sedation is regarded as ‘normal medical practice’ in the Netherlands, but argues that:

....[i]t is the task of the legislator (and not of a professional medical association or a multidisciplinary commission) to determine the basic framework, the conditions under which an act as far-reaching as CDS [continuous deep sedation] is permitted, especially since there is the underlying risk that it may be found to be a criminal act.⁶⁰

As to the question of the alleged distinction between acts and omissions, while this is widely referred to and often utilised in law, it has been argued to be a ‘distinction without a difference’ in some cases.⁶¹ While it is clear that in some situations my omissions will be at worst neutral but my acts would be culpable, it is debateable whether or not this applies to omissions that directly bring about death and where there is an existing duty of care, such as that owed by clinicians to patients. While courts in the UK (and elsewhere) have been content to justify the removal of ANH in patients in a permanent vegetative state, categorising it as either a solely medical decision or as an omission rather than an act – this conclusion can be – and has been – challenged, given that at the very least the death (a) results from the dehydration and (b) is at least foreseeable, which is sometimes legally sufficient to infer intent.⁶²

One further possible avenue for evaluating terminal sedation without ANH has been raised; namely, the use of the doctrine of necessity. Delbeke argues:

[t]he concept of necessity implies a conflict between two goods, one of which is considered more important and thus given priority. In the context of palliative care, the conflict exists between maintaining the patient’s life on the one hand, and alleviating the patient’s severe suffering on the other hand. In the case of CDS, the alleviation of the patient’s severe suffering is considered more important.⁶³

However, the author does not believe that necessity would work as a defence for two reasons. First, it is meant for use in exceptional cases and pain relief is not exceptional. Second, it would not provide caregivers with certainty since it is a question of interpretation for the courts. It can also be argued that the failure to provide ANH is directly contributory to the death, yet it is not obvious that this can easily – if at all – be covered by the necessity doctrine which refers rather

⁵⁷ *R v Arthur* (1981) 12 BMLR 1.

⁵⁸ Not least because this was a decision of one of the lower courts. For discussion, see JK Mason and GT Laurie, *Mason and McCall Smith’s Law and Medical Ethics* (Oxford University Press, 9th ed, 2013) particularly at 506-508.

⁵⁹ Margaret P Battin, ‘Terminal Sedation: Recasting a Metaphor as the *Ars Moriendi* Changes’ in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds) *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 240, 245.

⁶⁰ Delbeke, above n 32, 136.

⁶¹ See McLean, above n 47, particularly chapter 4.

⁶² *R v Woollin* [1999] 1 AC 82.

⁶³ Delbeke, above n 32, 134-135.

to *actions* taken in the face of competing interests, rather than the *choice* not to do something which would otherwise be effectively mandatory.

V CONCLUSION

It can reasonably be concluded from what has gone before that terminal sedation, particularly where it involves the withholding of ANH, is controversial. Not only that, its practice arguably rests on shaky ethical and legal premises. While initially it might have seemed that the dilemmas raised were mostly about the appropriate terminology to use and the normative values reflected in the language applied (and there is no doubt that this remains problematic), the real difficulties concern finding adequate ethical and legal justifications for its practice. On the one hand, questions about causation and intention are vitally important; on the other, they are highly problematic. As Rich says, neither ‘can be ascertained with sufficient certainty so as to provide an adequate foundation for the critical moral distinctions involving dying and death in the clinical setting that have often been based upon them.’⁶⁴

Further, the fact that the use of terminal sedation itself seems to be dependent on considerations that are as much – if not more – about the preferences, prejudices and values of doctors rather than patients, predictably entails uneven availability, despite the existence of guidelines. Thus even if we wish to maintain a bright line between terminal sedation without ANH and other assistance in dying, as Holm argues ‘[i]f we are right in believing that euthanasia should be (strictly) regulated, because there are risks of misuse that need to be guarded against, then we should also think about regulating TS [terminal sedation] with withdrawal of hydration and nutrition.’⁶⁵

But can we really maintain this distinction in any case? Where the patient dies following terminal sedation without ANH, arguably it is the medical act that has brought about the death, even where patients are imminently dying. In these cases, at best, medicine facilitates the death even if there is no real way of knowing precisely what the cause of the death actually is. Justification may be found in the patient’s consent, so that the sedation and accompanying deprivation of nutrition and hydration can be evaluated ‘by the extent to which it accommodates the patient’s authentic wishes and circumstances, and by a more expansive view of the role and responsibility of the physician in the care of such patients than that of merely prolonging life.’⁶⁶ However, as we have seen, consent is not always sought or obtained. Additionally, guidelines seem more concerned with limiting the availability of terminal sedation to situations which arguably avoid a direct comparison with assisted dying, rather than good management of symptoms – whether or not physical; and the relief of suffering – irrespective of life expectancy.

The conclusion that the cause, effect and intention in terminal sedation without ANH and voluntary euthanasia are sometimes indistinguishable may be uncomfortable, but for the meantime in many countries it appears that this discomfort is acceptable, at least to some members of the community, and most notably the sensibilities of the medical profession. Failure to call a spade what it is – to use Søren Holm’s analogy – may well be the result of perceived community values which ‘can result in frustration of the preferences of patients who do not share the values of their communities’ majorities.’⁶⁷ That this may result in unnecessary

⁶⁴ Rich, above n 46, 64.

⁶⁵ Holm, above n 40, 231.

⁶⁶ Rich, above n 46, 70.

⁶⁷ Orentlicher, above n 22, 118.

suffering seems to run counter to the stated desire to alleviate suffering, even if it does result in an earlier death.

In the long run, and as unpopular as this may be in some circles, the variations in practice between and within countries, the arguable lack of suitability of the widely used ethical justifications and the uncertain application of legal rules all seem to mandate that there is a primary – even critical – imperative for the law to take responsibility for establishing parameters for the use of terminal sedation, especially where ANH is not provided. However to do this it may – in some cases at least – mean a reconsideration of attitudes to all end of life decisions. Legal oversight and clearly established legal rules (as opposed to professional guidelines) may provide the kind of certainty that both patients and physicians should surely be able to expect and would most likely welcome.

In conclusion, it can be said that terminal sedation (even without ANH) can be good medicine. However, a ‘good’ act requires appropriate justification beyond ‘this is what doctors do’, or ‘this is a medical decision’. For this justification we need to look to ethics and from there to a law that reflects agreed, robust and sustainable ethical values. At present, the ethical principles commonly used to justify the provision of terminal sedation without ANH seem inadequate. Given this, it is scarcely surprising if legal contortions are sometimes necessary to justify a given practice. This is surely unacceptable, and the need to expose practice and analyse its appropriateness becomes ever more urgent as the use of terminal sedation continues to grow, reinforcing the need for clarification, consistency, transparency and accountability in this most sensitive of areas.