Continuous deep sedation at the end of life: balancing benefits and harms in England, Germany and France

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1. Introduction

Although various terms and definitions are used to describe continuous deep sedation (CDS) at the end of life (Morita et al. 2002a; Aubry et al. 2010), there is broad agreement that this involves the use of medication to induce and maintain unconsciousness until the patient dies, in order to relieve refractory symptoms. CDS generates significant controversies, regarding its arguable life-shortening effect (e.g. Sykes & Thorns 2003a; Maltoni et al. 2009; Rady & Verheijde 2010), the sustained privation of consciousness, the (frequently) associated discontinuation or withholding of food and fluids (Rady & Verheijde 2012) and the possibility that the practice can be used as a camouflage for euthanasia (Tännsjö 2004a; Jansen 2010). CDS accordingly prompts substantial questions about what it means to 'benefit' – and, indeed, to 'harm' – the terminally ill patient whose symptoms appear intractable.

In this chapter we consider how these questions are dealt with legally, practically and ethically in three countries: England, Germany and France. Common to these countries is the prohibition of euthanasia and a long-established (if beleaguered) principle that would appear to support the use of CDS: the doctrine of double effect (DDE), according to which purportedly 'bad' effects (like death or the removal of consciousness) might be justified, provided they are not directly sought but are merely pursuant to the achievement of some greater good (like the removal of otherwise intractable symptoms). Yet, there are, of course, also important differences between the three jurisdictions, not least in terms of the legal frameworks that govern palliative (and related terminal) care.

In order to illustrate the areas of similarity and difference, a common case study can be instructive. The case we describe below is based on a real case, albeit suitably anonymised (Horn 2009):

Mrs Martin, a 54-year-old cancer patient in terminal stage who is considerably confused, has become extremely agitated, prompting the oncology team to request input from specialist palliative care services. The palliative care doctors associate Mrs Martin's confusion with the progression of her cancer and her imminent death. In her confusion, Mrs Martin behaves aggressively towards the care team, her body thrashing, such that items cannot safely be stored in her immediate vicinity. Neither antidepressants nor weaker sedative drugs can calm her.

Communication with Mrs Martin is currently impossible. Communication was difficult before, since she refused to discuss her cancer with the team or her family. According to her husband, Mrs Martin always avoided discussing her problems and fears, following a family trauma during her childhood. Neither he nor their children ever speak with the patient about her illness.

The palliative care team believes total sedation[1] *offers the only possibility for calming Mrs Martin. Two days later the sedation is discontinued but, soon after waking, Mrs Martin becomes extremely agitated again, without becoming responsive to her environment.*

The palliative care team conclude that sedation should continue until Mrs Martin's death. They decide that the delivery of food and fluids by clinically assisted means (such as through a nasogastric tube) would be inappropriate considering her terminal stage. Long discussions are held with the family and the rest of the care team. Although the palliative care team are keen to control Mrs Martin's symptoms so that she might have a peaceful death, they also recognise the need to protect her family and the staff. A broad consensus is reached that this will be the most appropriate course. Two days after Mrs Martin is sedated, she dies.

Is the decision taken in Mrs Martin's case acceptable – professionally, legally and ethically? Crucially, what counts as 'beneficial' and what counts as 'harmful' when dealing with an adult patient in such a situation? In the following section we first focus on the professional and legal dimensions of these questions, as they pertain to England, Germany and France.

[1] 'Mild' sedation involves decreased consciousness; 'deep' or 'total' sedation removes consciousness (Cherny & Radbruch 2009).

2. Legal and professional perspectives in England, Germany and France

2.1. England

English healthcare law (generally that pertaining to England and Wales) has developed from numerous roots – including the civil law of tort, the family law and public law – to become its own body of law. Yet, the legal approach to end-of-life care is particularly indebted to the criminal law, particularly on homicide. In this jurisdiction, the harshest available penalty (mandatory life imprisonment) is reserved for murder, which essentially involves the intentional causation of death. Prompted by developments in medical science, the courts (and, to some extent, Parliament) have sought to clarify when and how healthcare professionals might avoid committing this crime when caring for terminally ill patients. Two distinctions have emerged as fundamental: one, between intending and (merely) foreseeing a result; another, between (positively) acting and (negatively) omitting to act.

The first difference originated in the 1957 trial of Dr John Bodkin Adams (Palmer 1957). Adams, a GP, was charged with murdering an 81-year-old patient, after an autopsy revealed high levels of barbiturates and opioids. The doctor argued he had intended only to kill pain, not his patient. Directing the jury, the trial judge, Devlin J, noted:

> If the first purpose of medicine, the restoration of health, can no longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may *incidentally* shorten life. (Davies 1998: 347)

The jury acquitted. Devlin J's principle thereafter became an 'established rule', gaining acceptance in the highest court (*Airedale NHS Trust* v. *Bland* 1993: 370D) and subsequently being applied in other trials involving opioids like diamorphine (Huxtable 2007: 84–114).

The second distinction, between acts and omissions, is also well established. An omission can be culpable – provided, that is, that the person who omitted to provide the necessities for life had been under a duty to do so. Various rulings have clarified when the duty might (not) be present. The leading ruling concerns Anthony Bland, who was in a persistent vegetative state (PVS) (*Airedale NHS Trust* v. *Bland* 1993). In line with the wishes of his family and doctors, the House of

Lords confirmed that it would be lawful to remove artificial nutrition and hydration[2] (ANH), with the inevitable (and, according to the Law Lords, intentional) shortening of Anthony's life, since the doctors were no longer under a duty to provide this, in view of medical opinion that there was no benefit in continued treatment of this sort. Comparable decisions have been reached for incapacitated adults afflicted with other conditions, like the minimally conscious state (MCS) (e.g. *W* v. *M and S and A NHS Primary Care Trust* 2011).

According to the relevant legislation (Mental Capacity Act 2005), the existence and scope of the duty turns on the 'best interests' of the patient (Huxtable 2012). The Act also emphasises the obligation to respect the autonomy of the incompetent patient, who – whilst competent – may have appointed a healthcare proxy (by conferring a 'lasting power of attorney') or made her wishes known in advance (such as via an 'advance decision to refuse treatment'). Similarly, the adult patient who retains the capacity to make the relevant decision can discharge the doctors from their duty to sustain life by issuing a contemporaneous refusal of (even life-saving) treatment (e.g. *Re B (Adult: Refusal of Medical Treatment)* 2002).

Legally, the duty to maintain life therefore finds its limits when death is (only) foreseen or attributable to a permissible omission. These limits are reflected and to some extent clarified in professional guidance (e.g. General Medical Council 2010). Of course, if these limits have not been reached, then the duty persists – especially the obligation to refrain from active, intentional killing. Exceptions to this obligation are not unprecedented, but they have been narrowly drawn (e.g. *Re A (Children) (Conjoined Twins: Surgical Separation)* 2000). Although the law tends to be lenient in operation (Huxtable 2007; Director of Public Prosecutions 2010), the formal resistance to legalised assisted dying continues to withstand legal challenge (e.g. *Case of Pretty* v. *the United Kingdom (Application No. 2346/02)* 2002; *R (on the application of Purdy)* v. *Director of Public Prosecutions* 2009; *R (on the application of Tony Nicklinson)* v. *Ministry of Justice* 2012) and calls for reform (e.g. Commission on Assisted Dying 2011). Such resistance might be unsurprising, as research 'suggests a culture of medical decision making informed by a palliative care philosophy' (Seale 2006: 8).

[2] Artificial nutrition and hydration is generally referred to as clinically assisted nutrition and hydration (CANH) in the UK. For consistency with the other chapters of this book, the term ANH is used in this chapter.

2.2. France

In France, a law of 22 April 2005 (Law n° 2005-370) clarified patients' rights and the boundaries of legal and illegal practices in end-of-life care. Although the law condemns any (positive) act that 'provokes death', it establishes the physician's right to 'let die' a terminally ill patient. As now stated in the Public Health Code (Code de la Santé Publique, CSP), a terminally ill patient has the right to refuse 'every' treatment, including ANH (Article L.1111-4, CSP). Yet, in the same article (L.1111-4), it is stated that the doctor is not required to accept such a request and may 'do all that is possible in order to convince the patient' to continue treatment when the refusal thereof endangers the patient's life.

The legal focus on the physician's, rather than the patient's, judgement (Thouvenin 2008: 404–5) becomes even more apparent in Article L.1110-5 CSP. This article specifies that therapeutic acts which 'seem futile or disproportionate or have no other effect than only artificial maintenance of life … *can* be suspended or not be undertaken' (our italics). The physician therefore enjoys the power to decide: she can withhold or withdraw futile or disproportionate treatments, but is not obliged to do so. The physician is, however, advised to 'preserve the dignity of the dying person and assure quality of life by dispensing [palliative care]' (Article L.1110-5 CSP). At this point the law introduces the idea that it might be acceptable for life to be shortened, provided that this is only foreseen and not intended; in such a situation, 'if the doctor finds that he can ease the suffering of a person in an advanced or a terminal stage of a serious and incurable disease … only by administering a treatment that may have a life-shortening side effect, he has to inform the sick person … the surrogate, the family or a close person. The procedure must be recorded in the medical notes' (Article L.1110-5 CSP).

A revised version of Article 37 of the French Code of Medical Ethics (Code de Déontologie Médicale, CDM) – which is part of the CSP and thus legally binding – further confirms the obligation to dispense palliative care. The patient's right to receive such care (Article L.1110-9 CSP) would seem to imply that there is a right to receive sedation as a last-resort option for treating refractory suffering. In its comments on Article 37 CDM, the French Board of Physicians (Ordre National des Médecins) has emphasised the principle of proportionality when employing analgesics and sedatives, i.e. doses should be administered proportionately and progressively. This principle seeks to guard against abuse, in the form of intentional killing using sedative drugs (Baumann et al. 2011).

The new version of Article 37 CDM also included a specific note requiring the use of sedation (and/or analgesics) when life-sustaining treatment is being withdrawn from patients in a vegetative state. This revision arose in 2010, following the removal (without sedation) of a gastric tube from a patient in a vegetative state, Hervé Pierra. After having endured seizures, Mr Pierra died six days after the tube was removed (Mission d'évaluation de la loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie 2008: 204–16). Mr Pierra's parents thereafter began a media campaign for the legal right to euthanasia, although this remains contrary to French law. In 2011, Michel Salmon, a patient with locked-in syndrome, refused ANH and he died three weeks later, while receiving CDS (Gorget 2012).

In addition to the law, there is pertinent professional guidance. In 2002, the French Society for Accompaniment and Palliative Care (Société Française d'Accompagnement et de Soins Palliatifs, SFAP) first published recommendations for the use of sedation for patients with uncontrollable distress. These guidelines were revised in 2004 following the parliamentary report (Mission d'information sur l'accompagnement de la fin de vie 2004) that preceded the 2005 law. Following Mr Pierra's case and the report evaluating the implementation of the law of 2005 (Mission d'évaluation de la loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie 2008), the SFAP reviewed their recommendations again in 2008. In addition to the principle of proportionality, the SFAP, in line with the CDM, emphasises the importance of using sedation in consultation with specialists in pain management, and, where possible, after consultation with the patient or the family.

Despite such guidance, evidence suggests ongoing confusion about the distinctions between sedation and euthanasia. Some doctors appear to resist the use of sedative drugs for fear of hastening death (as one might detect in the case of Mr Pierra), while others use such measures with this precise aim (Horn 2011). Significantly, the latter group appear more resistant to engaging with palliative care specialists. Indeed, collaboration between French hospital services and palliative care advisory teams is not always harmonious (Mino & Lert 2003; Horn 2011), which raises questions about the willingness of doctors from 'curative' services to consult with palliative care specialists before employing sedative medication.

2.3. Germany

Like English and French law, German criminal law (*Strafgesetzbuch*, StGB) prohibits the intentional causation of death (Section 216 StGB).

The atrocities committed by Nazi doctors have cast a long shadow here, under which people prefer not to talk of 'euthanasia', preferring to replace this term with 'active/direct assistance in dying'. Legally, this remains a crime, in its positive and direct form; however, again as elsewhere, what some term 'passive' assistance in dying (i.e. withdrawing life-sustaining treatment) and 'indirect' assistance in dying (i.e. administering analgesics with the aim of relieving pain, albeit at the purported risk of shortening life) are both lawful practices.

In the wake of the Nuremberg Trials, medical decision-making today is dominated by concerns for the patient's right to autonomy and physical integrity, which is enshrined in Article 2 II 1 of the German constitution (the so-called Fundamental Law or *Grundgesetz*, GG). Regarding indirect assistance in dying, the Higher Regional Court of Frankfurt stated in 1998:

> … a medical intervention that implies the risk of causing death is something different than a medical act that aims to cause death, because such an act does not serve the health of the concerned person. (20 W 224/98 1998)

This position was reconfirmed by the Federal Supreme Court in 2010 in a case in which the daughter of an 80-year-old comatose patient removed her mother's feeding tube, in accordance with her mother's previously expressed wish and on the advice of her lawyer. Underlining the consistency of the act with the patient's previously expressed wish, the judges stipulated that indirect assistance in dying, where the primary aim is not to cause death, is not unlawful (2 StR 454/09 2010).

Likewise, the German Medical Association (Bundesärztekammer, BÄK) has, since the 1990s, emphasised the difference between 'indirect' or 'passive' (lawful) and the 'direct' or 'active' (unlawful) assistance in dying. In its 2011 statement on end-of-life care, the BÄK repeats that:

> [P]alliation of the suffering of a dying person can be of such importance that an eventual inevitable shortening of life may be acceptable. (Bundesärztekammer 2011)

Research into the attitudes of German healthcare professionals seems to echo the BÄK view: Simon et al.'s (2007) study revealed that 98 per cent of medical and nursing professionals regarded the use of sedation in dying patients with refractory physical symptoms as acceptable. However, only 61 per cent considered acceptable the use of sedation in dying patients with incurable mental suffering. Schildmann et al.'s (2010) survey of members of the German Association for Palliative Care (Deutsche Gesellschaft für Palliativmedizin, DGP) later found

that 78.1 per cent of physicians estimated that the treatments they employed to alleviate suffering in terminally ill patients had a possible life-shortening effect. For such physicians, it seems foreseeing – but not intending – death may be permissible, and adherence to this distinction enables them to distinguish their practices (permissible) from euthanasia (impermissible).

2.4. Sedating Mrs Martin?

Although the jurisdictions do differ in their respective normative commitments (see Horn 2011), the legal and professional frameworks governing the use of CDS in England, France and Germany share some common features. First, to recap, if she were in England, Mrs Martin's care would be likely to be informed by a palliative care philosophy. Her confusion, and prior resistance to discussing her situation, make it difficult to discern her autonomous wishes (if any); at the time of the crisis, she would almost certainly be classed as incompetent under the Mental Capacity Act 2005, according to which capacity hinges (*inter alia*) on comprehension and communication. Any decision would therefore have to accord with Mrs Martin's best interests. Even in the absence of a formally conferred lasting power of attorney, her family could help the doctors to determine where these interests lie. And the doctors, in turn, might take comfort from Devlin J's principle: they may therefore direct their efforts towards relieving Mrs Martin's distress, even if such measures 'may *incidentally* shorten life'. On the same basis they might also refrain from providing Mrs Martin with food and fluids through tubes. Indeed, all of this can occur without the need for judicial oversight, since Mrs Martin is not afflicted with one of the disorders of consciousness for which judicial input is required (PVS and MCS) – although, of course, the courts are available to decide if a decision is needed.

Had Mrs Martin been a patient in France, then, again, the legislation and guidelines indicate that sedation could have been provided. Of course, she would need a willing doctor, and the successful relief of her symptoms would seem also to hinge on that doctor consulting appropriately with palliative care services. Furthermore, the SFAP (Aubry et al. 2010) cautions against the use of CDS in order to relieve the distress of the patient's family or healthcare providers. In France, then, Mrs Martin's benefit seems to be the central issue – but how benefit for (and to) her is interpreted and achieved seems, crucially, to rely on the physicians charged with her care. Considering the fact that only 12 per cent of physicians in a survey conducted in 2007 and 2008 knew that they have to take into account the patient's wish when making decisions

(Mission d'évaluation de la loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie 2008: 15), the benefit might be considered from a purely medical point of view. And even then, there is evidence that only a few doctors know the DDE (Mission d'évaluation de la loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie 2008: 15) or collaborate with palliative care specialists during the last days of life (Lalande & Veber, 2009: 4, 63).

Physicians in Germany, meanwhile, might hesitate to sedate, given the lack of consent from Mrs Martin (Horn 2011). However, they might well find comfort in the GMA's insistence that activities which only 'indirectly' shorten life can be justified. This idea that there is a distinction to be drawn between the foreseen (or indirect) and the intentional shortening of life has recurred throughout our survey of legal and professional norms in England, France and Germany. The implication – apparently supported by some empirical research into professionals' attitudes – would appear to be that CDS involves limiting the patient's life, albeit justifiably. But is this implication clinically accurate? And is this an ethically appropriate way of framing this issue?

3. Balancing benefits and harms (clinically, ethically and legally)?

3.1. In the clinic

In order ethically to evaluate CDS we need first to understand the practice: good ethics relies upon good facts. Here questions of benefit and harm come to the fore. The benefit would appear to be the relief of otherwise intractable symptoms, but the implied harm seems to be that life will be shortened or consciousness removed (Rady & Verheijde 2010). Yet, the proven and potential properties of CDS are not beyond dispute: many studies confirm that CDS has no life-shortening effect (Chiu et al. 2001; Morita et al. 2001a; Sykes & Thorns 2003a; Claessens et al. 2008; Radha Krishna et al. 2012); some find that it can even have a life-prolonging effect (Bakker et al. 2008; Maltoni et al. 2009; Mazer et al. 2011); but others detect a small risk (1.8–3.9 per cent) of respiratory and/or circulatory suppression, at least for some terminally ill patients during the last days or couple of weeks of life (Sykes & Thorns 2003a; Morita et al. 2005c). These findings require further consideration.

The risks appear clearest when an excessive dose is administered, since here the life-shortening effect will be most obviously detectable (Irwin 2001). Indeed, studies from The Netherlands (in which voluntary euthanasia is lawful) have suggested that some physicians there

have used sedative medication with the primary intention of hastening death (Rietjens et al. 2004; Sheldon 2007). Yet, where relief of symptoms is the primary aim, the European Association of Palliative Care (EAPC) recommends that the doses be increased gradually, in proportionate response to the patient's symptoms (Cherny & Radbruch 2009). As Morita et al. (2002a) suggest, the use of rapid, heavy doses in order to avoid confronting the psychological distress of patients can otherwise blur the line between euthanasia and sedation. Swart et al. (2012c) have similarly found that physicians who start with mild sedation appear inclined towards maintaining the patient's ability to interact with others, whereas those who have an earlier preference for deep sedation tend to fear facing up to their patients' suffering, favouring the maintenance of sedation until death.

Of course, the approach favoured by the EAPC requires physicians to be capable of determining the proportionate dose for the particular patient. This will not always be straightforward: Swart et al. (2012a) point to the difficulty of predicting end-of-life disease trajectories in non-cancer patients, for whom there might be unexpected deterioration and then death, and thus for whom appropriate doses can be difficult to assess. They add that this unpredictability also leads physicians to overestimate the life-shortening effect of sedative medication. Indeed, Sykes and Thorns (2003a) believe that the risk is entirely absent, at least when the patient is in the last hours (<48 h) of life. The risk will nevertheless be present for other patients: for example, Rady and Verheijde note that responding to breakthrough restlessness and agitation by escalating doses can lead to 'fatal respiratory or circulatory depression and life-shortening effect in dehydrated and hypoxic' terminally ill patients (Rady & Verheijde 2010: 209). It appears that the risk is run where the patient is not yet in her last hours of life, which would explain why the EAPC stipulates that 'continuous deep sedation should be only considered if the patient is in the very terminal stages of their illness with an expected prognosis of hours or days at most' (Cherny & Radbruch 2009: 584).

It seems, then, that we need to distinguish between the use of CDS in the last hours of life and its use elsewhere, such as in the treatment of patients who might have weeks or months left to live. There is a potential problem here, of course, concerning the accuracy of diagnoses and prognoses and thus the appropriate classification of a patient who is in the last hours of life. But, assuming that an agreeable criterion for differentiation can be found and applied, a distinction does appear to be warranted between the two groups of patients. The first group contains patients in their last hours of life who seem likely to benefit from

the relief of associated symptoms and unlikely to have their lives correspondingly shortened (provided, that is, that their clinicians refrain from administering large single doses or substantially escalating the levels). The benefit to a patient like Mrs Martin, who seems to occupy this group, would appear to reside in the relief of symptoms, both psychological and physical (Breitbart & Alici 2008). In such cases, even withholding ANH cannot be responsible for limiting the patient's lifespan; indeed, the introduction of tubes might be considered a cruel imposition on a dying patient, who is likely already to have forgone the delivery of food and fluids by more 'natural' means. For patients like Mrs Martin, the harm 'inflicted' by CDS (even with the associated denial of ANH) seems unlikely to be death. Instead, the harm appears to be the deprivation of consciousness.[3] There is, however, something of a paradox here, since this 'harmful' deprivation simultaneously provides the means by which the patient will benefit, since it is this deprivation that enables her to avoid her distressing symptoms.

The second group of patients encompasses those in their last weeks or months, who are experiencing unbearable suffering. Here – for at least a small number of such patients – the perceived threat appears not merely to concern consciousness, but also life. But, given cases like that of Hervé Pierra (who suffered for six days from seizures without having received sedation), there would appear to be patients who might benefit from total sedation. Yet, cases like that of Michel Salmon also suggest that CDS is unlikely to shorten life even if the patient has months left to live: this deeply sedated locked-in patient died three weeks after ANH was withdrawn, which seems to correspond with the estimated lifespan of a person lacking hydration (Jansen & Sulmasy 2002; Ganzini et al. 2003). Given these facts, how should the benefits and burdens of CDS be balanced for the occupants of either group of patients?

3.2. In ethics

The principle of balancing benefits and burdens that was articulated by Devlin J in the English courts, and is detectable also in Germany and France, is commonly known as the doctrine of double effect (DDE). Associated with Catholic theology and first formulated by the medieval theologian Thomas Aquinas (*Summa theologiae* II-II, q. 64, a. 7), the doctrine distinguishes between intended and foreseen 'bad' outcomes,

[3] Clive Seale made this point during a workshop held at Queen Mary, University of London (19 February 2010).

allowing the latter to be brought about only when four conditions have been satisfied (Marker 2011: 101):

1. The act is good in itself or at least ethically neutral.
2. The good effect is not obtained by means of the bad effect.
3. The bad effect, although foreseen, is not intended for itself, but only permitted.
4. There is a proportionately grave reason for permitting the bad effect.

In 1957, the year in which Devlin J effectively endorsed the principle in the trial of Dr Adams, Pope Pius XII also explicitly confirmed that the principle could apply to the suppression of pain and consciousness, a position affirmed in the 1980 'Declaration on Euthanasia' (Congregation for the Doctrine of the Faith 1980). For its supporters, the doctrine captures a crucial moral distinction, which they sometimes seek to illustrate through the use of thought experiments:

> Imagine a pot-holer stuck with two people behind him and the water rising to drown them. And suppose two cases: in one he can be blown up; in the other a rock can be moved to open an escape route but it will crush him to death … There might be people … who, seeing the consequence, would move the rock, though they would not blow up the man because that would be choosing his death as the means of escape. This is a far from meaningless stance, for they thus show themselves as people who will absolutely reject any policy making the death of innocent people a means or end. (Linacre Centre 1982: 49)

Many critics complain that such applications are 'contrived' (Singer 1993: 210) and lacking in 'intuitive plausibility' (Glover 1977: 91) and that the purported success of the distinction 'depends on how the action is described, and crucially on how to set limits to the redescription of any action' (Harris 1985: 44). Condemning the principle, Rachels refers to Pascal's satirical criticism: 'where we cannot prevent the action at least we purify the intention' (Rachels 1986: 92). Supporters nevertheless insist that the DDE captures genuine differences – not only conceptual and moral (in the differentiation between intended and foreseen outcomes), but also experiential (as the act of killing is said to feel significantly distinct from that of relieving symptoms) (Gillon 1999).

The defenders seem particularly inclined towards a narrow account of intention, which counts as intentional that outcome which is primarily or directly aimed at, as opposed to that which is merely secondary, indirect or only foreseen. Critics also reject this interpretation of intention and its ensuing account of moral responsibility. For one thing, they say, intentions may be multilayered (Quill 1993). Moreover, they claim that we might rightly be held accountable for more than the ends that

we directly aim to achieve. Beauchamp and Childress have thus suggested that intentional action must encompass both ends and means: the means chosen must at least be tolerated, which for them signals that foreseen consequences must count as intended (Beauchamp & Childress 1994: 208–11). John Harris, meanwhile, has argued that persons should be held to account for the 'worlds' they voluntarily bring about, i.e. for the consequences of their free choices (Harris 1997: 36–40).

Harris's reference to the consequences of one's free actions hints at a major difference between many of the supporters and critics of the DDE. Proponents appear to take a deontological line, in which duties, rights and intentions dominate, rather than consequences as such, while many opponents tend to adopt a consequentialist perspective, in which right and wrong are judged in terms of outcomes. According to consequentialist critics like Peter Singer, the DDE smuggles in 'a disguised quality of life judgment', since it implicitly signals that the allegedly prohibited result – death – need not be a bad thing for suffering patients (Singer 1993: 210). Singer would therefore prefer this evaluation to be made out in the open, ousting the usual presumption in favour of prolonging life. Many defenders of the doctrine, however, remain committed to the preservation of life; indeed, for its Catholic proponents, the sanctity of human life is a core commitment. But this too troubles opponents. For the doctrine to succeed at all, it requires prior moral work, specifically defining what will count as 'good' and 'bad' consequences. If such work appeals to an authority like God, then atheists and those with alternative faith-based commitments will have little reason to accept such sovereignty and might therefore have good reason to reject the doctrine (Glover 1977: 86–91).

Still the proponents insist that one need not be a (particular type of) theist to recognise the intrinsic value of human life (Keown 2002) and that intention remains fundamental. According to Sulmasy (2000), intention can be relatively easily tested, by asking the agent: how would you feel if the foreseen prohibited result did not ensue – would you feel that you had failed in what you set out to achieve? If the agent did not feel they had failed, then this result seems not to have been intended.

For such proponents, running the risk of a 'bad' outcome is preferable to embracing the undoubtedly bad outcome that would ensue if the DDE were to be abandoned. Without such a principle, they say, there is a risk that many clinicians would abandon the use of opioids and sedatives, so as to avoid the taint of euthanasia, and many patients would accordingly die in pain and distress (Sulmasy & Pellegrino 1999). This is a risk worth taking seriously, particularly in light of empirical research from the UK, which has found that 'the belief that opioids hasten death

is widely held' amongst patients, which in turn 'has a significant impact on pain management, as patients felt that an offer of opioids signified imminent death' (Reid et al. 2008). Notably, the authors found that 'opioids were more acceptable if healthcare providers had confidence in opioids and side-effects were well managed' (Reid et al. 2008). Of course, these findings could also promote the dissemination of better information regarding the effects and the appropriate use of opioids in pain management.

3.3. In the law

Unfortunately (but perhaps unsurprisingly), confusion and a lack of confidence has spilled over into the legal realm. The law as stated and as applied in England vividly illustrates the problems (Huxtable 2007: 84–114). The most pertinent examples from the case law in this jurisdiction concern the use of opioids, rather than sedatives (Huxtable 2008), and the cases reveal that the law can be unclear, unfair and even dangerous.

First, the judges are not always consistent in the ways that they conceptualise and apply Devlin J's principle. Some judges seem to see the principle as straightforwardly expressing the doctrine of double effect and, thus, primarily concerned with protecting intentions to achieve permissible outcomes from the full force of the criminal law. Devlin J himself appeared inclined towards this interpretation, when he described the doctor as 'entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may *incidentally* shorten life' (our italics). But Devlin J also – or perhaps alternatively – thought his principle was concerned with causation: 'the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term' (Devlin 1985: 171–2). At least one of Devlin J's successors appears to have added a third reading of the principle, according to which the doctor who pleads double effect is guilty of a crime, but he or she can claim a substantive defence for their actions, constructed along the lines of accepted professional practice (Arlidge 2000). This idea – that the doctor is a murderer, albeit a justified one – is remarkable and is unlikely to sit well with practitioners of palliative care.

The legal uncertainty seems to reflect some of the underlying philosophical and clinical confusion. But perhaps the precise category in which the relevant principle is stated should only trouble the criminal lawyers; maybe the rest of us need only concern ourselves with whether the law is being fairly and consistently applied. However, here too there

is cause for concern, since double effect reasoning does not appear available to everybody. Case law in England reveals that a member of the public who foresees (but does not intend) the adverse outcome of their actions might be held criminally culpable, including for murder (*R* v. *Woollin* 1998). Doctors, meanwhile, can continue to rely on the principle.

Whether the principle applies to the right doctors, in the right circumstances, nevertheless remains open to question. There appear to be three types of doctors who appeal to the doctrine: those who *use* it, those who *confuse* it and those who *abuse* it (Forbes & Huxtable 2006: 395). The *first group* seems likely to comprise experts in palliative care, who will be well versed in the stories told by the data we surveyed earlier. Even for these experts there may still be a 'grey zone of ambiguous intentions' (Douglas et al. 2008: 394) but, generally, they seem most likely to know which doses will involve risk to that patient's life, and when they will therefore need the DDE close to hand.

The *second group* are likely to lack this expertise and they may err in various ways, such as over-reporting death as a consequence of palliation, under-treating pain and distress, or even over-dosing their patients, sometimes with fatal consequences. Such errors can range from relatively harmless mistakes, all the way up to grossly negligent or reckless practice, which could result in conviction for manslaughter (Huxtable 2007: 106–7).

More problematic is the *third group*, who discuss double effect, but who, really, directly intend to end life, whether for beneficent reasons (as in euthanasia) or from more nefarious motives. Even Dr Adams was not all that he appeared. Adams had inherited under the deceased patient's will; too 'paltry' a reward, observed the trial judge, for a respected GP to risk the death penalty (the then mandatory sentence for murder). However, the reward may not have been so meagre, as Adams inherited under 132 wills over the course of a career caring for many elderly patients. Apparently the prosecution case was poorly handled; if Adams had been prosecuted for the alleged killing of a different patient, then a conviction might have resulted (Huxtable 2007: 98). There therefore appear to be sound clinical, ethical and legal reasons why double effect needs careful consideration, both in principle and in practice.

4. Conclusion: striking the balance?

Even excluding extreme cases, these diverse clinical, ethical and legal considerations provide conflicting accounts of how CDS might benefit and/or harm patients like Mrs Martin. Yet, it seems consensus – or at

least compromise – can be constructed from the competing accounts of what it means to value human life that seem to underlie these considerations.

As noted earlier, three accounts of the value of life appear to be in play, which respectively emphasise its intrinsic, instrumental and self-determined nature (Huxtable 2007, 2012). Proponents of the *intrinsic* value of life (like those who espouse the sanctity of life) argue that life itself matters, such that it should not intentionally be brought to a premature end. Yet, such proponents acknowledge that there are limits, which the DDE helps to clarify. Advocates of the *instrumental* value of life object to the DDE and argue that life is only a vehicle for achieving other goods: where the vehicle is sufficiently damaged – say, where there is extensive suffering and inability – then it might be permissible to bring such a life to an early end. Adherents to the *self-determined* value of life, meanwhile, emphasise notions like autonomy and thus leave the determination to the liver of the life – she may decide what makes life valuable for her, and whether or not to continue with that life.

Each of the perspectives commands support in the laws of England, Germany and France, albeit to different extents (Huxtable 2007; Horn 2011, 2012). This might signal inconsistency, but we might do well to prevent the dominance of any one: the intrinsic value of life may be too closely associated with (particular) religious doctrine, while preoccupation with perceived suffering might raise the spectre of eugenics, as Peter Singer discovered when lecturing in Germany (Singer 1993: 337–59). Even the ever-popular autonomy might do insufficient work in the context of CDS, if someone like Mrs Martin has not indicated her wishes in advance or nominated a proxy. But, equally, we should not necessarily abandon any of these perspectives. Their prevalence and tenacity in end-of-life debates must tell us something.

Yet, even retaining something of each moral tradition, there remains the problem that the accounts can point in different directions. However, there may still be room for consensus: it seems unlikely that anyone would wish to see patients dying in pain, or distressed and suffering. Even supporters of assisted dying might be unlikely to want this practised unnecessarily, i.e. when patients' needs can be tackled without ending life, although some might still prefer assisted dying to CDS. Proponents of each position might still support the use of CDS. Those in favour of the intrinsic value of life might insist that this is a matter of intending to achieve a permissible outcome (relief of symptoms). Those who favour life's instrumental value might argue that the DDE is hypocritical and they would prefer to go further, with euthanasia also being permitted. But, in the absence of such a development, even

these critics would probably prefer that CDS still be allowed. Those who prefer self-determination might add the caveat that CDS should occur, at least wherever possible, at the (current or previous) behest of the suffering patient.

Of course, each proponent might still have cause to complain: of boundaries being wrongly extended; of boundaries not being sufficiently extended; and of clinicians' interests dominating over patients' wishes. Even if consensus is not entirely likely or defensible, a case can still be made for compromise, where CDS can continue. Compromise on moral matters looks appropriate when there is great uncertainty and complexity, not every competing value can be respected simultaneously, a decision is needed and the disagreeing parties must continue to coexist as peacefully as possible (Huxtable 2012: 132–5). These conditions are amply satisfied here, with uncertainty and complexity particularly rife: diagnosing and prognosticating about terminal illness is seldom straightforward; the effects and side-effects of drugs are unpredictable; and judgements about the value of life (and, indeed, consciousness) remain contentious.

The idea of compromise in end-of-life ethics is gaining currency (Huxtable 2007, 2012; Mullock 2012. How might a compromise on CDS appear? Like the consensus position, compromise might simply be what we have, i.e. CDS may be practised, according to the DDE and thus within specified boundaries. Of course, to count as a compromise, which splits the difference between disputants, the boundaries need to be carefully drawn and policed. This should at least involve ensuring that the true properties and potentials of the relevant drugs are known (by clinicians, lawyers and the public alike), so that distinctions can be made between those who use the drugs within the boundaries, those who abuse them and those who are confused. To recap, the DDE seems most applicable where the patient is suffering but not near the end of life; elsewhere, no one needs to be unduly fearful of the assumed life-shortening effect of CDS.

Drawing up the boundaries necessitates further debate, to which this volume makes a useful contribution. Disputants should advance their claims in a reflective, reliable and respectful manner, so that the most suitable compromise is found (Huxtable 2012: 135–40). Where the lines will finally be drawn remains to be seen; for now, we hope to have defended the middle ground, which strikes an appropriate balance between the different benefits and harms at stake in these debates.