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The Provision of Nutrition and Hydration to Vulnerable Patients: An Analysis of the Clinical and Ethical Issues

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Executive Summary

- The provision of food and fluids to vulnerable patients is an essential part of medical care. For a variety of reasons, some patients are unable to take food and fluid by mouth, in which case alternate means are needed. These include via nasogastric tube, percutaneous endoscopic gastrostomy (PEG), or fluid intravenously or subcutaneously. Nutrition and/or hydration by these means is termed artificial nutrition and hydration (ANH), or more recently, clinically assisted nutrition and hydration (CANH).
- Over the past 20 – 25 years there has been a change in how CANH has been perceived. Earlier, CANH was viewed as basic care, like washing, wound care, or toileting. However, various legal judgments and cultural changes mean it is now widely viewed in the literature, by peak bodies, and in law, as medical treatment rather than basic care. Because of this, it has become much easier for CANH to be withheld or withdrawn, much like other medical treatment. However, there remain medical professionals, nurses, ethicists, family members, and other carers who consider CANH to be basic care that should be administered unless there are compelling reasons not to do so. This is based upon a strong intuitive sense that food and fluid, even when provided by a tube, are so basic to life itself, that it seems obvious they should be routinely provided.
- Common contexts in which CANH is used include oropharyngeal malignancy, stroke, head injury, motor neurone disease, multiple sclerosis, Parkinsonism, cerebral palsy, and HIV. In these circumstances, using CANH is uncontroversial, and it generally improves survival rates.
- CANH can also be used in advanced dementia, when death is considered imminent, and for prolonged disorders of consciousness (PDOCs). In these circumstances, using CANH can be controversial.
- In advanced dementia, some evidence suggests that CANH is being overused. Survival rates in late stage dementia are mostly not improved by using CANH compared with slow and careful hand feeding. In some settings CANH is being routinely used to the detriment of patients because it is cheaper and easier than hand feeding. In the US, the proportion of patients with advanced dementia who receive CANH has been in decline since about the year 2000 – from 11.7% in 2000 to 5.7% in 2014. There is a risk that the ineffectiveness of CANH in advanced dementia may be generalised to other conditions where CANH is in fact effective.
- CANH use at the end of life when death is imminent can be controversial. This is because there will be circumstances when forgoing CANH involves an intention to hasten death, in which case, it is euthanasia by omission – sometimes called ‘slow euthanasia’. Determining when someone is dying and death is imminent within days to a week has been proven to be very difficult. One of the markers is clear evidence that someone’s body is shutting down, hunger and thirst subside, and they are not able to assimilate food and fluids. Under these circumstances CANH may not necessarily be beneficial, but may do no harm and yet provide relief for family members.
- The considerable latitude possible with a prediction that death is imminent allows for CANH to be forgone when it should not be; that is, when someone could live considerably longer than days or weeks, but requires CANH to do so. In Belgium, 77% of decisions involving forgoing CANH had an intention to hasten death. In The Netherlands, all cases where CANH was forgone involved an

intention to hasten death. The rate of forgoing CANH was between 2.6% and 10.9% of all deaths in six European countries, being highest in those countries with a culture of intentionally ending life. Forgoing CANH when someone is not actually imminently dying, with an intention to hasten death, constitutes euthanasia by omission, in which case the immediate cause of death will be dehydration, and possibly starvation.

- Decisions about forgoing CANH are distressing for physicians, nurses, families and other caregivers. An argument for routinely using at least hydration has been made in the interests of family members, even when the benefits may be uncertain. This would allay concerns about the cause of death, ensuring it was from the underlying condition rather than by dehydration.
- The place of CANH in end of life care has become more complicated by the increasing use of palliative sedation. Ethicists generally consider palliative sedation appropriate when it is used in a proportionate way to relieve suffering that is unable to be alleviated by alternate means. Palliative sedation guidelines likewise include guidance to this effect.
- Palliative sedation for existential suffering is controversial amongst ethicists and guidelines vary with respect to how they deal with it. As sedation is not typically recommended or used for existential suffering that is relatively common in contexts outside the context of the end of life, its use within it seems to be an anomaly.
- Palliative sedation that intentionally induces unconsciousness is unethical. Unconsciousness as a foreseen but unintended side effect of sedation is permissible, but ought to be a rare occurrence, which can be intermittent and monitored. When sedation to unconsciousness is intended to continue until death, it is also unethical. This is called continuous deep sedation (CDS) and most often involves the intention to hasten death.
- The way in which palliative sedation has been used varies significantly not only through time, but in different jurisdictions. Prior to the year 2000, in different countries, most studies of palliative sedation show it was used to alleviate refractory symptoms with no intention to hasten death. However, the rates of use varied enormously, from 0% to 60% of patients in palliative care settings. The depth of sedation also varied significantly. Some palliative care specialists expressed concern that available strategies to treat difficult symptoms were not being implemented.
- In countries like The Netherlands, Belgium and Switzerland, beginning in the nineties, a particular form of palliative sedation was increasingly being used. This involved CDS to death, often with routine removal of CANH and an intention to hasten death. This protocol is slow euthanasia or euthanasia by omission.
- In the Netherlands, CDS as a percentage of all deaths increased from 8.2% in 2005, to 12.3% in 2010, then 18.3% in 2015. In Belgium CDS increased from 8.2% in 2005 to 12.3% in 2010, then to 12% in 2013. In Switzerland CDS increased fourfold from 6.6% in 2001 to 24.5% in 2013. In the UK, albeit with some reservations about the accuracy of the data, the rate of CDS was approximately 17% in 2007-2008. There are few studies from other countries, some of which suggest an increased incidence of CDS in countries where euthanasia and/or assisted suicide are legally permitted compared with countries where they are not.
- In 2007/2008 in Flanders, the Dutch-speaking north of Belgium, CDS was used in 21.8% of deaths of children compared with 14.5% of adults. In 91% of the child cases, there was no request or consent, even though 28% of the children were over the age of 12 and of a sufficient age for their views to be relevant. This is contrary to Belgium guidelines on palliative sedation.
- In some specific sectors of Belgian palliative care, palliative sedation is used in a very different and limited way, with rates of CDS far below the national figures, and palliative sedation used in a proportionate manner. Researchers from the group argue that most other practitioners have a poor understanding of symptom control.

- France has become the first country to formally legislate for a 'right to CDS', even for mild symptoms, and coupled with routinely forgoing CANH. It is unsurprising that in public debate some French Senators have described the practice as a 'Trojan horse' for euthanasia.
- Apart from physicians in Belgium and The Netherlands, the majority of medical practitioners, and in particular palliative care specialists, think palliative sedation should be proportionate, that CDS should be rare, and exclude an intention to hasten death. Similarly, most medical professionals do not think palliative sedation should be used to treat existential distress, although Belgian nurses expressed a contrary view. In some settings, decisions about palliative sedation led to considerable distress and emotional burden felt by nurses.
- Withdrawing CANH from patients with PDOCs is a clearer example of its removal causing death. Patients with PDOCs are not imminently dying, so when CANH is removed, dehydration, and to a certain extent starvation, become the immediate causes of death.
- It has been argued that CANH for a patient with a PDOC is futile, and should therefore be forgone, just as other futile medical treatments can be forgone. But such reasoning is false, because food and fluid by a tube is assimilated by the person's body as hunger and thirst are assuaged, and the person then enabled to continue living, even if in a severely disabled state. If CANH were indeed futile, removing it would change nothing. But that is not the case.
- Patients with a PDOC may be either in a vegetative state (VS), or a minimally responsive state (MCS). VS, because of the dehumanising connotations of the term 'vegetative', has also been called 'unresponsive wakefulness syndrome'. In the UK, there are estimated to be approximately 24,000 people with VS and MCS.
- Someone may enter a VS or MCS after traumatic or non-traumatic brain injury. For severe traumatic brain injury the percentage entering VS ranges from 0.52% to 7.33% at 6 months.
- The rate of misdiagnosis of VS and MCS is approximately 40%, and as new diagnostic tools become available the rate may be proven to be higher, with greater numbers having 'covert consciousness' than presently thought.
- Research on recovery from a PDOC is limited, but such studies as exist point to rates of improvement in awareness of up to 32%, although if limited to PDOCs resulting from a traumatic injury, the rate can be as high as 52%. Rather than limiting the outcome to an improvement in awareness, more recent research suggests that about 20% of PDOC patients 'eventually regain independence in the home environment'.
- Some research on caregivers points to a high level of grief and loss. Caregivers are also often strongly averse to the removal of CANH, even though some may be conflicted about their loved one continuing to live.
- In the UK, withdrawing CANH has recently become much easier with rescinding of the requirement to bring a request for removal to the Court of Protection to decide. Approximately 100 such cases had come before the Court over the past 25 years. Now a medical practitioner, with the family, may decide if it would be in the patient's 'best interests' to be denied food and fluids by CANH. Guidance from the British Medical Association states that the cause of death should exclude any mention of CANH removal.
- The various practices described here that constitute euthanasia by omission - whether CDS coupled with CANH removal for those at the end of life, or CANH removal from those with a PDOC - more firmly establish the practice of intervening to end human life. This contrasts with caring and palliating distressing symptoms till life draws to its natural end. Euthanasia by omission has the potential to advance more active means to end the lives of vulnerable human beings.

Introduction

Sustenance is essential to life. We eat and drink to live, to nourish our bodies so that we may exist, and do those things we value. Without sustenance we fade, progressively losing our abilities and faculties until finally succumbing to death.

There are limits in the time that life remains possible without food and water. For a healthy individual those limits may be around 1 - 2 weeks without water and 4 - 6 weeks without food. Individual variation, health status, activity, and environment all play a role in determining the timeframe for survival.

For a person who is unwell, basic medical care typically involves finding ways to ensure they receive enough food and fluid to sustain life and optimize living. This may mean that the provision will be slow and difficult and require specialized foods, or that alternatives to food and fluid by mouth may be needed. These may include tube feeding via the nasal passages (nasogastric tube) or abdominal wall (percutaneous endoscopic gastrostomy: PEG). Hydration by itself may also be administered intravenously or subcutaneously. These alternate means are sometimes called artificial nutrition and hydration (ANH), or more recently clinically assisted nutrition and hydration (CANH).

Whatever the case, for the vulnerable patient, the basic need for food and water should be met unless any adverse effects arising from provision, or the means of provision, create sufficient harm to outweigh the natural benefit of receiving sustenance. The well-being and best interests of the patient should be the measure used in decisions about providing, or not providing, food and fluids. Other factors such as a desire to hasten death or cost savings must not be part of the decision making process.

Decisions about providing nutrition and hydration, whether by mouth or CANH, are often straightforward, and include circumstances where someone cannot feed themselves, or where CANH is used in critical care, in the short term as a bridge to recovery, or for non-terminal conditions where a patient is able to consent.¹ More difficult decisions arise for those who are imminently dying or unable to consent, either because of injury or illness, or heavy sedation, in which case CANH is often relevant.

This paper will deal with three different sets of circumstances where CANH is being used. First, for advanced dementia patients who may live for several years before succumbing to their illness. For these persons, eating and drinking may be possible but compromised, in which case a decision to use CANH may be made. Second, for people at the end of life who are nearing death or are in the process of dying over several days or weeks. For these people, an additional and crucial question arises. What is the role of sedation? Heavy sedation will render someone who might otherwise eat and drink - albeit with difficulty - unable to do so, raising the possibility of using CANH. Some people may already be on CANH, whereupon a decision to sedate may raise a question about withdrawing it. And third, for those with prolonged disorders of consciousness (PDOCs). This third group includes those in a minimally conscious state (MCS) and those in a vegetative state (VS). For these people, who have often been on CANH for many years, a decision to withdraw it will then lead to their death, the immediate cause of which will be dehydration and starvation.

For advanced dementia, it turns out there may be an *overuse* of CANH that could adversely affect people's survival, whereas for the end of life (death imminent) and for PDOCs, CANH is being forgone more often than before and is adversely affecting people's survival. In many cases there is an intention to hasten death, making CANH removal an instance of euthanasia by omission. What all three contexts share in common is an increasing failure to recognise people's inherent dignity, and treat them accordingly. Sometimes it is also the burden and cost of their care, or a desire for access to inheritance, that precipitates poor treatment and/or the hastening of death.

There is some similarity between CANH for people with PDOCs and those heavily sedated at the end of life. For those with PDOCs, the damage to consciousness has been a result of illness or injury, but for

¹ See for example the Guidelines produced by the European Society for Parenteral and Enteral Nutrition. <https://www.espen.org/guidelines-home/espen-guidelines> Accessed 2 Feb 2019

the heavily sedated the loss of consciousness has been an intended state in response to some measure of suffering, or at least an unintended but foreseen state. Either way, loss of consciousness is often the context within which a decision to withhold or withdraw CANH arises.

The wishes of individual patients themselves are of course a crucial element of the decision-making process, but so too are the wishes of surrogate decision-makers, and their wishes take on more significance when those of the patient cannot be known. And while decisions about nutrition and hydration have life and death significance for patients, surrogates such as family members, as well as physicians and nurses, are often deeply impacted too. Whether a course of action coheres with these participants' core values will to some extent determine how they will live with any given decision. At another level, these decisions are critically important for the community, inasmuch as they align or otherwise with the goals of medicine. Decisions about the way we care for our vulnerable members can be revealing about what kind of community we have become.

Decisions about withholding or withdrawing nutrition and/or hydration also inevitably raise questions about euthanasia, because there will be circumstances that either obviously or in a covert way involve a desire to hasten death. Euthanasia involves an intention to cause or hasten death, whether by taking active steps to do so, for example by lethal injection, or by withdrawing a life-sustaining measure with the intention to cause or hasten death. These latter circumstances may be called euthanasia by omission, whereas the former direct acts constitute euthanasia by commission. The majority opposition to euthanasia in the medical community and amongst lawmakers means that a careful eye is, we hope, directed towards delineating good medical care from practices that might constitute euthanasia. Thus, how nutrition and hydration for the vulnerable is handled is under close scrutiny, not only for the sake of those patients themselves, but also to ensure that euthanasia by more covert means does not lead to euthanasia by more overt means. In other words, to take care that no *in principle* acceptance of intentionally ending life by one means leads to other ways of doing so. Normalising euthanasia by omission can be used as a stalking horse for euthanasia by commission, contributing to more widespread acceptance that suffering is *in principle* best eliminated by death.

What is the Nature of CANH?

There are significant ethical and legal consequences that proceed from how CANH is understood. Though it may seem a simplistic dichotomy to make, CANH may be seen as basic care that should always be provided, like washing, wound care, or toileting, or as medical *treatment* that can be refused. It is somewhat unfortunate that medical care is fractured in this way, because ultimately all care, whether basic or medical in nature, should be directed towards the welfare of the patient.

Finding a bright line between basic care and medical treatment is not simple, and drawing a firm distinction has the potential to allow too much latitude for refusing to provide 'treatment' that is in the best interests of the patient, especially in contexts where cost and perceived burden are given undue weight due to failures adequately to value the lives of patients.

Because the distinction has been codified in guidance to professionals as well as in law, with CANH being defined as medical treatment rather than basic care², the result has been an increasing trend towards the denial of food and fluids to vulnerable patients. In the UK, the critical judgment came with *Airedale NHS Trust v Bland*³, where construing CANH as medical treatment allowed the removal of food and fluids from Tony Bland, who died soon after. The definition of CANH as medical treatment rather than

² In some legislation, rather than medical treatment being defined separately from basic care, it is instead defined separately from palliative care, medical treatment able to be refused but palliative care not. In Victorian legislation for example, palliative care may not be refused, and includes "the reasonable provision of food and water".

See http://www.austlii.edu.au/cgi-bin/viewdoc/au/legis/vic/consol_act/mtpada2016351/s3.html and <https://www.liv.asn.au/Professional-Practice/Medical-Treatment-Act> Both accessed 22 march 2019.

³ House of Lords Judgement. *Airedale NHS Trust v Bland* [1993] AC 789 (HL).

basic care is now widely accepted, with some exceptions.⁴ It is noteworthy that the change in terminology from ANH to CANH construes the act of providing food and fluids by tube as a clinical and hence medical phenomenon. Although some interpret the change differently, calling something clinical seems to drive home the intention to see food and fluids provided by this means as essentially 'medical'.

Judgements about when to use, withhold, or withdraw CANH are not easy, and there will be differing contexts in which each of these is appropriate. But characterising CANH as medical treatment that can be refused has arguably allowed decisions to be made with less ethical reflection than is demanded by the circumstances, thereby bringing an illusory ease of conscience to some. Additionally, it may have enabled those who would want to hasten death to do so under the protection of legal and professional licence.

On ethical grounds medical treatment may be refused if it is futile or overly burdensome and disproportionate to benefit. To make this type of judgment relies on medical evidence and expertise as well as the wishes of an individual, particularly with regard to what may be considered 'overly burdensome'. In practice, because the decision to refuse medical treatment lies either with the individual or surrogate decision maker, on occasions medical treatment will be refused even though it is *not* futile or overly burdensome and disproportionate to benefit. Nevertheless, in law the right to refuse medical treatment will be exercised even if to do so would seem unreasonable or even unethical to someone else. Now that CANH has been construed as medical treatment, the gate is open that much wider for unreasonable or unethical refusal to occur.

The reasoning used to designate CANH as medical treatment includes that placing a nasogastric tube or PEG requires professional medical expertise on the part of a doctor, that it is a medical response to a pathology (inability or difficulty swallowing), and that it is artificial. Each of these is partly true. However, a nasogastric tube may also be passed by nurses and other carers, and whilst a PEG requires a surgical procedure by a doctor, its operation can be undertaken by other non-medical individuals. More importantly, placing a PEG is a medical procedure, but the feeding that then ensues is not, and this was the purpose for the PEG in the first place. It would really be stretching things to say that nourishment is medical, otherwise hunger and thirst would then become pathologies, rather than the natural bodily drives for sustenance that they are. In other words, CANH may be a response to the pathology of the inability to swallow, but the needs it ultimately responds to are the non-pathological and entirely natural phenomena of thirst and hunger. CANH can also be necessary when there is no pathology of swallowing but instead sedation is used that renders food and fluid by mouth impossible. This would not be the only intervention that serves a complex of goals. And on the question of artificiality, it is a fuzzy concept, and one might just as well argue that bottle-feeding babies is artificial, as is cutlery.

It has been argued that in some cases CANH is futile, and since there is good agreement that medical treatments that are futile can be legitimately withdrawn, so can CAHN⁵. This argument about CANH being futile is flawed. In the Victorian case of BWV who had Pick's disease, Morris J of the Supreme Court of Victoria argued that "the provision of nutrition and hydration via the PEG, is futile, in the sense that it has no prospect whatever of improving her condition".⁶ But as Fleming argues,

The point of providing nutrition and hydration via the PEG is to provide sustenance and hydration to the patient who could not be fed and hydrated in any other way. Clearly this was not futile as the medical witnesses alleged. BWV was not dying of starvation and dehydration. Nutrition and hydration was not being provided to stall the inexorable progress of Pick's disease. Why then should it have been judged on criteria not relevant to

⁴ Address of Pope John Paul II (20 March 2004) to the participants in the international congress on "Life-sustaining treatments and vegetative state: scientific advances and ethical dilemmas". See http://w2.vatican.va/content/john-paul-ii/en/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc.html Accessed 11 December 2018.

⁵ Gardner; re BWV [2003] VSC 173 (29 May 2003).

⁶ *Ibid.* at para 8.

its purpose? It is about as sensible as arguing for the withdrawal of morphine because it is not slowing the inexorable progress of cancer.⁷

If BWV was actually dying of starvation and dehydration and providing food and fluids made no difference, then the judge's claim of CANH's futility may have held up. But in point of fact the opposite was true – she was alive because of CANH, and made to die of starvation and dehydration by its removal.

BWV had a PDOC, but for someone who is deeply sedated near the end of life, and therefore similarly vulnerable, it has likewise been argued that CANH is futile⁸. However, it is not futile if a person assimilates the food and fluid so that life is sustained. What may instead be meant by futility in this context is that once a decision to sedate till death has been made, providing CANH may prolong life, thereby frustrating the intention for death to be hastened. Once a decision has been made to deeply sedate until death, death becomes the measure of success of the treatment of this type of sedation, and hence anything that may hinder that, is deemed 'futile'. In both PDOCs and deep sedation intended to continue until death, what may instead be meant by the line of argument that CANH is futile, is really that the life the patient is living is deemed futile, that is, a purposeless existence. This is a disturbing value judgment of a different sort than a fair-minded argument that CANH, despite achieving its goal of sustenance, is actually futile.

There is some irony in the fact that CANH is now widely viewed as medical treatment rather than basic care. For even if it is to be called medical treatment, then it should be subject to proper scrutiny as to whether it is actually futile or overly burdensome disproportionate to benefit. As we have seen, it is most often not futile. Moreover, more often than not, CANH is quite straightforward and not overly burdensome; but there may be circumstances when, for a variety of reasons, it is overly burdensome and disproportionate to the benefits. But these deliberations cannot be avoided, and simply relying on a designation of CANH as medical treatment to warrant forgoing it is not only intellectually and ethically feeble, but potentially openly dishonest. Furthermore, however CANH is designated, the reasons for denying something as central to human life as food and fluid to a vulnerable patient need to be quite robust.

CANH in Advanced Dementia

The aging population across the globe has brought a dramatic rise in the incidence of dementia, and in the UK alone there are estimated to be 850,000 people living with dementia.⁹ As these people reach the end stages of their disease, problems with eating and drinking will arise, and when that happens some patients will be given CANH. In the US, the proportion of patients with advanced dementia who receive CANH has been in decline since about the year 2000 – from 11.7% in 2000 to 5.7% in 2014.¹⁰

The reason for the decline has been a body of evidence that has questioned the efficacy of CANH in advanced dementia. In 1999, Finucane and colleagues undertook a review of the evidence for CANH in patients with advanced dementia, concluding that the data does not support the use of CANH to increase survival rates, prevent aspiration pneumonia (food in airways), the incidence of pressure ulcers, or other infections.¹¹ They also conclude that there are a range of other adverse effects that can be very distressing for all involved, including that patients may need to be restrained to stop them removing a feeding tube.

⁷ Fleming JI (2003) Euthanasia by omission in Australia. What the parliament does not allow, the courts allow. *Bioethics Research Notes* 15(2):1-4.

⁸ Royal Dutch Medical Association (KNMG) (2009) *Guideline for Palliative Sedation*. Utrecht, the Netherlands. See https://www.palliativedrugs.com/download/091110_KNMG_Guideline_for_Palliative_sedation_2009_2_%5B1%5D.pdf

⁹ Alzheimer's Research UK, Dementia Statistics Hub. See <https://www.dementiastatistics.org/statistics-about-dementia/prevalence/> Accessed 15 November 2018.

¹⁰ Mitchell SL *et al.* (2016) Tube Feeding in US Nursing Home Residents With Advanced Dementia, 2000-2014. *JAMA* 316(7):769-770.

¹¹ Finucane TE *et al.* (1999) Tube feeding in patients with advanced dementia. *JAMA* 282:1365-1370.

This work has been followed up in more recent years by other researchers, who have come to similar conclusions.^{12,13} Even so, work by other researchers again has come to the opposite conclusion, namely that feeding tubes do improve survival rates, if only marginally.^{14,15}

In a study from Israel, tube feeding had a beneficial impact on survival¹⁶, in a country where 53% of patients with advanced dementia were being fed by CANH¹⁷, pointing to significant cultural differences between countries.

But the critical point that has not always been made clear is that the studies all compared CANH with the slow and time-demanding business of hand feeding.¹⁸ These patients were not *unable* to eat or drink, but instead had significant problems associated with eating and drinking and were at the same time losing weight and experiencing deteriorating condition - the response to which was to sometimes initiate tube feeding. But on most counts tube feeding was no better than hand feeding, and on some, may have been worse. It is noteworthy that the final stage of dementia can last for years, with 6-month survival rates ranging from 10% to 85% depending on the study.^{19,20,21,22} Why there should be such a high variation between studies is not clear, but it is possible that differing practices in institutions with regard to how effectively feeding was being done – either by hand or tube – may contribute. That is to say, the culture of any given institution and the level of care provided are likely to vary. To what extent the variations may result from the intentional denial of reasonable care, leading to poorer survival rates, is unknown.

Rather than promoting CAHN for patients with advanced dementia, several authors have instead suggested the following:

Feeding patients small amounts of food by spoon, giving small sips of fluids, keeping the mouth and lips moistened and good oral care are more important than tube feeding in most patients.²³

Physicians, professional organisations, hospitals, and nursing homes should recommend to patients and their families that nutrition be provided orally, not through a feeding tube, during the final stage of dementia.²⁴

¹² Teno JM *et al.* (2012) Does Feeding Tube Insertion and Its Timing Improve Survival? *J Am Geriatr Soc* 60:1918–1921.

¹³ Sanders DS *et al.* (2000) Survival Analysis in Percutaneous Endoscopic Gastrostomy Feeding: A Worse Outcome in Patients With Dementia. *Am J Gastroenterology* 95(6):1472–1475.

¹⁴ Rudberg MA *et al.* (2000) Effectiveness of feeding tubes in nursing home residents with swallowing disorders. *J Parenteral & Enteral Nutrition* 24:97-102.

¹⁵ Cowen ME *et al.* (1997) Survival Estimates for Patients with Abnormal Swallowing Studies. *J Gen Intern Med* 12:88–94.

¹⁶ Jaul E *et al.* (2006) Tube Feeding in the Demented Elderly with Severe Disabilities. *Israel Med Assoc J* 8:870-874.

¹⁷ Clarfield MA *et al.* (2006) Enteral feeding in end-stage dementia: a comparison of religious, ethnic and national differences in Canada and Israel. *J Gerontol A Biol Sci Med Sci* 61:621–7.

¹⁸ In their analysis in the *New England Journal of Medicine* on the appropriate use of CANH, Casarett and coworkers reiterated the findings, but failed to make it clear that the studies all compared CANH with the slow and time-demanding business of hand feeding, rather than with no feeding at all. In response to their article, one letter writer (Glick SM) to the journal found it ‘inconceivable’ that CANH could not affect survival compared with no nutrition at all. This is undoubtedly true, but unfortunately, rather than correct the misunderstanding, in their response Casarett *et al.* merely criticized the author of the query on other grounds, making it appear as if Casarett *et al.* did not appreciate that the comparison group was those who received careful hand feeding, rather than no feeding at all. (Casarett D *et al.* (2005) Appropriate Use of Artificial Nutrition and Hydration - Fundamental Principles and Recommendations *New Engl J Med* 353(24):2607–2612; Glick SM (2006) Appropriate Use of Artificial Nutrition and Hydration. *New Engl J Med* 354(12):1321; Casarett D *et al.* reply same page).

¹⁹ Rudberg MA *et al.* (2000) *Op. Cit.*

²⁰ Murphy LM & Lipman TO (2003) Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Arch Intern Med* 163:1351-1353.

²¹ Sanders DS *et al.* (2000) *Op. Cit.*

²² Meier DE *et al.* (2001) High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. *Arch Intern Med* 161:594-599.

²³ Kumar CTS & Kuriakose JR (2013) End-of-life care issues in advanced dementia. *Mental Health in Family Medicine* 10:129–32.

²⁴ Gillick MR (2000) Rethinking the role of tube feeding in patients with advanced dementia. *New Engl J Med* 342(3):206-210.

This type of care is not cheap, and there is a financial incentive for facilities to use tube feeding, even when the evidence mostly suggests that conscientious hand feeding is better for patients.²⁵

This brief consideration of the use of CANH for patients with advanced dementia is important, because there is a risk that the research highlighted above may be misused to argue that there is something inherently problematic about CANH that renders it ineffective in circumstances *other* than those for advanced dementia described above. After all, a patient with advanced dementia will reach a point where they are considered to be at the end of life, and therefore similar to patients with other conditions at the end of life. CANH can be delivered in different ways and can be used for different conditions at different stages of someone's illness, injury or decline at the end of life. It is therefore important that cases are considered on an individual basis as much as the overarching principles are used to guide practice.

Besides advanced dementia, other conditions where CANH is used include oropharyngeal malignancy, stroke, head injury, motor neurone disease, multiple sclerosis, Parkinsonism, cerebral palsy, and HIV. For these conditions, the benefits of CANH over other forms of feeding and nutrition are more obvious, with survival rates at 2 years around the 30-40% mark.²⁶

CANH at the End of Life

To say that someone is in a phase called the 'end of life' is a difficult judgement call that requires considerable expertise. It seems obvious to say, once someone has died, that in the week or so prior to death they were in such a phase; however, to actually *predict* the time of death with any degree of accuracy is a difficult task for which health practitioners have proven themselves time and again to have quite limited powers. Several studies have suggested that many physicians are overly optimistic about survival, but that the level of inaccuracy overall is high, and independent of branches of the profession.^{27,28,29,30}

With specific reference to determination of the terminal phase when death is imminent within a few days, the authors of the Neuberger Review of the Liverpool Care Pathway stated the following:

... diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life.³¹

The authors of the review also note research by Dein and George³², which shows that,

The timing of a patient's death may be less related to the physical processes, but more by symbolically meaningful occasions such as birthdays, anniversaries and festivals".³³

This suggests that rather than simple disease progression, an individual's personal circumstances and desires play a significant role – both of which may not be known to a treating physician.

²⁵ Mitchell SL (2003) Financial Incentives for Placing Feeding Tubes in Nursing Home Residents with Advanced Dementia. *J Am Geriatrics Soc* 51(1):129–131.

²⁶ Sanders DS *et al.* (2000) *Op. Cit.*

²⁷ White N *et al.* (2016) A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? *PLoS ONE* 11(8): e0161407. doi:10.1371/journal.pone.0161407.

²⁸ Christakis NA & Lamont EB (2000) Extent and determinants of error in physicians' prognoses in terminally ill patients: prospective cohort study. *Western J Med* 172(5):310-313.

²⁹ Hussain J *et al.* (2014) Triggers in advanced neurological conditions: prediction and management of the terminal phase. *BMJ Supportive & Palliative Care* 4:30–37.

³⁰ Kumar CTS & Kuriakose JR (2013) *Op. Cit.*

³¹ Neuberger J *et al.* (2013) More Care, Less Pathway A Review of the Liverpool Care Pathway. See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf p 19.

³² Dein S & George R (2001) The time to die: symbolic factors relating to the time of death. *Mortality* 6(2):203-211.

³³ Neuberger J *et al.* (2013) *Op. Cit.* p 20.

Questions about CANH were part of the reason for the demise of the Liverpool Care Pathway³⁴, with sufficient instances of the inappropriate removal of food and fluids to warrant a government review,³⁵ which then resulted in the Pathway's discontinuation. Also of concern was the coupling of CANH removal at the same time as sedation was instituted, sometimes sedation until death.³⁶ There appeared to be many cases that did indeed look like an intention to hasten death was involved.

Despite the propensity towards overestimation of the time till death, general uncertainty makes it equally possible (and easier if there are covert reasons for doing so), for practitioners to predict a shorter time till expected death, and then to set in motion actions that will guarantee such a prediction. Hence, short predictions can become self-fulfilling prophecies. For example, if it is estimated that someone will likely only live for a week, and all food and fluids are removed, it will be unsurprising when they die within a week. It is possible that their body was not able to assimilate food and fluids, and that they were in the natural and last phase of dying when hunger and thirst subside and the desire for food and fluid fades³⁷, and that they then died entirely of natural causes, or from whatever underlying condition they may have had. But it is also possible that if food and fluids had been provided, either by mouth or CANH, they may have lived longer, and maybe considerably longer. And during that time, important events, reconciliations, closures, or even enlightenments may have occurred. This phase is potentially more acutely cut short if at the time food and fluids are withdrawn, the person is deeply sedated. Then there is no possibility of communication from them about their desires, needs or wishes, possibly including for food and fluids. Therefore, questions about sedation at the end of life become just as important as questions about nutrition and hydration.

As we will see, there has been a fairly strong emphasis placed upon separating the decision about nutrition and hydration from that about sedation. But the two cannot, and in practice have not always, been separated. For example, a decision to continuously deeply sedate typically means that a patient will no longer be able to eat and drink, and hence the possibility of using CANH arises. Or a patient may be on CANH already, and deep sedation till death has then been argued to render CANH futile, leading to its withdrawal. Or a patient may be on intermittent sedation for symptom relief, and lack of nutrition and hydration during the sedated periods will have a significant impact upon the person's well being, raising the possibility that CANH may be used.

Palliative sedation will be considered shortly in some detail, but what of those circumstances in which sedation is not being used, or decisions about its use come later? When should CANH be used, and when should it not be used? What evidence is there that might assist?

This is an area in which there is limited research, and what does exist is equivocal on the benefits of CANH for the patient. In two major Cochrane reviews by Good and associates in 2008, the authors came to the conclusion that there was insufficient evidence to support the use of nutrition or hydration in the imminently dying.^{38,39} Nevertheless, some studies did identify some symptoms that were improved by hydration. This was confirmed when one of the reviews, on hydration alone, was updated in 2014, with the addition of another study.⁴⁰ Similarly, Raijmakers *et al.*, in their review that included some different papers to those reviewed by Good *et al.*, found a variety of positive and negative effects of CANH, that made it difficult to identify those patients for whom it may be beneficial from those for whom it may be overly burdensome.⁴¹

³⁴ Knights D *et al.* (2013) The Liverpool Care Pathway for the dying. What went wrong? *Brit J Gen Practice* DOI: 10.3399/bjgp13X673559.

³⁵ Neuberger J *et al.* (2013) *Op. Cit.*

³⁶ Stephenson J (2012) The Liverpool Care Pathway. *Triple Helix* Winter 14-15. See <https://www.cmf.org.uk/resources/publications/content/?context=article&id=25963> Accessed 15 Oct 2018

³⁷ Dev R *et al.* (2012) Is there a role for parenteral nutrition or hydration at the end of life? *Curr Opin Support Palliat Care* 6:365–370.

³⁸ Good P *et al.* (2008) Medically assisted nutrition for palliative care in adult patients. *Cochrane Database Syst Rev* CD006274.

³⁹ Good P *et al.* (2008) Medically assisted hydration for palliative care patients. *Cochrane Database Syst Rev* CD006273.

⁴⁰ *Ibid.* (23 April 2014) See <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006273.pub3/full>

⁴¹ Raijmakers NJH *et al.* (2011) Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects. *Annals of Oncology* 22:1478–1486.

What is striking from the review by Raijmakers *et al.* (keeping in mind that it is limited to cancer patients in the last week of life) is the variation in prevalence of CANH from study to study. These authors report a range of 3% to 50% for artificial nutrition, and 12% to 88% for artificial hydration.⁴²

Clearly more research in this area is needed, but because of the uncertainty involved, it has been suggested that at least hydration should be trialed so that symptom burden can be assessed and a decision then made to continue hydration or not.⁴³ This view is also endorsed by the recently published guideline from the *European Society for Parenteral and Enteral Nutrition (ESPEN)*.⁴⁴

A recent paper by Bruera *et al.* provides a good example of the careful scrutiny that needs to be applied to studies about CANH at the end of life.⁴⁵ This study examined the benefit or otherwise of subcutaneous hydration in patients with advanced cancer, using the gold standard of rigour in clinical studies, that is, a double-blind, randomised, placebo-controlled trial. The test group of patients received 1000ml of hydration per day and the placebo group received 100ml per day. The conclusion of the study was that “hydration at 1 L [1000ml] per day did not improve symptoms, quality of life, or survival compared with placebo ... Our study supports current hospice practice of not administering hydration routinely.” Taken at face value this conclusion seems to suggest that there is no point in using artificial hydration in patients with advanced cancer. It doesn’t improve overall symptoms or survival, although there was a small trend towards improvement in the hydration group that was not statistically significant.

The conclusion drawn by the authors might potentially make sense if the patients in the study group were clearly imminently dying – a few days to a week, in which case their bodies would likely be shutting down and hydration may be expected to provide little if any benefit. However, that was not the case. Whether receiving 1000 ml per day or 100ml per day, most of the patients lived beyond one week. In fact, in both groups, 50% were still alive at 2 weeks and 20% at 7 weeks. Some lived for 3 months or more. What is happening when some patients who were receiving just 100ml of fluid per day lived for months? A healthy person receiving such a small amount of fluid would not be expected to survive past 2 weeks, perhaps 3 at the most. The answer comes in the study design, and is acknowledged by the authors, even though they nevertheless came to their definitive conclusion describe above. They state, “... we did not monitor oral fluid intake during the study and therefore were unable to account for the potential cointervention effect of oral intake as a result of home visits by research nurses and patient/family ...”. In other words, any patient could have received considerable food and fluid intake in the unmonitored home setting, explaining why many lived for weeks or months. And presumably those receiving just 100ml of subcutaneous fluid would be far more likely to request and receive food and fluids, potentially bringing their overall intake into the same range as patients receiving 1000 ml of subcutaneous hydration. If this were not enough to call into question the entire study and the conclusions drawn, patients with severe dehydration at the outset were excluded from the study, even though they would potentially be the ones most likely to benefit from subcutaneous fluids.

This was a deeply flawed study.

Unfortunately, it has already contributed to the unrefined and growing general claim that CANH is ineffective at the end of life.⁴⁶ This is deeply problematic as it has the potential to contribute to a culture in which CANH is routinely refused even for cases where it is obvious that it could be beneficial and patients could live for many weeks or months. In which case refusing CANH can potentially become a contributing cause of death.

⁴² Raijmakers NJH *et al.* (2011) *Op. Cit.*

⁴³ Dev R *et al.* (2012) *Op. Cit.*

⁴⁴ Druml C *et al.* (2016) ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition* 35:545-556. See Statement 9, p547.

⁴⁵ Bruera E *et al.* (2013) Parenteral Hydration in Patients With Advanced Cancer: A Multicenter, Double-Blind, Placebo-Controlled Randomized Trial. *J Clin Oncology* 31(1):111-118.

⁴⁶ Maeda I *et al.* (2016) Effect of continuous deep sedation on survival in patients with advanced cancer (J-Proval): a propensity score-weighted analysis of a prospective cohort study. *Lancet Oncol* 17: 115–22.

For someone imminently dying, expected to live days or a week at most, the benefits of CANH may be equivocal. The problem is, all that is required to refuse CANH is a flawed prediction that death is imminent. The accepted inaccuracies inherent in making such predictions, combined with the pressures coming from various sources to hasten death - sometimes even from the patient him or herself – mean there is a significant incentive to deny CANH.

Hastening death has been identified in three studies that were not part of the reviews cited above. In a Belgian study by Chambaere *et al.*, physicians who were surveyed indicated that their decision to forgo CANH resulted in life shortening in 77% of cases (1 month or more in 6.6%).⁴⁷ These findings were confirmed in a study from The Netherlands where all cases of the withholding or withdrawal of CANH were considered to have shortened life, 13% by between 1 and 6 months, and 4% by more than 6 months.⁴⁸ These results strongly suggest that the withholding/withdrawal of CANH has constituted the cause of death, having been undertaken many weeks and sometimes months before death was expected.

A different type of study looking at the practices of foregoing CANH in six European countries found that the rate varied from 2.6% to 10.9% of all deaths (that is, taken from a random sample of death certificates). The rates were highest in The Netherlands, Belgium and Switzerland, compared with Denmark, Italy and Sweden. The former three countries have a more liberal culture with regard to the intentional ending of life, possibly explaining the difference.

Overall, these results together imply that, despite the limited number of studies involved, the forgoing of CANH has occurred outside of the context of imminent death and has therefore become the proximal cause of death.

Despite some of the complexities and uncertainties about the research evidence, patients and relatives often have a positive view of CANH. They see hydration as enhancing comfort, dignity and quality of life.

Patients and caregivers saw hydration as improving patients' comfort by reducing pain; enhancing the effectiveness of pain medication; and nourishing the body, mind, and spirit.⁴⁹

This highlights the importance of communication with patients and families, but possibly more important is the fact that patients and families may see different value in the administering of hydration compared with medical staff.

Distress caused to families by the withholding/withdrawal of CANH can be significant⁵⁰, and because of this, it has been suggested that on the grounds of the well being of families, hydration at least may be more appropriate to use than current practice might suggest.

Even when death is inevitable, the simple and safe measure of a subcutaneous infusion may not be futile. It may be of some help to the patient, and may comfort the relatives, calm their fears, and reduce the incidence of pathological grief and post-traumatic stress reactions. It may also reassure all concerned that the patient died of his or her disease, rather than the treatment.⁵¹

This view is also supported by the *American Hospice and Palliative Nurses Association*, who acknowledge that “in certain situations, [C]ANH may be continued to honor the patient’s goals of care, beliefs, or

⁴⁷ Chambaere K *et al.* (2014) Forgoing artificial nutrition or hydration at the end of life: a large cross-sectional survey in Belgium. *Journal of Medical Ethics* 40(7):501-504.

⁴⁸ Onwuteaka-Philipsen BD *et al.* (2001) Withholding or withdrawing artificial administration of food or fluids in nursing-home patients. *Age & Ageing* 30:459-465.

⁴⁹ Cohen MZ *et al.* (2012) The Meaning of Parenteral Hydration to Family Caregivers and Patients With Advanced Cancer Receiving Hospice Care. *J Pain Symptom Management* 43:855-865.

⁵⁰ Dev R *et al.* (2012) *Op. Cit.*

⁵¹ Craig GM (1996) On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues. *Journal of Medical Ethics* 22:147-153.

values despite the lack of supporting evidence for its efficacy.”⁵² Nurses are naturally key stakeholders in care at the end of life as well as often having a role as participants in the decision-making process concerning CANH. They can feel “guilt and sadness” like family members⁵³, and are also uncertain about whether CANH should be viewed as basic care or medical treatment.⁵⁴ Uncertainty about when to use CANH has been expressed by nurses more generally, along with some misconceptions about the practice itself and its efficacy.^{55,56}

Concerns about intentionally hastening death by the withholding/withdrawal of CANH have been sharpened over the past few decades by the increasing use of sedation in end of life care. Sedation clearly has a place, but its misuse, often intentionally in conjunction with forgoing food and fluids, has become a means of euthanasia by omission, what some have called ‘slow euthanasia’, or simply ‘terminal sedation’ - use of the word ‘terminal’ referring to the goal of sedation rather than the phase of life in which it is applied.

The next section will look at the use of sedation at the end of life, using the commonly accepted term ‘palliative sedation’, drawing distinctions between its legitimate use and euthanasia by omission (‘slow euthanasia’ or ‘terminal sedation’).

Palliative Sedation

The primary purpose of sedation in any medical context is to treat conditions that are distressing. Sedation is used in a wide variety of circumstances, but in particular at the end of life, when there is suffering that cannot be controlled by any other available means – that is, the symptoms are refractory to treatment - sedation is sometimes used.

Palliative Sedation Ethics

In a recent issue of *Theoretical Medicine and Bioethics*, a series of papers^{57,58,59,60,61,62} were produced that were dedicated to the question of the appropriate use of palliative sedation.⁶³

The authors first noted that there are two differing ways that suffering is to be understood at the end of life. The first may be termed neuro-cognitive suffering, which is essentially that type of suffering that medicine aims to relieve. It includes physical pain, dyspnea (shortness of breath), nausea, seizures, delirium, and depression, amongst other things.⁶⁴ The second may be called existential or ‘agent-narrative’ suffering, and includes ‘loneliness, alienation, rejection, guilt, despair, doubt and self-

⁵²Buck HG (2012) Refusing artificial nutrition and hydration in advanced illness. DOI-10.1097/01.NURSE.0000418621.22089.07

⁵³ Bryon E *et al.* (2012) ‘Because we see them naked’ – Nurses experiences in caring for hospitalized patients with dementia: considering artificial nutrition or hydration (ANH). *Bioethics* 26(6):285–295.

⁵⁴ Bryon E *et al.* (2008) Nurses’ Attitudes towards Artificial Food or Fluid Administration in Patients with Dementia and in Terminally Ill Patients: A Review of the Literature. *Journal of Medical Ethics* 34(6):431-436.

⁵⁵ Ke L-S *et al.* (2008) Knowledge, Attitudes, and Behavioral Intentions of Nurses Toward Providing Artificial Nutrition and Hydration for Terminal Cancer Patients in Taiwan. *Cancer Nursing* 31(1):67-76.

⁵⁶ Smith L *et al.* (2015) Instrument Validation and Measurement of Home Healthcare Nurses’ Knowledge of Artificial Nutrition and Hydration at End of Life. *Home Healthcare Now* 33(1):38-43.

⁵⁷ Sulmasy DP (2018) Sedation and care at the end of life. *Theoretical Medicine and Bioethics* 39:171–180.

⁵⁸ Cavanaugh TA (2018) Proportionate palliative sedation and the giving of a deadly drug: the conundrum. *Theoretical Medicine and Bioethics* 39:221–231.

⁵⁹ Meilaender G (2018) Comforting when we cannot heal: the ethics of palliative sedation. *Theoretical Medicine and Bioethics* 39:211–220.

⁶⁰ Curlin FA (2018) Palliative sedation: clinical context and ethical questions. *Theoretical Medicine and Bioethics* 39:197–209.

⁶¹ Farrow D (2018) Reckoning with the last enemy. *Theoretical Medicine and Bioethics* 39:181–195.

⁶² Sulmasy DP (2018a) The last low whispers of our dead: when is it ethically justifiable to render a patient unconscious until death? *Theoretical Medicine and Bioethics* 39:233–263.

⁶³ Sulmasy DP (2018) *Op. Cit.*

⁶⁴ Sulmasy DP (2018a) *Op. Cit.*

loathing'.⁶⁵ The question of the first being within the remit of palliative sedation is generally uncontroversial; however, the role of palliative sedation when it comes to existential distress is more controversial, and amongst these authors there were somewhat differing perspectives.

Sulmasy notes that several subtle shifts have taken place that have given rise to the much more widespread use of sedation at the end of life. The first was a move from symptom control to the suppression of the conscious awareness of the symptoms, and the second was the inclusion of existential distress as warranting treatment by sedation.⁶⁶

Both these changes not only widened the scope for the use of sedation in general, but perhaps more importantly, made it easier to legitimize the use of sedation to induce complete unconsciousness and for that to be carried through till death.

Sulmasy considers there to be three types of ways in which sedation can be used. These are:

- Proportionate sedation, which entails the use of sedation that is proportionate to the symptoms and relies on double effect reasoning. It is to accept sedation as an unintended side effect of the relief of neurocognitive suffering. Use of sedation in this way is often light, intermittent and strives to avoid complete unconsciousness, recognising the high value that medicine has always placed on being conscious.
- Parsimonious direct sedation, which entails sedation that is intended to lead to an unconscious state. Use of sedation in this way for the relief of extreme neuro-cognitive suffering that effectively overwhelms the ability to operate as a conscious being, is legitimate in rare circumstances. The suppression of consciousness is not intended to proceed till death occurs, but in such rare circumstances, it can be accepted that it may.
- Sedation to unconsciousness and death, sometimes called continuous deep sedation (CDS). This entails the *intention* to sedate to total unconsciousness until death occurs. It may or may not involve the withholding/withdrawal of all food and fluids. Depending on the circumstances surrounding how CDS is implemented, it is possible, and perhaps likely, that there is an explicit or implicit intention to hasten death.

The first two are considered morally legitimate and consistent with the goals of medicine, whereas the last is not. Under certain conditions, CDS may constitute a form of euthanasia. Nevertheless, it is considered morally legitimate by some, most often by those who are in any case in favour of assisted suicide and euthanasia by commission (eg by lethal injection). Accepting that CDS with an intention to hasten death is morally legitimate is sometimes accompanied by the claim that because it is not so morally different to euthanasia by commission, which is true, the latter should be chosen as a more humane and quicker means of death, and to “save a lot of time and energy for health-care workers, as well as resources, and spare family members the waiting period”.⁶⁷ In contrast, the Dutch consider CDS as distinctly different to euthanasia, and a form of palliative sedation that falls within the remit of normal medical practice.⁶⁸ The Dutch Guidelines on palliative sedation appear to be at pains to draw a distinction between the two, a consequence of which has been the failure to subject CDS to the kind of ethical scrutiny it demands.⁶⁹ The Dutch Guidelines also consider the administration of CANH during CDS as ‘medically futile’, acknowledging that denying CANH during CDS would likely hasten death in an unknown number of cases. Designating CANH as ‘medically futile’ during CDS is in reality a belief expressed in the Dutch Guidelines that there is no point using CANH when a decision has already been

⁶⁵ *Ibid.*

⁶⁶ *Ibid.*

⁶⁷ Materstvedt LJ & Bosshard G (2009) Deep and continuous palliative sedation (terminal sedation): clinical-ethical and philosophical aspects. *Lancet Oncol* 10:622–27.

⁶⁸ Royal Dutch Medical Association (KNMG) (2009) *Op. Cit.*

⁶⁹ Janssens R *et al.* (2011) Palliative sedation: not just normal medical practice. Ethical reflections on the Royal Dutch Medical Association’s guideline on palliative sedation. *Journal of Medical Ethics* 38:664–668.

made to use CDS to hasten death – CANH would likely sustain and prolong life, so it is seen as ‘medically futile’.

On the difficult question of whether sedation should be used to treat existential or ‘agent-narrative’ suffering, Sulmasy and others believe that sedation is inappropriate for this kind of suffering, that instead, “palliative care of agent-narrative suffering should be restorative”.⁷⁰ That is to say, the

... aim ought to be to promote opportunities for growth at the end of life, to the extent possible, making room for those “last low whispers.” ... The proper means of assisting patients with agent-narrative suffering ... include presence, listening and communication.⁷¹

Sulmasy also notes a disconnection between sedation in this context compared with others.

If one would not prescribe a barbiturate-induced coma for despair or existential angst outside of a terminal context, why would such measure suddenly be indicated when a patient is dying?⁷²

The point is fair, because there is no shortage of existential suffering in human experience at just about any stage of life, for which sedation is not seen as a solution. The role of the doctor does not extend to all problems of the human condition. Moreover, sometimes this type of suffering has resolution even at the end of life. Suffering from broken relationships, angst related to the loss of meaning, or spiritual distress related to matters like repentance and forgiveness can all be held in hope of resolution and/or redemption if opportunities are sought and answered to address them.

In summary, sedation at the end of life should be aimed at symptom relief with the acceptance that on rare occasions this may mean sedation to unconsciousness that continues through to death, as a foreseen but unintended consequence. The term ‘rare’ in medical settings typically means at a level of between 0.01% and 0.1%, that is, from 1 in 10000 to 1 in 1000.⁷³ As noted above, *intentional* CDS to death is unethical and should not occur at all. Even more clearly unethical is when CDS, coupled with forgoing CANH for no good clinical reason, includes an intention to hasten death in which case it is ‘slow euthanasia’ (euthanasia by omission).

Palliative Sedation Statements and Guidelines

In their analysis of international guidelines and statements on palliative sedation, Gurschick *et al.* note that their development is relatively recent⁷⁴, and can be traced to the year 2000 when a position statement was published by the *American College of Physicians – American Society of Internal Medicine (ACP-ASIM) End-of-Life Care Consensus Panel*.⁷⁵ From that point on, Guidelines or Statements have been produced by a variety of peak bodies, including the *European Association for Palliative Care*⁷⁶, the *American Academy of Hospice and Palliative Medicine*⁷⁷, and the *Royal Dutch Medical Association*⁷⁸, to name just a few.

⁷⁰ Sulmasy DP (2018a) *Op. Cit.*

⁷¹ *Ibid.*

⁷² *Ibid.*

⁷³ These definitions have been determined by the Council for International Organizations of Medical Sciences (CIOMS), an organisation established by WHO and UNESCO. They are described in the CIOMS training manual, which can be found at http://www.who.int/medicines/areas/quality_safety/safety_efficacy/trainingcourses/definitions.pdf Accessed 1 Nov 2018.

⁷⁴ Gurschick L *et al.* (2015) Palliative Sedation: An Analysis of International Guidelines and Position Statements. *American Journal of Hospice & Palliative Medicine* 32(6):660-671.

⁷⁵ Quill TE & Byock IR (2000) Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids. *Ann Intern Med.* 132:408-414.

⁷⁶ Cherny NI & Radbruch L (2009) European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Medicine* 23(7):581–593.

⁷⁷ American Academy of Hospice and Palliative Medicine. (2013) Statement on palliative sedation. See <http://aahpm.org/positions/palliative-sedation> Accessed 11 Dec 2018.

⁷⁸ Royal Dutch Medical Association (KNMG) (2009) *Op. Cit.*

There are several core matters that the guidelines all have in common. These are that the patient must be in the terminal stage of a terminal illness (death must be imminent), the physical symptoms must be unable to be treated by any other means, the intention of sedation is symptom relief, informed consent must be obtained, an interdisciplinary team must make the decision, documentation must be thorough, and there must be no intention to hasten death (the principle of double effect can be used to justify the possibility that death may be hastened unintentionally).⁷⁹ This level of agreement does confer a significant level of conformity across guidelines.

However, there remain some significant inconsistencies on issues that have significant ethical and practical ramifications.

First, the guidelines allow for variation in the level and pattern of sedation, so that as Gurschick *et al.* note, there is in reality a lack of consistency about what palliative sedation actually means, leaving it open in some of the guidelines for interpretation about matters like proportionality in symptom control as well as when CDS may be permissible. The concern here is that intentional deep sedation may well end up being carried out with an intention to hasten death and that death itself becomes the measure of successful implementation of this form of sedation. When food and fluids are withheld or withdrawn in conjunction with CDS the intention to hasten death may especially be an issue, where the removal could signify a failure to value sufficiently the patient's life.

Second, the time at which palliative sedation may be initiated prior to the expected time of death varies from one guideline to another - from hours and days to weeks. For example, the Dutch guidelines say up to 2 weeks, but the European ones say "hours to days". But this guidance is of minimal usefulness because of the inherent inaccuracy involved in making such a prediction, as noted earlier, so that coming up with a figure is wide open to abuse. An intention to hasten death could be masked by a prediction of a few hours or days till death and a decision to forgo food and fluids - with recourse to the equivocal benefit of CANH in the last few days or week of life as described above. Sedation could then be initiated - in keeping with the guidelines - on the grounds of some degree of distress, and if deep enough, would then render impossible any response from the patient until death occurred.

Third, the documents vary on the nature of the symptoms for which palliative sedation may be used, in particular whether palliative sedation may be used to treat existential distress. As noted earlier, this is an area of some debate, and while ethicists like Sulmasy consider sedation for this reason to be an inappropriate target for a medical intervention, others do not, and in several of the guidelines, such as the *Dutch (KNMG)* and *Hospice and Palliative Nurses Association*⁸⁰, existential distress is specifically mentioned as a reason for using palliative sedation. Others, such as those of the *American Medical Association*, do not consider sedation for existential distress appropriate, while in some guidelines the matter is not raised at all.

Fourth, the guidelines treat differently the question of CANH. Given the controversial nature of the use of CANH at the end of life, it is not surprising that there is a significant variation between the guidelines, and a certain amount of lack of clarity, if not outright vagueness. Notably, the Dutch and one other guideline (that of the *National Comprehensive Cancer Network*) are the only ones that require discontinuation of CANH. And when this happens weeks before death is expected, in reality it can become the proximal cause of death. In contrast, the majority of guidelines say that decisions regarding palliative sedation and those regarding CANH should be made separately. That is to say, decisions about either palliative sedation or CANH should be based on considerations of clinical effectiveness, risks and adverse events. Even so, the case for inclusion of clear guidance in the guidelines is easy to make as the context of the end of life is one in which both arise with significant frequency.

Finally, there are significant inconsistencies about the types of medications that should be used as well as the specific regimes. The detail on this is complex, but suffice to say that the regimes used do have

⁷⁹ Gurschick L *et al.* (2015) *Op. Cit.*

⁸⁰ Kirk TW & Mahon MM (2010) Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee. National hospice and palliative care organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. *J Pain Symptom Management* 39(5):914-923.

significant ethical significance because of the specific ways in which they work and the target of their use. For example, the use of opiates for sedation may be inappropriate as increasing the dose may hasten death whereas use of another sedative may achieve symptom relief whilst not necessarily hastening death.

Other analyses of the various guidelines have been done⁸¹, some more widely⁸², and have come to similar conclusions as Gurschick *et al.* As will be seen in the next section on actual practice, the need for guidelines that are more consistent is imperative given that it appears that practices in palliative sedation are growing more divergent rather than less. Indeed, at least one commentator has argued that because practice has shifted so far from ethically sound norms, the term 'palliative sedation' should no longer be used, so confused has it become, particularly in relation to euthanasia by omission.⁸³ Others have gone further and suggested that because practice has deviated from the guidelines, the guidelines themselves are too restrictive and should be changed.⁸⁴

Before moving on, one final and related point needs to be made. Gurschick *et al.* argue that the use of opiates for pain control, and benzodiazepines for managing the symptoms of agitation, have long been a part of quality palliative care, since well before the term palliative sedation came along. Such *undefined* symptom management may be occurring on a relatively constant basis without reference to the term palliative sedation.

The intermittent titrating of both the opioids and benzodiazepines, each for their own indication, is discussed as "symptom management," with a side effect of sedation, not with sedation as the primary intent. It is the intention in this common scenario that exempts the intervention from being defined here as "palliative sedation." Maybe there is not as much undefined practice happening as previously thought; what to some may look like palliative sedation is actually symptom management in the actively dying, with physiologic sedation and a sedative side effect from medications.⁸⁵

Although this is important to acknowledge, any such undefined practice is well within the ethically acceptable framework of proportionate palliative sedation as defined by Sulmasy. The uncertainty comes in looking for the incidence of a practice that may be routine, and routinely not identified as palliative sedation. To the extent that this occurs, whether called undefined practice or palliative sedation, it can be considered ethically acceptable and not in the arena of concern raised by practices such as intentional CDS that often comes within the province of euthanasia.

Palliative Sedation in Practice

There are two main reasons why interpreting the findings of research studies on the prevalence of palliative sedation is complicated.

First, because the term has been understood in different ways at different times and places. What some researchers call palliative sedation may encompass all three of the categories identified by Sulmasy. Others specifically refer to proportionate sedation alone, Sulmasy's first category, or to CDS alone, Sulmasy's third category. Moreover, the critical question of intention, which can be difficult to determine unless e.g. verbally expressed, has not often been properly examined in many studies. So for example, a study may ask physicians whether they instituted CDS, but fail to ask critical questions that might distinguish CDS that intentionally hastens death from deep sedation in rare cases that would fall

⁸¹ Schildman E & Schildman J (2014) Palliative Sedation Therapy: A Systematic Literature Review and Critical Appraisal of Available Guidance on Indication and Decision Making. *J Palliative Medicine* 17(5):601-612.

⁸² Abarshi E *et al.* (2017) International variations in clinical practice guidelines for palliative sedation: a systematic review. *BMJ Supportive & Palliative Care* 7:223-229.

⁸³ Twycross R (2017) Second thoughts about palliative sedation. *Evid Based Nurs* 20(2):33-34.

⁸⁴ den Hartogh G (2016) Sedation Until Death: Are the requirements laid down in the guidelines too restrictive? *Kennedy Inst Ethics J* 26(4):369-397.

⁸⁵ Gurschick L *et al.* (2015) *Op. Cit.*

within Sulmasy's second category, parsimonious direct sedation – the latter ethical, but the former not. Even so, it is almost certain that almost all reports of CDS fall into the former category, given the expected rarity of ethically legitimate parsimonious direct sedation alongside the relatively high prevalence of CDS in some jurisdictions.

Second, because the way data is expressed varies from one study to another. Some will report the incidence of palliative sedation as a percentage of all participants in the study group, which could be hospice or hospital residents, or specifically palliative care patients in a home setting. Alternatively, it may be expressed as the percentage of all deaths in an area or country. Moreover, a study may survey practitioners from a particular specialty, for example GPs or palliative care specialists, each of whom may behave somewhat differently not only because of their level of experience, but because of the type of patient who falls within their care, and the particular culture within which they operate.

In their review of palliative sedation, Claessens *et al.* lament the “... huge number of contradictions in the international empirical literature on the subject.”⁸⁶

Nevertheless, whilst negotiating this variable landscape is difficult, it is possible to gain a sense of what is happening and how in some jurisdictions it has changed through time. However, one should be careful about the simplistic and unqualified use of figures to compare experiences in one time, setting or country with another.

Some earlier studies primarily from before the year 2000 will be examined first, which broadly tend to include all cases of sedation. In general, the practice of CDS does not take a prominent place, and it is reasonable to conclude, particularly given the descriptions within the studies, that sedation was directed at proportionate symptom relief without an intention to hasten death, although it is not possible to be definitive. Eleven studies from this era were considered in a review by Rousseau, where palliative sedation was directed only at refractory symptoms and defined as specifically excluding an intention to hasten death.⁸⁷

None of the eleven studies came from The Netherlands where the intentional hastening of death was considered a legitimate part of medical practice at that time. Various studies reporting on end of life practices in the Netherlands included a question about CDS, but only beginning in 2005, where the incidence was 8.2% of all deaths.⁸⁸ Prior to 2005, in the reports of 1990, 1995 and 2001, while there was no CDS question, it is possible that an unknown proportion of cases falling under the heading ‘Intensified alleviation of symptoms’ were in fact cases of CDS. The likelihood that CDS was happening to a significant extent in The Netherlands at this time was confirmed in a study by Rietjens *et al.* that analysed responses from physicians in 2000 and 2001. In that study, 10% of all deaths were the result of ‘terminal sedation’, the term used to describe CDS until death specifically entailing the withholding/withdrawal of CANH.⁸⁹ In about two thirds of cases, doctors indicated that there was an intention to hasten death.

What is perhaps the more important piece of information regarding CDS in The Netherlands, is that its incidence increased steadily from 8.2% in 2005 to 12.3% in 2010, then 18.3% in 2015, of all deaths.^{90,91} Similarly, in Belgium, even though euthanasia legislation was not enacted until 2002, cases of CDS increased from 8.2% in 2001 to 14.5% in 2007, then 12% in 2013, as a percentage of all deaths.^{92,93}

⁸⁶ Claessens P *et al.* (2008) Palliative Sedation: A Review of the Research Literature *J Pain Symptom Management* 36:310-333.

⁸⁷ Rousseau P (2000) The ethical validity and clinical experience of palliative sedation. *Mayo Clin Proc* 75:1064-1069.

⁸⁸ van der Heide A *et al.* (2017) End-of-Life Decisions in the Netherlands over 25 Years. *New Engl J Med* 377(5):492-494.

⁸⁹ Rietjens JAC *et al.* (2004) Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. *Ann Intern Med* 141(3):178-185.

⁹⁰ Onwuteaka-Philipsen BD *et al.* (2012) Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 380:908–15.

⁹¹ van der Heide A *et al.* (2017) *Op. Cit.*

⁹² Bilsen J *et al.* (2009) Medical End-of-Life Practices under the Euthanasia Law in Belgium. *New Engl J Med* 361(11):1119-1121.

⁹³ Chambaere K *et al.* (2015) Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium. *New Engl J Med* 372(12):1179-1181.

Unlike in The Netherlands, there was a decline in CDS from 2007 to 2013 in Belgium; however, this occurred at the same time as an increase in euthanasia from 1.9% to 4.6% of all deaths.⁹⁴

Returning to the studies reviewed by Rousseau, the extent to which palliative sedation was happening in other countries during the 90s varied significantly, and it is in the very early 90s that debate really began about the extent of the use of, or need for, sedation, and specifically sedation that might lead to unconsciousness until death (CDS). Possibly the first report in the literature, by Ventafridda *et al.* found that 52.5% of patients in an Italian home-based palliative care program were sedated to unconsciousness, specifically for symptom management.⁹⁵ This high figure took many researchers by surprise and prompted research into practices in other countries. The following year, Fainsinger *et al.* reported an incidence of 16% in a Canadian hospital-based palliative care unit.⁹⁶ Various other studies from the 90s reveal figures between these two.^{97,98,99,100}

Two important facts emerge from these papers, and other more recent ones. First, sedation was only used in the last few days of life. In a separate study by Greene and Davis, the average time of sedation was 23 hours, with carefully titrated doses that 'would have barely caused drowsiness in a healthy patient.'¹⁰¹ Second, in several studies, there was no difference in survival time between sedated and non-sedated patients^{102,103,104} (25 days versus 23 days¹⁰⁵; 28 days versus 25 days¹⁰⁶). In fact, in a separate study, sedated patients actually survived longer than non-sedated patients.¹⁰⁷ Clearly, for patients to survive nearly a month suggests careful attention to hydration. In this context, it was argued that palliative sedation was used for proportionate symptom control rather than hastening death, a fact supported by the maintenance of hydration in the majority of cases. Stone *et al.* concluded that "... the need for sedation is an indicator of impending death and not a cause of premature death".¹⁰⁸

Nevertheless, an incidence of sedation between 16% and 52.5%, some or all of which cases were sedation to unconsciousness, is very high and hard to square with the expectation by Sulmasy that sedation to unconsciousness - as in parsimonious direct sedation, or perhaps some cases of proportionate sedation that resulted in sedation to consciousness - should be a rare occurrence.

On this point, others have found remarkably different rates of any sedation. In their research of a hospital-based palliative care team over the space of one year, Fainsinger describes just 2 out of 278 terminally ill patients who required 'a deliberately sedating approach'.¹⁰⁹ At 0.7%, this is far below the rates described by others, leading Fainsinger to question,

⁹⁴ *Ibid.*

⁹⁵ Ventafridda V *et al.* (1990) Symptom prevalence and control during cancer patients' last days of life. *J Palliat Care* 6(3):7-11.

⁹⁶ Fainsinger R *et al.* (1991) Symptom control during the last week of life on a palliative care unit. *J Palliat Care* 7(1):5-11.

⁹⁷ Stone P *et al.* (1997) A comparison of the use of sedatives in a hospital support team and in a hospice. *Palliative Medicine* 11:140-144.

⁹⁸ Morita T *et al.* (1996) Sedation for symptom control in Japan: The importance of intermittent use and communication with family members. *J Pain Symptom Management* 12(1):32-38.

⁹⁹ Peruselli C *et al.* (1999) Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliative Medicine* 13:233-241.

¹⁰⁰ Cameron D *et al.* (2004) Use of sedation to relieve refractory symptoms in dying patients. *S Afr Med J* 94: 445-449.

¹⁰¹ Greene WR & Davis WR 1991 Titrated intravenous barbiturates in the control of symptoms in patients with terminal cancer. *Southern Med J* 84(3):332-337.

¹⁰² Stone P *et al.* (1997) *Op. Cit.*

¹⁰³ Maltoni M *et al.* (2009) Palliative sedation therapy does not hasten death: results from a prospective multicenter study. *Annals of Oncology* 20:1163-1169.

¹⁰⁴ Maltoni M *et al.* (2012) Palliative Sedation in End-of-Life Care and Survival: A Systematic Review. *J Clin Oncol* 30:1378-1383.

¹⁰⁵ Ventafridda V *et al.* (1990) *Op. Cit.*

¹⁰⁶ Chiu T-Y *et al.* (2001) Sedation for Refractory Symptoms of Terminal Cancer Patients in Taiwan. *J Pain Symptom Management* 21(6): 467-472.

¹⁰⁷ Mercadante S *et al.* (2009) Controlled Sedation for Refractory Symptoms in Dying Patients *J Pain Symptom Management* 37(5):771-779.

¹⁰⁸ Stone P *et al.* (1997) *Op. Cit.*

¹⁰⁹ Fainsinger RL (1998) Use of sedation by a hospital palliative care support team. *J Palliative Care* 14(1):51-54.

Can we really feel comfortable that the need to use sedation is always an indicator of impending death, that it is not sometimes a cause of premature death, and that reversible causes for the intractable symptom complex have all been excluded?¹¹⁰

Hence, even without an identified intention to hasten death, there were large variations in practice with respect to the use of sedation for intractable or refractory symptoms. Indeed as the quote suggests, perhaps more diligence regarding creative ways to treat symptoms initially thought to be intractable may have diminished resorting to sedation.

Fainsinger's concerns were corroborated by Peruselli *et al.* in their study of Italian palliative care practices, where the rate of 'total pharmacological sedation' (to unconsciousness) ranged from 0% to 60%, revealing quite different approaches to the use of sedation depending on the facility.¹¹¹ It should be noted that sedation was within the last 12 hours of life only, but nevertheless, the wide variation prompted concern from the authors that,

... the choice to sedate the patient may reflect the provider's behaviour or services' policy rather than the patients' preferences or needs.¹¹²

This suggests that sedation was not always aimed at symptom control, or if it was, the notion of level of sedation required and for what symptoms or severity, varied greatly. And again, even though there was no clear evidence of an intention to hasten death, especially since sedation was restricted to the last 12 hours of life, such a wide variance suggests that at the time there was minimal agreement on any accepted standards.

On the question of intentionally hastening death by using sedation, concern had been mounting during the 90s that such practices were growing in frequency.^{113,114} This was partly because of an awareness of what was happening in The Netherlands, but also perhaps because sedation was beginning to be used in ways and with a frequency that suggested death may have been intentionally hastened, even if there was no overt admission that it was. Some were quick to respond that this was not the case in their experience. For example, in Japan, Morita *et al.* studied all terminally ill cancer patients admitted to their palliative care unit and found that sedation was solely directed at symptom control, hydration was maintained in the majority of patients, and there was no evidence of an intention to hasten death.¹¹⁵ Similarly, in a global survey that mainly included palliative care experts from the UK and Canada, all respondents indicated that sedation to unconsciousness, whilst necessary from time to time, was for symptom control and not to hasten death.¹¹⁶ A majority (77%) had used 'terminal sedation' during the past year, but usually infrequently, and in a way likely to be consistent with Sulmasy's 'parsimonious direct sedation'.

In their study of the use of palliative sedation in a German hospital palliative care unit over the period from 1995 to 2002, Muller-Busch *et al.* found that a total of 14.6% of patients had received some degree of sedation during their last 48 hours of life.¹¹⁷ Doses were slowly increased until symptom control was achieved, then lowered to allow observation, feeding, communication, and assessment. Careful attention was directed towards a level of sedation that maximized communication, indicative of the desire to draw as clear a distinction as possible between such palliative care and CDS.

The Muller-Busch *et al.* report is close to a paradigmatic example of how palliative sedation should proceed. They did however find an increase in palliative sedation from 7% in 1995 to 19% in 2002, most of the difference resulting from the increasing use of sedation for psychological distress, which includes

¹¹⁰ *Ibid.*

¹¹¹ Peruselli C *et al.* (1999) *Op. Cit.*

¹¹² *Ibid.*

¹¹³ Billings JA & Block SD (1996) Slow euthanasia. *J Palliative Care* 12(4):21-30.

¹¹⁴ Quill TE *et al.* (1997) Palliative options of last resort. A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 278:2099-2104.

¹¹⁵ Morita M *et al.* (1999) Do hospice clinicians sedate patients intending to hasten death? *J Palliative Care* 15(3):20-23.

¹¹⁶ Chater S *et al.* (1998) Sedation for intractable distress in the dying – a survey of experts. *Palliative Medicine* 12:255-269.

¹¹⁷ Muller-Busch HC *et al.* (2003) Sedation in palliative care – a critical analysis of 7 years experience. *BMC Palliative Care* 2:2.

existential distress. Over the time period an increasing number of patients requested sedation, making this the likely cause, at the same time as it placed doctors in a difficult position identifying what the proper limits of palliative sedation should be.

Despite all of the above observations, including the expansion into sedation for existential distress, concerns that palliative sedation has been increasingly including CDS had been growing. The way that sedation at the end of life was being used in The Netherlands and Belgium, along with various trends towards the wider acceptance globally of euthanasia and assisted suicide seem to be the drivers for the growing use of CDS.

This is being confirmed in the studies that have begun to emerge in the last decade and a half. It needs to be noted however, that some caution is necessary with prevalence figures for CDS. Some authors are concerned that “... biases from extrinsic, contextual factors impeding accuracy of reported prevalence tend to remain unidentified and unaddressed.”¹¹⁸ It can therefore be more helpful to compare changes through time in one specific context.

As noted above, in the two key European legislatures where euthanasia has been established for some time, CDS has been increasing in frequency, with the exception of Belgium where there was a small decline from 2007 to 2013. There are not many studies from other countries, but some useful data taken at the same time can provide a few comparisons. For example, in one survey from 2006 (with study data from 2001 and 2002), Miccinesi *et al.* found the following rates of CDS as a percentage of all deaths: Belgium 8.2, Denmark 2.5, Italy 8.5, The Netherlands 5.7, Sweden 3.2, and Switzerland 4.8.¹¹⁹ If the percentage of CDS cases where CANH was forgone are taken into account, the percentage of all deaths with CDS *and* no CANH, are as follows: Belgium 3.2, Denmark 1.6, Italy 3.0, The Netherlands 3.6, Sweden 1.8, and Switzerland 2.9. The only difference that appears to be significant is that Denmark and Sweden have lower rates than the other countries.

While there are studies that will be addressed later about the experiences of physicians and others with CDS, with regard to actual attempts to ascertain prevalence, there appears to be data from few other countries, one being the UK. There have been studies from Australia¹²⁰ and New Zealand¹²¹ that have looked at the prevalence of end-of-life decisions, but questions about CDS were absent in both. In any case, the methodology used in the Australian study, a methodology similar to that used in the NZ study, was strongly and rightly criticised.¹²²

In the UK, in two separate studies by Searle and co-workers, the prevalence of CDS in 2007-2008 was found to be 16.5%¹²³ and 17%.¹²⁴ In the second of these studies, where the UK figure was 17%, data from The Netherlands (2005) and Belgium (Flanders only, 2007) was also collected and found to be 8% and 15% respectively (in keeping with the figures cited above). This shows that the prevalence of CDS in the UK was higher at approximately the same time compared to either The Netherlands or Belgium.

However, it is important to note that the UK data was collected in a different manner, where a survey was sent to a random sample of UK doctors. In contrast, in The Netherlands and Belgium, data was collected by death certificate analysis and subsequent targeting of doctors, leading to much higher response rates. Regarding the UK data, the authors note “it is possible that respondents included patients where sedation was an unintended side effect of the drugs given. This may have led to an

¹¹⁸ Papvasiliou E & Payne S (2015) Unaddressed biases in reported prevalence of continuous deep sedation until death. *J Clin Epidemiol* 68:1241-1243.

¹¹⁹ Miccinesi G *et al.* (2006) Continuous Deep Sedation: Physicians' Experiences in Six European Countries. *J Pain Symptom Management* 31(2):122-129.

¹²⁰ Khuse H *et al.* (1997) End-of-life decisions in Australian medical practice. *Med J Australia* 166:191-196.

¹²¹ Mitchell K & Owens RG (2003) National survey of medical decisions at end of life made by New Zealand general practitioners. *BMJ* 327:202-203.

¹²² Fisher A *et al.* (1997) End-of-life decisions in Australian medical practice. *Med J Australia* 166:506.

¹²³ Searle C (2009) End-of-life decisions in the UK involving medical practitioners. *Palliative Medicine* 23:198-204.

¹²⁴ Anquinet L *et al.* (2012) The Practice of Continuous Deep Sedation Until Death in Flanders (Belgium), The Netherlands, and the U.K.: A Comparative Study *J Pain Symptom Management* 44(1):33-43.

overestimation of the number of deaths involving continuous deep sedation.”¹²⁵ Hence, there should be some caution in making comparisons between the UK and other European countries, specifically those with permissive end-of-life cultures. Corroboration for this caution can be found in earlier work by Searle in 2004, where he concluded that “UK end-of-life decision-making is particularly collegiate and reflects caution about actions that significantly shorten life”¹²⁶, and that in the UK there is “... a culture of medical decision-making informed by a palliative care philosophy.”¹²⁷ Taken together, these observations throw some doubt on whether CDS is actually occurring at a greater frequency in the UK compared with countries like The Netherlands and Belgium.

Searle undertook another study of CDS in the UK, targeting some characteristics of the decision-making process, and found that “Doctors supporting legalisation of euthanasia or physician-assisted suicide, or who were nonreligious, were more likely to report using CDS.”¹²⁸

The general increase in cases of CDS appears most acute in Switzerland, where the rate has increased fourfold from 2001 to 2013 (6.7% to 24.5%).¹²⁹ In this study, when physicians were asked about intention to hasten death or not postpone death, there was an increase from 18.7% to 32%, and for these people, CDS was instituted for 9.6% of them in 2001 compared with 41.6% in 2013. Hence, without a change in any of the characteristics of the patient population, CDS with the intention to hasten death has dramatically increased from 2001 to 2013 in Switzerland, pointing to significant changes in patient/physician behaviour over that time, and therefore in the culture of how terminally ill patients are being treated. This can be taken to specifically indicate a dramatic increase in ‘slow euthanasia’ by a combination of CDS, forgoing of treatment (most likely CANH but not expressly identified in the study) and the ‘intensified alleviation of symptoms’.¹³⁰

There are some more detailed and nuanced observations about CDS that come from Belgium primarily, where the majority of the research in this area seems to have been done.

First, there is a difference in prevalence of CDS in the Dutch-speaking region of Flanders in the north compared with the southern French-speaking region (9.3% v 15.8%, respectively). This is the reverse of the prevalence of euthanasia (2.7% v 0.7%, respectively), leading the authors to wonder whether there may be a link between reluctance to perform euthanasia and greater readiness to perform CDS, noting nevertheless that their findings are inconclusive.¹³¹ Even if Flemish Dutch-speaking doctors are less inclined to use CDS, its prevalence in Flemish nursing homes more than trebled from 2.9% in 2001 to 9.4% in 2007¹³², possibly suggesting instead that readiness to perform euthanasia went hand in hand with the increasing use of CDS. Depending on the study, in these nursing homes, between just 1% and 6% of patients received CANH, suggesting that there was a common practice of instituting CDS along with forgoing food and fluids.^{133,134} This is completely different to a country like Singapore for example, where CANH is routinely provided during CDS unless there are clear clinical reasons not to do so.¹³⁵ Krishna notes that this is partly because of the “... prevailing sociocultural view of maintaining hydration

¹²⁵ *Ibid.*, 39.

¹²⁶ Searle C (2006b) Characteristics of end-of-life decisions: survey of UK medical practitioners. *Palliative Medicine* 20:653-659.

¹²⁷ Searle C (2006) National survey of end-of-life decisions made by UK medical practitioners *Palliative Medicine* 20:3-10.

¹²⁸ Searle C (2010) Continuous Deep Sedation in Medical Practice: A Descriptive Study. *J Pain Symptom Management* 39(1):44-53.

¹²⁹ Ziegler S *et al.* (2018) Continuous Deep Sedation Until Death—a Swiss Death Certificate Study *J Gen Intern Med* 33(7):1052–1059.

¹³⁰ *Ibid.*

¹³¹ Chambaere K *et al.* (2010) Continuous deep sedation until death in Belgium: A nationwide survey. *Arch Intern Med* 170:490-493.

¹³² *Ibid.*

¹³³ *Ibid.*

¹³⁴ Rys S *et al.* (2014) The Practice of Continuous Sedation Until Death in Nursing Homes in Flanders, Belgium: A Nationwide Study. *J Am Geriatr Soc* 62:1869–1876.

¹³⁵ Krishna LKR (2015) Addressing the concerns surrounding continuous deep sedation in Singapore and Southeast Asia: a palliative care approach. *Bioethical Inquiry* 12:461-475.

and nutrition even in the terminal stages of life amongst local patients and families.”¹³⁶ The forthcoming Singaporean Guidelines on CDS are expected to reflect this practice.¹³⁷

Second, CDS in Belgium is not restricted to adults. Of all deaths of children in Flanders in 2007/2008, 21.8% received CDS. This indicates a higher use of CDS amongst children compared with adults (14.5%). In 54% of the cases of children receiving CDS, CANH was administered until death, but there was an explicit intention or co-intention to end life in 23% of all cases.¹³⁸ This latter finding is disturbing, apart from being contrary to Belgian guidelines on CDS. Moreover, the authors expressed concern that in 91% of cases there was no request or consent by children to the CDS they received, which is contrary to the Belgian Law on Rights of the Patient (2002).¹³⁹ Approximately 28% of the children were 12 years and older, and would have been quite able to express a view on their treatment. The authors assert with understatement that this is “less than optimal”.

Third, in Belgium there are differences in the practice of CDS between specialties.¹⁴⁰ The 2007 rate of CDS by General Practitioners was 11.3% compared with 18.4% by medical specialists, a finding that is incongruent with the fact that GPs reported higher rates of severe symptoms – which would be expected to result in a *greater* use of CDS by GPs rather than a lower one. This of course rests on the assumption that CDS is being used primarily for symptom control, which is likely not the case. This possibility is given some weight by the finding that CANH was forgone in 97.2% of GP-initiated CDS, compared with just 36.2% for specialists. This suggests a routine forgoing of CANH by GPs when they initiated CDS, which is strongly suggestive of an intention to hasten death. When it came to the question of consent, medical specialists more often initiated CDS without the consent of the patient or family compared with GPs (27.9% v 4.7% of cases, respectively). The authors offer various reasons for the discrepancies, but nevertheless conclude that there were “wide deviations from professional guideline recommendations”.¹⁴¹

Fourth, in their review of the key determinants of CDS in different countries and contexts, van Deijck *et al.* found a range of relevant associations:

The following nine factors were found to be associated with the administration of continuous palliative sedation: younger age, male sex, having cancer, feelings of hopelessness, dying in a hospital, living in a Dutch speaking community setting, very nonreligious or extremely nonreligious physicians, physicians working in “other hospital” specialties, and physicians in favor of assisted death.

These factors tell us some important things about how CDS is being used, and several of them are similar to those associated with life-ending practices like euthanasia and physician assisted suicide. This might be taken to reinforce the concerns of many authors that CDS is often in fact ‘slow euthanasia’.

However, despite much of the research that has come out of Belgium, Claessens and co-workers have been at pains to argue that palliative sedation in Belgium is clearly not ‘slow euthanasia’.

Palliative sedation is neither slow euthanasia nor an ambivalent practice. It is an intentional medical treatment which is administered in a proportional way when refractory suffering occurs. It occurs in extraordinary situations and at the very end of the dying process.¹⁴²

¹³⁶ *Ibid.*, 466.

¹³⁷ *Ibid.*

¹³⁸ Pousset G *et al.* (2011) Continuous Deep Sedation at the End of Life of Children in Flanders, Belgium. *J Pain Symptom Management* 41(2):449-455.

¹³⁹ *Ibid.*

¹⁴⁰ Papavasiliou E *et al.* (2014) Physician-reported practices on continuous deep sedation until death: A descriptive and comparative study. *Palliative Medicine* 28(6):491-500.

¹⁴¹ *Ibid.*

¹⁴² Claessens P *et al.* (2012) Level of Consciousness in Dying Patients. The Role of Palliative Sedation: A Longitudinal Prospective Study. *American Journal of Hospice & Palliative Medicine* 29(3):195-200.

It is important that the work by Claessens is examined, because it casts such a contrary picture about CDS in Belgium that it could lead to seriously erroneous conclusions about what is really happening.

Claessens *et al.* found a low rate of palliative sedation of 7.5%, even though they used a very broad definition of palliative sedation. The level of sedation varied from light and intermittent to deep and continuous, starting on average 4 days before death, and for most patients evolving to deep sedation on average 2 days before death. This pattern of sedation is unlike the use of CDS reported by others. Moreover, there was no intention to hasten death, and no routine foregoing of CANH.¹⁴³ Indeed, oral food and fluid intake continued up till a few days before death.¹⁴⁴

Why is this picture so different to other research coming out of Belgium?

First, the studies are limited to palliative care units only, where staff are dedicated to a palliative care philosophy, and highly experienced in symptom control. This point is picked up by Claessens *et al.* in their reply to a letter¹⁴⁵ querying the low rate of palliative sedation in general and of continuous sedation in particular. Claessens *et al.* note that in their specific PCU the rate of “deep and continuous palliative sedation” dropped from 7% in 1999-2000 to 1-2% in all the years since then.¹⁴⁶ They argue that most other practitioners have a poor understanding of symptom control and may therefore more readily resort to CDS.

Second, even though all 29 PCUs in Flanders were approached by Claessens’ team, only 8 participated, 5 of which were Roman Catholic in origin, making them unlikely to sanction CDS with an intention to hasten death. Of all patients sedated, 83% were Christian.¹⁴⁷

Taken together, these observations suggest that what Claessens *et al.* are reporting upon is a unique setting where, rather than CDS, largely ethically appropriate proportionate palliative sedation is happening unlike what is occurring elsewhere in the country.

To a certain extent it is possible, and even likely, that CDS as practiced in some other countries may likewise not necessarily involve an intention to hasten death, but perhaps look more like ‘parsimonious direct sedation’.

In a recent study of 58 palliative care institutions across Japan for example, even though 15% of patients received CDS before death, use was in accordance with the national clinical guideline, and no difference was found between survival of patients who had received CDS compared with those who had not.¹⁴⁸ This suggests that CDS was given only when death was imminent. Moreover, CANH was provided in 62% of CDS cases compared with 58% of non-CDS cases. The authors came to the following conclusion:

Our findings suggest that CDS in patients with advanced cancer, cared for by palliative care specialists, did not hasten patient death ... CDS can be provided as a last resort for dying patients with intolerable suffering if it is given to patients with advanced disease refractory to medical treatments and a short life expectancy, and the treatment decision is made through multidisciplinary team discussion including palliative care specialists.¹⁴⁹

Even though CDS, when used to *intentionally* render patients unconscious until death is unethical, the results of this study indicate that, without an intention to hasten death (implied by there being no difference in survival between CDS and non-CDS cases), coupled with the high use of CANH, CDS does not in this context constitute ‘slow euthanasia’. Nevertheless, the fact that 15% of patients received

¹⁴³ Claessens P *et al.* (2014) Food and fluid intake and palliative sedation in palliative care units: A longitudinal prospective study. *Progress in Palliative Care* 22(1):1-8.

¹⁴⁴ Claessens P *et al.* (2011) Palliative Sedation, Not Slow Euthanasia: A Prospective, Longitudinal Study of Sedation in Flemish Palliative Care Units. *J Pain Symptom Management* 41(1):14-24.

¹⁴⁵ Chambaere K *et al.* (2011) Palliative sedation in Flemish palliative care units. *J Pain Symptom Management* 41(6):e1-e2.

¹⁴⁶ Broeckart B *et al.* (2011) What’s in a name? Palliative sedation in Belgium. Reply to Chambaere *et al.* *J Pain Symptom Management* 41(6):e2-e5.

¹⁴⁷ Claessens P *et al.* (2011) *Op. Cit.*

¹⁴⁸ Maeda I *et al.* (2016) *Op. Cit.*

¹⁴⁹ *Ibid.*

CDS suggests inadequate attention to alternative means of treating distressing symptoms, and more importantly, the principle that sedation must be proportionate to symptoms was not honoured. Oddly, some physicians in The Netherlands, in justifying immediate deep sedation rather than a titrating approach, have expanded the notion of proportionality beyond symptom management to include the “wishes of relatives and aesthetic consequences”.¹⁵⁰

The data in the Japanese study just cited was collected from late 2012 to mid 2014. In a much smaller Japanese study from just one PCU, and using data from mid 2005 to late 2011, the rate of CDS was less than one tenth (1.39%) of that in the broader and later study.¹⁵¹ It is possible that the later study is indicative of a culture shift in use of CDS, although this is unlikely over such a short timeframe. More likely is that this instead again points to the possibility that, depending on the expertise and possibly intentions of the staff, as well as the culture of the PCU itself, distressing symptoms can be managed without too readily resorting to CDS.

Any discussion about CDS would not be complete without reference to the ‘French exception’.^{152,153} In 2016, France became the only country in the world to legislate on CDS, effectively granting patients a right to CDS. Legislating in this way sets CDS apart from normal medical practice, something also true of euthanasia in the Dutch and Belgian contexts; in all other settings palliative sedation, even rarely involving sedation to unconsciousness and death (Sulmasy’s parsimonious direct sedation), is considered a means of controlling distressing symptoms at the end of life as a part of normal medical practice.

In the French exception, the right to CDS is tied to always foregoing CANH. It can also be applied when symptoms are deemed refractory to treatment, even if suffering is mild. Understandably, this has been met with considerable controversy. After all, it is difficult to see how using CDS until death with the express removal of CANH and for mild symptoms could involve anything other than an intention to hasten death.

During the Senate debates, it became clear that many Senators considered the creation of a legal right to continuous deep sedation as nothing more than a first step on the road to the decriminalisation of physician-assisted suicide or euthanasia. For this reason, continuous deep sedation was labelled a ‘Trojan horse’.¹⁵⁴

Whether this turns out to be prophetic for France remains to be seen.

What are the views and experiences of the physicians and nurses who have been involved with palliative sedation?

The various studies in which medical professionals have been queried about palliative sedation, either by surveys or focus groups, reveal not only considerable variance in views and experiences, but also a relatively high level of uncertainty about its use in both practical and ethical terms.

The key aspects that have been explored are whether hastening death should be part of palliative sedation and therefore how it relates to euthanasia, what is the significance of intention, whether existential suffering should be considered within its remit, what is the place of CANH during sedation, and dealing with patients/families. Other findings that have emerged tell us something about the

¹⁵⁰ Swart SJ *et al.* (2012) Considerations of physicians about the depth of palliative sedation at the end of life. *Can Med Assoc J* 184(7):E360-E366.

¹⁵¹ Koike K *et al.* (2015) Effectiveness of multidisciplinary team conference on decision-making surrounding the application of continuous deep sedation for terminally ill cancer patients. *Palliative and Supportive Care* 13:157-164.

¹⁵² Horn R (2017) The ‘French exception’: the right to continuous deep sedation at the end of life. *J Med Ethics* 44:204–205.

¹⁵³ Raus K *et al.* (2016) Controversies surrounding continuous deep sedation at the end of life: the parliamentary and societal debates in France. *BMC Medical Ethics* 17:36.

¹⁵⁴ *Ibid.*

emotional impact on professional staff as well as families, and differences in views and experiences between palliative care physicians and other specialties.

The majority of physicians do not think palliative sedation in any form should sanction intentionally hastening death.

In an Australian study of 18 palliative care physicians that sought to explicitly explore the distinction between *foreseeing* the possibility that death may be hastened versus *intentionally* hastening it, there was a strong aversion to the idea that palliative sedation could be used to intentionally hasten death, even though on occasions it may have done so.

“ ... the nearly unanimous view was that it is important ... to cultivate an intention that focuses exclusively on the relief of symptoms.”¹⁵⁵

In a recent study in which 21 international palliative care experts were asked about palliative sedation, there emerges a consistent concern about the need to draw as clear a distinction as possible between palliative sedation and euthanasia, and the role of intention was seen as central to that distinction.¹⁵⁶ These experts believed that palliative sedation ought to remain a part of normal medical practice, but given so many difficult and blurred boundaries with euthanasia, much greater clarity was required. On the question of CDS in particular, it should be seen as an “extreme facet of sedation that should be rarely used and restricted to certain conditions.”¹⁵⁷ This perspective was somewhat different to the position taken by ethicists like Sulmasy described earlier, as well as other physicians, who consider CDS unethical.¹⁵⁸ In contrast, like Sulmasy, 85% of respondents in a broad survey of US physicians went further on the question of intention, believing that it was unethical to directly intend that a patient be rendered unconscious.¹⁵⁹

There have been few studies aimed at comparing the views of physicians in different countries, but Seymour and coworkers have done so for The Netherlands, Belgium and the UK.^{160,161} A dominant view coming from UK respondents was that palliative care skills should be and were directed at symptom control, and when such skill had been well-developed and was being used, the need for palliative sedation was rare. Moreover, they also thought that what constituted a refractory symptom had as much to do with the environment and context of care as the clinical condition of the patient. UK respondents also rarely mentioned euthanasia. In contrast, respondents from Belgium and The Netherlands emphasised the distinctions between euthanasia and palliative sedation, even though there was an acceptance of the blurred boundaries that existed and that CDS could be construed as ‘slow euthanasia’. The authors noted the following:

While the European Association for Palliative Care has issued an ethical statement distinguishing between the two practices, our data suggest that the perceptions of practitioners working in countries where euthanasia has been legalized may take a different view ...¹⁶²

¹⁵⁵ Douglas CD *et al.* (2013) Narratives of ‘terminal sedation’, and the importance of the intention-foresight distinction in palliative care practice. *Bioethics* 27(1):1-11.

¹⁵⁶ Papavasiliou E *et al.* (2014a) Current debates on end-of-life sedation: an international expert elicitation study. *Support Care Cancer* 22:2141–2149.

¹⁵⁷ *Ibid.*

¹⁵⁸ Rietjens JAC *et al.* (2014) Approaches to suffering at the end of life: the use of sedation in the USA and Netherlands. *J Medical Ethics* 40(4):235-240.

¹⁵⁹ Putman MS *et al.* (2013) Intentional Sedation to Unconsciousness at the End of Life: Findings From a National Physician Survey. *J Pain Symptom Management* 46(3):326-334.

¹⁶⁰ Seymour JE *et al.* (2007) Relieving suffering at the end of life: Practitioners’ perspectives on palliative sedation from three European countries. *Social Science & Medicine* 64:1679–1691.

¹⁶¹ Seymour JE *et al.* (2015) Using continuous sedation until death for cancer patients: a qualitative interview study of physicians’ and nurses’ practice in three European countries. UNBIASED Consortium. See <https://doi.org/10.1177%2F0269216314543319> Accessed 9 Jan 2019.

¹⁶² *Ibid.*

In several studies specifically from Belgium^{163,164,165}, the view that CDS was used to intentionally hasten death was widely expressed. Nurses involved in administering CDS thought there was an implicit or explicit intention to hasten death in 77% of cases, and a possible or certain life-shortening effect in 96%.¹⁶⁶ In a study delivering palliative sedation to patients at home, GP's were prepared to call their use of sedation 'slow euthanasia' in response to patient requests for euthanasia.¹⁶⁷ In fact they expressed a preference for 'slow euthanasia' over euthanasia by lethal injection. The authors also concluded that the practice of GPs often deviated from guidelines, and that GPs also exhibited a 'shortage of knowledge'.¹⁶⁸

As noted earlier, part of the reason why palliative sedation, and CDS in particular, has expanded considerably is the changing view about how serious a refractory symptom needs to be to warrant sedation, and what the depth of sedation should be, and in particular the increasing use of sedation for existential distress. Compared with their views in 2000, in 2016 Japanese palliative care specialists found palliative sedation more difficult to implement. This was based on perceptions of an increased risk of inappropriate use of palliative sedation, difficulty in determining the medical indications for its use, and concern that if its use were to become more widespread, "less effort would be made for necessary palliative care."¹⁶⁹

In Belgium, most nurses thought CDS for existential suffering was appropriate, although others thought it was best treated by non-medical means. Physicians more readily agreed with this latter group of nurses.¹⁷⁰ Physicians from different countries were also generally uncomfortable with the idea itself, feeling they did not necessarily have the right tools to deal with existential distress.^{171,172,173,174}

This discomfort about sedation for existential distress felt by medical professionals is hardly surprising. Although dealing with just one aspect of existential distress, in a systematic review of existential loneliness (EL) and end-of-life care, the authors, specialists in philosophy, ethics and medicine, were cognisant of the "lack of agreement and a profound lack of conceptual clarity regarding the meaning of EL".¹⁷⁵ This is very difficult territory for medical professionals who are confronted with such distress on a fairly regular basis.

Part of the problem with coming to agreement about sedation for existential distress is that there will be quite different approaches by patients, their families, doctors and nurses to the fundamental questions of human existence that are the province of existential distress. Twycross' identification of these questions sharpens the point: What is the essence of human nature? What comprises personhood? What are the meaning and purpose of suffering, if any? What can we learn from Near Death Experiences and deathbed visions? Does consciousness survive beyond physical death?¹⁷⁶

¹⁶³ Inghelbrecht E *et al.* (2011) Continuous Deep Sedation Until Death in Belgium: A Survey Among Nurses. *J Pain Symptom Management* 41(5):870-879.

¹⁶⁴ Sercu M *et al.* (2014) Belgian General Practitioners' Perspectives on the Use of Palliative Sedation in End-of-Life Home Care: A Qualitative Study. *J Pain Symptom Management* 47(6):1054-1063.

¹⁶⁵ Anquinet L *et al.* (2012) *Op. Cit.*

¹⁶⁶ Inghelbrecht E *et al.* (2011) *Op. Cit.*

¹⁶⁷ Sercu M *et al.* (2014) *Op. Cit.*

¹⁶⁸ *Ibid.*

¹⁶⁹ Maeda S *et al.* (2018) Changes in opinions on palliative sedation of palliative care specialists over 16 years and their effects on clinical practice. *Supportive Care in Cancer* See <https://doi.org/10.1007/s00520-018-4497-2> Accessed 1 Feb 2019.

¹⁷⁰ Raus K *et al.* (2014) Factors that facilitate or constrain the use of continuous sedation at the end of life by physicians and nurses in Belgium: results from a focus group study. *Journal of Medical Ethics* 40(4):230-234.

¹⁷¹ Beauverd M *et al.* (2014) French Swiss physicians' attitude toward palliative sedation: Influence of prognosis and type of suffering. *Palliative and Supportive Care* 12:345-350.

¹⁷² Blondeau D *et al.* (2005) Physicians' and pharmacists' attitudes towards the use of sedation at the end of life: influence of prognosis and type of suffering. *J Pall Care* 21:238-245.

¹⁷³ Putman MS *et al.* (2013) *Op. Cit.*

¹⁷⁴ Papavasiliou E *et al.* (2014a) *Op. Cit.*

¹⁷⁵ Ettema EJ *et al.* (2010) Existential loneliness and end-of-life care: A systematic review. *Theor Med Bioeth* 31:141-169.

¹⁷⁶ Twycross R (2019) Reflections on palliative sedation. *Palliative Care: Research and Treatment* 1-16, DOI: 10.1177/1178224218823511.

Close juxtaposition of carers to patients who struggle with such questions may in part explain why nurses and doctors find this area so emotionally challenging, especially when their choices about sedation hasten death and thereby foreshorten any opportunity for their patients to address these questions. In some settings nurses seem to have borne the brunt of the emotional burden, having had to administer and monitor CDS in the absence of a GP.^{177,178}

In a more general sense, even beyond existential questions, and perhaps more closely related to the ethical question of hastening death, palliative sedation takes a toll on professional staff.

[This study] highlights the uncertainty experienced by these providers with regard to the medical, psychosocial and ethical justification for sedation. This uncertainty affecting them is a source of psychological burden and moral distress, and in addition it has proved to be a major source of suffering in the workplace.¹⁷⁹

This quote comes from the French context, one in which it was nurses who had the greatest misgivings about the use of sedation. A contrary result was found for Dutch nurses, where 96% agreed with the use of CDS, and there was no evidence of emotional burden.¹⁸⁰ Similarly, in a review of three papers from 2002 – 2007, the authors found that for healthcare professionals working with CDS, there was no association with “lower emotional well-being”.¹⁸¹ These results should be interpreted with caution however, in part because two of the papers were from Japan where there was no apparent culture of intentional hastening death at the end of life¹⁸², in which case one would therefore expect less emotional distress.

On the question of the place of CANH during sedation, there is surprisingly little research on what medical professionals think, surprisingly because the place of CANH is such a central part of discussions amongst ethicists. In the study of palliative care experts cited above, some expressed the view that forgoing CANH was potentially life-shortening and could cross the line between the alleviation of symptoms and hastening death. These respondents were concerned that sedation in this context could amount to ‘covert euthanasia’.¹⁸³ In a study of palliative sedation practitioners from the UK, Belgium and The Netherlands, withdrawing/withholding hydration was mostly considered to be “part of the same decision to commence sedation”, thereby signaling the central place it has in whether death was foreshortened or not.¹⁸⁴

To conclude, there is already justifiable concern not only with the practice of CDS itself, but also that just like with physician assisted suicide and active euthanasia, CDS could constitute a means of streamlining dying, with scant regard for the critical significance, meaning and opportunities that attend this last phase of life.

The end of life should not be synonymous with sedation. Physicians must resist requests for a scheduled death.¹⁸⁵

¹⁷⁷ Anquinet L *et al.* (2015) Descriptions by General Practitioners and Nurses of Their Collaboration in Continuous Sedation Until Death at Home: In-Depth Qualitative Interviews in Three European Countries. *J Pain Symptom Management* 49(1):98-109.

¹⁷⁸ Abarshi EA *et al.* (2014) The Complexity of Nurses’ Attitudes and Practice of Sedation at the End of Life: A Systematic Literature Review *J Pain Symptom Management* 47(5):915-925.

¹⁷⁹ Leboul D *et al.* (2017) Palliative sedation challenging the professional competency of health care providers and staff: a qualitative focus group and personal written narrative study. *BMC Palliative Care* 16:25.

¹⁸⁰ Arevalo JJ *et al.* (2015) Day-to-day care in palliative sedation: Survey of nurses’ experiences with decision-making and performance. *Int J Nurs Studies* 50:613–621.

¹⁸¹ Ziegler S *et al.* (2017) The impact of the inpatient practice of continuous deep sedation until death on healthcare professionals’ emotional wellbeing: a systematic review. *BMC Palliative Care* 16:30.

¹⁸² Morita M *et al.* (1999) *Op. Cit.*

¹⁸³ Papavasiliou E *et al.* (2014a) *Op. Cit.*

¹⁸⁴ Seymour JE *et al.* (2007) *Op. Cit.*

¹⁸⁵ Baumann A *et al.* (2011) The ethical and legal aspects of palliative sedation in severely brain-injured patients: a French perspective. *Philosophy, Ethics, and Humanities in Medicine* 6:4.

Terminal sedation should not become so routine that the end of life is scheduled like elective surgery, for the convenience of the doctor or the family, or because the patient's care is no longer economically viable.¹⁸⁶

If these concerns do eventuate, it is hard to see why 'scheduling' death with CDS would not progress to assisted suicide and active euthanasia. After all, rejecting the principle that death should not be hastened undergirds a significant proportion of CDS practice in the same way as it does assisted suicide and euthanasia in its more active form. Moreover, as noted above, CDS is a slow way of achieving what can be done much more quickly, and with significant cost-savings.

In their comparison of palliative sedation practices with euthanasia, ten Have and Welie are well aware of the overlap that can happen between the two, but also of the way in which sedation at the end of life is leading to a new culture surrounding aging and death – one that has elements of death denial as well as dehumanisation.

Most difficult to manage is the "mission creep" that appears to be occurring. A proliferation of sedative practices far beyond the original case of palliative sedation is indicative of and fueled by widespread and culturally anchored convictions about the meaning of aging, vulnerability, dependence, suffering, and dying. And, these are once more the same convictions that drive the euthanasia practice. As a result of this mission creep, the field of palliative and hospice care itself is changing. We are actually witnessing a vanishing of the original hospice philosophy as a result of the incorporation of palliative sedation. Present day palliative end-of-life care is reiterating the very characteristics of the traditional medical approach to end-of-life care that motivated the development of the hospice movement in the first place: the focus on therapy rather than care, the physical dimension rather than the whole person, the individual patient rather than the community, and the primacy of intervention rather than receptiveness and presence. Euthanasia, although often presented as an alternative to the traditional medical approach to the end of life, paradoxically has the very same focus.¹⁸⁷

CANH and PDOCs

The third category of circumstances in which CANH is relevant concerns patients with prolonged disorders of consciousness (PDOCs).

In this context the withholding/withdrawal of CANH is not only ethically, legally and emotionally charged, but arguably has the greatest potential to drive debate about euthanasia and apply pressure to permit it. The key reason for this is that when CANH is removed from a patient with a PDOC it more clearly constitutes the immediate cause of death. PDOC patients are typically not imminently dying and often live for many years. The removal of the feeding tube is not done because tube-feeding is futile or overly burdensome and disproportionate to benefit. It is done not only *foreseeing* that death will result, but *intending* that it will result. It is therefore clearly often euthanasia by omission. Many cases of CDS combined with foregoing CANH likewise constitute euthanasia by omission, but the circumstances in which they occur are often ambiguous enough to make it difficult to be sure what was actually intended.

When CANH is removed from a PDOC patient and death by dehydration and starvation occur over a week or so, it is easy to see why some argue that a lethal injection is 'more humane'. The *in principle* acceptance that CANH removal is a permissible means of bringing about death has already laid the groundwork for more active means.

¹⁸⁶ Hartocollis A (2009) Hard choice for a comfortable death: sedation. *New York Times* Dec 26, See <https://www.nytimes.com/2009/12/27/health/27sedation.html> Accessed 13 Feb 2019.

¹⁸⁷ Ten Have H & Welie JVM (2014) Palliative Sedation Versus Euthanasia: An Ethical Assessment *J Pain Symptom Management* 47(1):123-136.

PDOC patients have experienced either a traumatic brain injury such as from automotive or other accidents, or a non-traumatic brain injury from stroke, heart attack, meningoencephalitis, or the last stages of some neurodegenerative conditions like Alzheimer's disease and Huntington's disease. Some time is often spent in a coma before awakening. After approximately 4 weeks, patients may either be diagnosed as being in a vegetative state (VS) or a minimally conscious state (MCS).

VS has sometimes been prefixed by the word 'permanent', 'persistent' or 'chronic', or alternatively referred to as 'post-coma unresponsiveness', 'post-coma unawareness', or more recently as 'unresponsive wakefulness syndrome'.¹⁸⁸ It may be described as follows:

... a transient state of wakefulness without awareness characterized by cyclic sleep patterns, spontaneous eye opening and movement, and normal body temperature yet a lack of purposeful responsiveness to stimuli, cognitive function, and speech.¹⁸⁹

Use of the word 'vegetative' is problematic because it implies a subhuman existence. But the literature continues to use the term, so for clarity VS will remain the working descriptor here.

MCS can be distinguished from VS because MCS patients show intermittent behavioural signs of consciousness. In other words, they are sometimes aware and may follow simple commands. MCS has also been referred to as the 'minimally responsive state'.¹⁹⁰

Estimates of the prevalence of VS and MCS vary significantly, revealing how poorly researched and reported conditions they are. In the UK, prevalence of VS has been estimated to be between 4,000 and 16,000 (170 – 242 per million), with 'thousands more' in MCS¹⁹¹. A combined figure for the UK of 24,000 (364 per million) has also been reported.¹⁹² In the US, the figures for VS range from 5,000 to 42,000 (15 – 128 per million), and for MCS from 112,000 to 280,000 (344 – 859 per million).¹⁹³ Variance between these figures could result from differences in diagnostic criteria, coding, or methods of data collection. In a systematic review from 2014, besides confirming these variable findings on prevalence, different studies found the percentage of VS and MCS cases resulting from traumatic conditions ranged from 22% to 54% (non-traumatic therefore from 46% to 78%).¹⁹⁴

Clearly not everyone who suffers a traumatic brain injury for example, will be in a VS once the acute phase of recovery is over. A recent review of 21 studies found that 6 months after a severe traumatic brain injury, between 0.52% and 7.33% of patients had VS, the variation likely resulting from differences in the emergency care available in different countries at different times and contexts.¹⁹⁵ It is also likely that variation in the way VS is diagnosed could contribute.

As more is becoming known about patients with VS and MCS, a disturbing observation is that the rate of misdiagnosis is high – estimated to be around the 40% mark (37-43%).^{196,197} That misdiagnosis was a problem with VS was known in the nineties.¹⁹⁸ More recently, in work by Schnakers *et al.*, of 103 patients tested by standard behavioural means by a full clinical team, 44 were deemed to be in VS, 41

¹⁸⁸ Giacino JT *et al.* (2018a) Comprehensive Systematic Review Update Summary: Disorders of Consciousness. *Arch Physical Med & Rehab* 99:1710-1719.

¹⁸⁹ Paz JC & West MP (2014) Acute Care Handbook for Physical Therapists (4th ed), 1-9.

¹⁹⁰ Australian Government (2008) National Health and Medical Research Council. Ethical guidelines for the care of people in post-coma unresponsiveness (vegetative state) or minimally responsive state. See <https://www.nhmrc.gov.au/about-us/publications/ethical-guidelines-care-people-post-coma-unresponsiveness#block-views-block-file-attachments-content-block-1> Accessed 5 October 2018.

¹⁹¹ See <https://www.bbc.com/news/magazine-37444379> Accessed 1 March 2019

¹⁹² *Ibid.*

¹⁹³ Giacino JT *et al.* (2018a) *Op. Cit.*

¹⁹⁴ Pisa FE *et al.* (2014) The Prevalence of Vegetative and Minimally Conscious States: A Systematic Review and Methodological Appraisal. *J Head Trauma Rehabil* 29(4):E23–E30.

¹⁹⁵ Tang Q *et al.* (2017) Prevalence of persistent vegetative state in patients with severe traumatic brain injury and its trend during the past four decades: A meta-analysis. *NeuroRehabilitation* 40:23–31.

¹⁹⁶ Bender A *et al.* (2015) Persistent Vegetative State and Minimally Conscious State. A systematic review and meta-analysis of diagnostic procedures. *Deutsches Ärzteblatt International* 112:235–242.

¹⁹⁷ Giacino JT *et al.* (2018a) *Op.Cit.*

¹⁹⁸ *Ibid.*

in MCS, and 18 given an uncertain diagnosis. However, when tested by researchers using more refined behavioural testing, 18 (41%) of the VS patients were actually in MCS, 4 (10%) of the MCS patients had emerged from MCS, and 16 (89%) of the patients given an uncertain diagnosis were actually in MCS, and therefore “manifested signs of consciousness”.¹⁹⁹

This is particularly pertinent because when cases come before the courts, judgements rely significantly on the diagnosis; and given that the data shows the misdiagnosis is towards assigning *less* consciousness than patients really have, court decisions are more likely to favour the removal of tube feeding resulting in death of the patient. It is more than likely that if the courts had been presented with a more accurate diagnosis, they would have resisted tube removal more often.

Misdiagnosis will likely remain a problem, and could even be revealed to be worse than it already is. New diagnostic tools are being explored that are beginning to show higher rates of consciousness than behavioural tests might suggest. So, in addition to what was revealed by Schnakers *et al.*, who used refined behavioural tests, other researchers are now using EEG and other neuroimaging techniques together with feedback to assess awareness. In 2011, Cruse and co-workers developed an EEG-based technique to explore awareness in VS patients, finding that 19% of patients displayed ‘covert awareness’. This was despite them being ‘behaviourally entirely unresponsive’ as measured by the usual criteria. Therefore, this 19% rate of misdiagnosis is additional to the 40% misdiagnosis figure cited above.²⁰⁰

This type of finding has been backed up by others using neuroimaging techniques with direct neural feedback from the patient to show that some are actually conscious.

Beyond preserved awareness, the brain-injured patient’s ability to follow commands via brain activity provides evidence of a complex cognitive repertoire, including language comprehension, decision-making, working memory, and executive function.²⁰¹

At the time this statement was published, *viz.* 2017, the authors noted,

Efforts to translate these neuroimaging techniques for use in clinical practice are ongoing.

Therefore, until that happens, many VS and MCS patients will continue to be misdiagnosed - with the potential that life or death decisions will be made about their future based on inaccurate information.

... PVS is often overdiagnosed because the clinical state is uncommon and few physicians have the skill to examine patients appropriately ...²⁰²

How much recovery is possible for patients with VS or MCS?

Yelden *et al.* note that studies on recovery from VS and MCS are limited. In their research of 34 patients with VS or MCS, 32% showed improvement in awareness when assessed 2 to 16 years after their trauma; however, all remained severely disabled, with only one person progressing “to the level of functional verbal communication and object use.”²⁰³ Most of the 32% had progressed from VS to MCS. Estraneo *et al.* found something similar, with 25% of VS patients showing an improvement in responsiveness, half of whom regained consciousness.²⁰⁴ Luauté *et al.* found that after 1 year, whilst a third of the MCS

¹⁹⁹ Schnakers C *et al.* (2009) Diagnostic accuracy of the vegetative and minimally conscious state: Clinical consensus versus standardized neurobehavioral assessment. *BMC Neurology* 9:35 doi:10.1186/1471-2377-9-35.

²⁰⁰ Cruse D *et al.* (2011) Bedside detection of awareness in the vegetative state: a cohort study. *Lancet* 378:2088–94.

²⁰¹ Graham M *et al.* (2018) Minimizing the Harm of Accidental Awareness Under General Anesthesia: New Perspectives From Patients Misdiagnosed as Being in a Vegetative State. *Anesthesia & Analgesia* 126(3):1073-1076.

²⁰² Wijdicks EFM (2006) Minimally Conscious State vs Persistent Vegetative State: The Case of Terry (Wallis) vs the Case of Terri (Schiavo). *Mayo Clin Proc.* 81(9):1155-1158.

²⁰³ Yelden K *et al.* (2018) Late recovery of awareness in prolonged disorders of consciousness –a cross-sectional cohort study. *Disability and Rehabilitation* 40(20):2433-2438.

²⁰⁴ Estraneo A *et al.* (2010) Late recovery after traumatic, anoxic, or hemorrhagic long-lasting vegetative state. *Neurology* 75(3):239-45.

patients emerged from MCS with severe disabilities, none of the VS patients improved.²⁰⁵ Baricich *et al.* found that 12 % of VS patients progressed to MCS at the 4 year mark.²⁰⁶ When the group of VS patients is restricted to those resulting only from traumatic brain injuries, the figures are better, with 52% regaining consciousness at 12 months.²⁰⁷

To some extent, these studies stand in contrast to research cited by Giacino and co-workers in a major 2018 review by the *US Academy of Neurology* and other peak bodies. The author's comments are critical to understanding the current state of knowledge, so it is worth quoting the authors directly:

... relatively few natural history and prognostic studies reported long-term functional outcomes. In many studies, outcome assessment focused exclusively on recovery of consciousness or eMCS [emergence from MCS] or both, without attention to the corresponding level of disability. Importantly, studies that tracked functional outcome beyond 1 year suggest up to 1 in 5 patients with prolonged DoC - especially those who transition to MCS before 6 months - eventually regain independence in the home environment.²⁰⁸

Although research in this area is markedly limited, this observation in particular casts a far more hopeful light on the extent to which recovery from a PDOC is possible.

Besides a natural history of recovery that is described in these studies, there is also evidence that certain interventions may assist. For example, drugs like amantadine and zolpidem have been shown to improve patients' recovery^{209, 210}, as have neurostimulation methods like deep brain stimulation, transcranial magnetic stimulation (TMS), and vagal nerve stimulation.²¹¹

When problems with misdiagnosis are considered together with new findings on the course of natural recovery, and the development of promising interventions, what was once considered true of patients with VS and MCS is now in a state of significant reappraisal. Patients may be more aware than previously thought. They may recover to a greater extent than previously thought. And there may be new treatments that can offer a significant chance of improvement.

What is it like for caregivers of patients with a PDOC?

In a recent systematic review of 18 studies that assessed the well being of caregivers of someone with a PDOC, several consistent observations emerged.²¹² First, the experience of grief and loss was both understandable and prolonged. It was also associated with the caregiver being younger and also with denial and self-blame. Fewer grief symptoms were experienced by caregivers who used "active and problem-focused coping styles". Second, one third to a half of caregivers experienced depressive symptoms that were perceived to contribute to a poorer quality of life. Third, many of the 18 studies identified evidence of physical, financial and psychosocial burden. Finally, caregivers utilised a variety of coping strategies, some more effective than others – for example, positive attitude, social support, and a problem-oriented approach.

²⁰⁵ Luauté J *et al.* (2010) Long-term outcomes of chronic minimally conscious and vegetative states. *Neurology* 75:246–252.

²⁰⁶ Baricich A *et al.* (2017) Recovery from vegetative state of patients with a severe brain injury: a 4-year real-practice prospective cohort study. *Functional Neurology* 32(3):131-136.

²⁰⁷ The Multi-Society Task Force on PVS (1994) Medical Aspects of the Persistent Vegetative State. *New Engl J Med* 330(21):1499-508.

²⁰⁸ Giacino JT *et al.* (2018a) *Op.Cit.*

²⁰⁹ Giacino JT *et al.* (2018) Practice guideline update recommendations summary: Disorders of consciousness. *Neurology* 91:450-460.

²¹⁰ Fins JJ & Bernat JL (2018) Ethical, Palliative, and Policy Considerations in Disorders of Consciousness. *Archives of Physical Medicine and Rehabilitation* 99:1927-1931.

²¹¹ *Ibid.*

²¹² Soeterik SM *et al.* (2017) The psychological impact of prolonged disorders of consciousness on caregivers: a systematic review of quantitative studies. *Clinical Rehabilitation* 31(10):1374-1385.

What also emerged from this review was that caregivers experienced a particular form of loss:

... a unique and complex form of loss, an ambiguous loss, where the injured person is physically present but psychologically absent to the caregiver.²¹³

Nevertheless, it has also been found that caregivers can underestimate the extent to which some degree of communication is actually possible.²¹⁴ As more advanced techniques become available the possibility for communication may improve even further.

On the critical question of nutrition and hydration, caregivers are generally strongly averse to the withdrawal of CANH.²¹⁵ However, in a UK study by Kitzinger and Kitzinger²¹⁶, something disturbing was identified. While there was very little support for the removal of CANH, and most respondents found the idea that their loved one would starve and dehydrate to death “utterly abhorrent”, “barbaric”, or “cruel”, there was instead “ ... a widespread perception that lethal injections would be more humane.”²¹⁷ In fact, many interviewees had given some thought to killing the patient themselves. This opposition to the withdrawal of CANH by caregivers should be tempered by the reality that some caregivers are clearly in favour of its removal as evidenced by the 100 or so cases in the UK that have made their way to the Court of Protection over the past 25 years.²¹⁸

Furthermore, this study should be viewed with caution as there is no way to be certain how representative the views are, particularly as the authors conclude by arguing that “full ethical consideration” should be given to “other ways of bringing about the death of PVS/MCS patients.” In a qualitative study such as this, selected comments from interviewees that will bolster the conclusion could introduce bias. Elsewhere, the same authors have used philosophical deliberation about the status of VS patients to argue for euthanasia.

... such patients are neither straightforwardly alive nor simply dead ... we argue that standard objections to allowing active euthanasia for this particular class of permanently vegetative patients are weakened by these patients’ distinctive ontological status.²¹⁹

In other words, these authors have consigned VS patients to an especially diminished class of being that would legitimise their medical killing. This is chillingly reminiscent of other arguments used to dehumanise groups of vulnerable human beings by denying their full dignity as human persons. Moreover, there is something particularly callous about arguing for euthanasia on the grounds of the extreme vulnerability of patients who cannot speak for themselves. Most often advocates argue for euthanasia and/or assisted suicide on the basis of autonomy. And the authors are not unknown or inactive in the field. One of them (Professor Celia Kitzinger) was a member of the core group that oversaw the development of the BMA guidance on CANH.²²⁰

Recent changes in the UK have significantly shifted the goalposts regarding how easy it will now be to withdraw CANH from patients with a PDOC. In 2018, the Supreme Court ruled in 2 cases that it would no longer be necessary to go to the Court of Protection.²²¹ It will now suffice for the medical staff and

²¹³ *Ibid.*

²¹⁴ Jox RJ *et al.* (2015) Diagnosis and Decision Making for Patients With Disorders of Consciousness: A Survey Among Family Members. *Archives of Physical Medicine and Rehabilitation* 96:323-30.

²¹⁵ *Ibid.*

²¹⁶ Kitzinger C & Kitzinger J (2014) Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives. *J Med Ethics* 0:1–4. doi:10.1136/medethics-2013-101799.

²¹⁷ *Ibid.*

²¹⁸ Berg S (2016) Permanent vegetative state: A family's agony. See <https://www.bbc.com/news/magazine-37444379> Accessed 1 March 2019

²¹⁹ Holland S *et al.* (2014) Death, treatment decisions and the permanent vegetative state: evidence from families and experts. *Med Health Care and Philos* 17:413–423.

²²⁰ British Medical Association & Royal College of Physicians (2018) Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in England and Wales. p 1. See <https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/can-h-guidance> Accessed 19 January 2019.

²²¹ See <https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf> Accessed 19 October 2018.

relatives to agree that the removal of food and fluids is in the patient's 'best interests'. The judgements were then followed by new guidance from the *British Medical Association* (BMA) and the *Royal College of Physicians* (RCP) with endorsement from the *General Medical Council* (GMC).²²² Prior to the Supreme Court judgement or the release of the BMA Guidance, in a 2017 paper by English and Sheather in the *Journal of Medical Ethics*, the authors argued that the role of the Court of Protection was unnecessary.²²³ One of the authors, Veronica English, was also a member of the core group that oversaw the development of the BMA guidance on CANH²²⁴, and as Head of Medical Ethics and Human Rights at the BMA would doubtless have been involved with the BMA submission to the Supreme Court, a submission to which the Justices refer on several occasions. This would not be the first time that prominent academics have published work that is then influential in key legal cases and guidance documents. In this case however, the influence has resulted from particularly close associations with the development of important public policy.

PDOCs and Ethics

There are several matters common to the Supreme Court judgements as well as the various guidelines and other court judgements about CANH that rest upon core ethical considerations, some of which were alluded to earlier.

First, whether CANH is basic care or medical treatment. CANH is used not because there is a deficiency in the digestive processes. It is true that a simple medical procedure is used to enable the feeding tube to deliver food and fluids, much as a tracheal tube once in place inertly allows air to flow, but the goal of CANH is sustenance. There is no pathology of needing sustenance. Hunger and thirst are not pathologies that are being medically treated. This is brought into sharper relief when considering what will happen if CANH is removed - there being nothing pathological about the assimilation of food and fluids, the patient will die of dehydration and starvation. In the court judgements as well as many guidelines, labeling CANH as medical treatment is consistently and doggedly used to justify its removal.

Second, the error in thinking about CANH as medical treatment is compounded when it comes to determining and reporting the cause of death. By comparison, if a patient is removed from artificial respiration, they will die from their pathology of respiration, and hence it will be the cause of death. But if CANH is removed from a patient who is not imminently dying, as is true for PDOCS, then dehydration and starvation will be the proximate cause of death. Strangely, the 2013 RCP guidelines acknowledge this and yet recommend that physicians draw up the death certificate with the original brain injury as the cause of death.²²⁵ Rady and Verheijde are scathing in their criticism of the RCP guidelines about this, concerned that,

... this could be interpreted as an infringement of the long-held assumption in society and law that the medical profession holds truthfulness as one of its moral priorities.²²⁶

The new BMA guidelines are not quite so explicit, but provide guidance recommending that the cause of death exclude any mention of CANH withdrawal, and that instead multi-organ failure or bronchopneumonia be listed as the direct cause of death and original brain injury as the underlying cause.²²⁷ Besides recommending dishonesty, this means that research about CANH removal in PDOCS

²²² British Medical Association & Royal College of Physicians (2018) *Op. Cit.*

²²³ English V & Sheather JC (2017) Withdrawing clinically assisted nutrition and hydration (CANH) in patients with prolonged disorders of consciousness: is there still a role for the courts? *J Med Ethics* 43:476–480.

²²⁴ British Medical Association & Royal College of Physicians (2018) *Op. Cit.* p1.

²²⁵ Royal College of Physicians: Prolonged disorders of consciousness: National clinical guidelines. London, RCP. 2013, http://www.rcplondon.ac.uk/sites/default/files/prolonged_disorders_of_consciousness_national_clinical_guidelines_0.pdf Accessed 12 January 2019.

²²⁶ Rady MJ & Verheijde JL (2014) Nonconsensual withdrawal of nutrition and hydration in prolonged disorders of consciousness: authoritarianism and trustworthiness in medicine. *Philosophy, Ethics, and Humanities in Medicine* 9:16. See <http://www.peh-med.com/content/9/1/16>

²²⁷ British Medical Association & Royal College of Physicians (2018) *Op. Cit.* 2.11.

will become very difficult, if not impossible. Its extent and the circumstances surrounding removal will fly under the radar.

Third, decisions about whether to remove CANH are informed by ‘best interests’ arguments – something the BMA guidance attempts to address in detail. This is a difficult area that can be nebulous, but nevertheless takes into consideration the clinical details, the previously expressed wishes of the patient and the views of family. It has been criticised for being overly utilitarian in its burdens versus benefits approach.²²⁸ Often a senior clinician will end up being the decision-maker. But because such determinations are so hazy and ill defined, there is a very real risk that individual views about life and its value, as well as the interests of next of kin and of the institution in which the patient resides will unjustifiably bear upon the final assessment. These other ideological, emotional and financial interests would not be articulated, but potentially constitute the real drivers for CANH removal even if best interests discussions are couched in the terms expressed in the BMA guidance. And now that the Court of Protection need no longer be involved, the door is wide open for abuses of all types.

There is something jarring in the notion that death can be in someone’s best interests, which was part of the Supreme Court’s ruling, that death might weigh on the benefit side of the ledger of best interests. Perhaps this goes to the question of the sanctity of life. The Catholic Church has been clear in its support of the provision of CANH for PDOC patients, not only on sanctity of life grounds but also because CANH is basic care and not medical treatment.²²⁹ Others who do not share this view argue that sanctity of life unjustifiably interferes with the determination of best interests.²³⁰

Fourth, the failure to recognise or admit that CANH removal from someone who is not imminently dying can constitute an act of euthanasia by omission masks the moral responsibility that goes with the act. When a critical distinction is *not* made between CANH removal in PDOCs and the removal of futile or overly burdensome medical treatment that is disproportionate to benefit, pressure for active euthanasia will expand. This will be exacerbated as CANH removal from patients with PDOCs becomes more commonplace and accepted – in the UK at least.

Fifth, a not uncommon argument used to justify the withdrawal of nutrition and hydration from someone with a PDOC is they are not really a person, or that they are really dead already, or that they might have biological life, but not social life²³¹, that they may be alive but not really living a life.²³² Such arguments may have a *prima facie* appeal to some, but in reality they amount to a dualism that not only unjustifiably fractures someone’s personhood, but also is used to fundamentally diminish them. And it is this diminishing over and against someone’s inherent dignity as a person that is used to permit such actions that would be impermissible for anyone else. Historically as well as currently, this fundamental error lies at the heart of so much abuse of the vulnerable.

Sixth, the Supreme Court judgement extends beyond those with PDOCs. Speaking of CANH, the judgement states:

The need for it can arise also, for example, in the advanced stages of a degenerative neurological condition such as Huntington’s disease or multiple sclerosis, or in the advanced stages of dementia, where there may be a recognised downward trajectory. Presently, the BMA say, in the case of patients who have suffered a severe stroke, or are significantly cognitively impaired but conscious, or are suffering from a degenerative neurological condition or other condition with a recognised downward trajectory, decisions

²²⁸ Rady MJ & Verheijde JL (2014) *Op. Cit.*

²²⁹ Address of Pope John Paul II (20 March 2004) to the participants in the international congress on “Life-sustaining treatments and vegetative state: scientific advances and ethical dilemmas”. See http://w2.vatican.va/content/john-paul-ii/en/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc.html Accessed 11 December 2018.

²³⁰ Glannon W (2013) Burdens of ANH outweigh benefits in the minimally conscious state. *J Med Ethics* 39:551–552.

²³¹ Sheather JC (2013a) Should we respect precedent autonomy in life-sustaining treatment decisions? *J Med Ethics* 39:547–550.

²³² Nucci ED (2013) Withdrawing artificial nutrition and patients’ interests. *J Med Ethics* 39(9):555-556.

to withhold or withdraw CANH are made on a regular basis without recourse to the courts.²³³

The justices were convinced (by the BMA) that the removal of CANH for PDOC patients is essentially the same as CANH removal for conditions with a 'downward trajectory' like stroke and degenerative conditions; and because the latter do not have to go to court, neither should the former. But these two are not the same. While it is not entirely clear what a 'downward trajectory' means – is it referring to those who are imminently dying or those who are on CANH for other reasons but who could live for months or years? The argument could have the effect of endorsing CANH removal in circumstances far more broad than for PDOCs. One could imagine a dementia patient on CANH because spoon-feeding is too costly, who may live for years, but for whom, just as for a PDOC or MCS patient, it is determined to be in their 'best interests' for CANH to be removed. Adding deep sedation would then remove overt signs of distress while dehydration and starvation ensued.

Instead, perhaps the court should have expressed concern that the BMA was admitting to 'decisions to withhold or withdraw CANH on a regular basis' merely for conditions with a 'downward trajectory'.

In 1993, Fergusson wrote a critique of the Bland case, noting how difficult it was to consider that case alone without an eye on the precedents set by the judgement. Fergusson identified three of them:

- a. That if tube-feeding were considered a medical treatment, the change in concept of what feeding means might in time come to affect many other patients in much larger categories;
- b. That we might change our view of the requirements for human life to be considered present, to the detriment of much larger groups of patients;
- c. That intentional killing by omission might seem to be acceptable and so lead in time to widespread euthanasia.²³⁴

That was just 26 years ago, and yet there is a certain prescience in his predictions. The slide towards widespread euthanasia identified by Fergusson has not yet eventuated, at least not in the UK, but there can be little doubt that changes in the treatment of patients have brought things much closer. This latest development, where arguably the most vulnerable of patients can more easily receive euthanasia by omission, both in principle and practice, incrementally draws active euthanasia closer.

Conclusion

This document has sought to examine research evidence concerning the artificial provision of nutrition and hydration to vulnerable patients, typically referred to as CANH. Because of the close association between CANH and the use of sedation at the end of life, it has also necessitated scrutiny of palliative sedation as well. There are many settings in which both CANH and palliative sedation are being used in ethically sound ways, but unfortunately, broadly speaking the evidence reveals a growing use of sedation at the end of life, and in particular continuous deep sedation up until death, often coupled with forgoing CANH, which intentionally leads to the patient's death. Added to the likelihood that the removal of CANH in PDOCs will grow in prevalence, it would be fair to say that end of life practice is increasingly leading to prematurely ending the lives of vulnerable patients.

Throughout this review, an attempt has been made to draw distinctions between proper medical care and euthanasia. The underlying principles that drive euthanasia are fundamentally different to those that undergird medical care and palliation of human suffering, such that if even covert or indirect means to intentionally end life are accepted, more overt and direct means will eventually creep in. Crossing

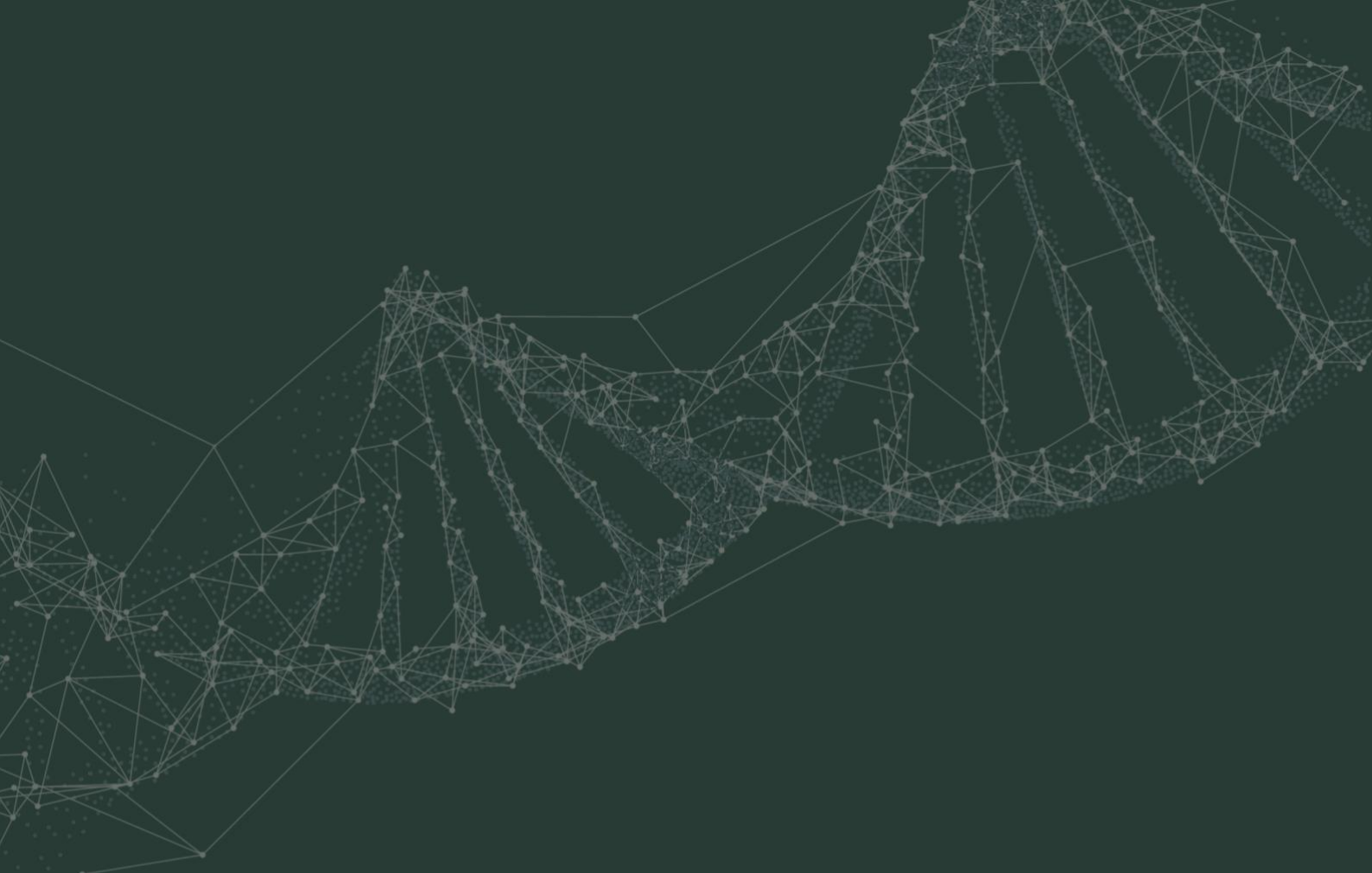
²³³ [2018] UKSC46, *An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellants)* p 43-44. See <https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf> Accessed 6 Mar 2019.

²³⁴ Fergusson A (1993) *Should Tube-feeding be Withdrawn in PVS? – A brief review of the issues*. In: *CMF Euthanasia Booklet*, Chapter 6 <https://www.cmf.org.uk/resources/publications/content/?context=article&id=1368> Accessed 6 March 2019.

into a culture of euthanasia has been likened to crossing the Rubicon.²³⁵ The reasons these distinctions are so important is because experiments with euthanasia in Holland and Belgium have proven again and again that euthanasia is uncontrollable and will break out of attempts to restrain it. The fine distinctions between good medical care and euthanasia by omission are hard to make but are crucial, and the evidence of more euthanasia by omission has the strong potential to drive practices and acceptance of euthanasia by commission (lethal injection).

The care of vulnerable patients at the end of life, or in other circumstances such as PDOCs or degenerative conditions, requires a commitment to what is genuinely in their best interests and those of people close to them. It will always be a challenging area, and the potential to do serious injustice to vulnerable people - many of whom could have the opportunity for life-affirming and sometimes profound experiences - is not only a possibility, but a present, and increasingly present, reality. We have some of the best tools at hand in all of human history for dealing with suffering, neurocognitive and perhaps even existential. Our communities should utilise them to honour and respect people, embrace this challenging work, and build a genuinely compassionate community of care.

²³⁵ Kelly P (2017) Good palliative care would avoid social experiment of euthanasia. The Australian, October 14. See <https://www.theaustralian.com.au/news/inquirer/good-palliative-care-would-avoid-social-experiment-of-euthanasia/news-story/909689ff7df68739a1901c50dd5d5778> Accessed 6 March 2019.



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