Palliative sedation: Controversies and challenges

Francine Rainone

Our Lady of Lourdes Memorial Hospital, 169 Riverside Drive, Binghamton, NY 13903, USA

Palliative sedation (PS) is used increasingly commonly for symptom management in terminally ill patients in the Western world. The main controversies involving PS are whether it is the same as euthanasia, whether the practice supports patient autonomy, whether sufficient safeguards are or could be in place to prevent its abuse and what its spread may mean for the future of palliative care. While other reviews consider them separately, here the legal, scientific, ethical, and pragmatic challenges to the practice are examined together to provide a broad context in which to assess the current state of the practice.

Keywords: Palliative sedation, Ethics, Autonomy, Provider–family conflict, Maleficence, Beneficence

Introduction

Most reviews of the controversies regarding of palliative sedation (PS) are limited to one aspect of the debate, such as legality or ethics. The purpose of this review is to examine the issues surrounding PS by delineating the relationships among its legal, scientific, ethical, and pragmatic aspects. While it is possible to construct strong arguments that PS is both ethical and beneficial for a select group of patients, current evidence suggests that the way it is currently practiced in the USA and elsewhere generates moral concerns that demand serious attention, reflection, and reform.[1,2]

At this point, I doubt there are many physicians who would want to ban PS in all cases. There is ample evidence that even with excellent care many patients at the end of life experience intractable symptoms.[3–5] Some of these people may welcome the option of sedation. PS is now an accepted part of medical practice whose legality is established and is endorsed by most major medical societies. In my opinion, the current debate ought not to be about banning PS, but about how to regulate it to ensure the prevention of harm.

The law: PS, euthanasia, and physician-assisted suicide (PAS)

No comprehensive discussion of PS is possible without examining the legal background against which the ethical debates have taken place. Specifically, the questions of whether PS is the same as euthanasia or the same as PAS, whether an appeal to patient autonomy justifies PS, and whether PS inflicts harm have all been addressed using the arguments articulated by the US Supreme Court. Ruling on two cases brought to challenge state laws against PAS, the US Supreme Court specifically addressed sedation for intractable symptoms at the end of life, and affirmed its legality. The language they used suggested that PS is sometimes euthanasia, which they did not carefully distinguish from PAS. Adequately distinguishing among these three practices, as we shall see below, continues to be a matter of debate. Reviewing the Supreme Court's decisions helps provide the context for the current debate.

The Court definitively ruled against the legality of PAS in two unanimous decisions, released on the same day in 1997.[6,7] In *Washington v. Glucksberg* five physicians, three terminally ill patients and Compassion in Dying (a non-profit that counsels those considering assisted suicide) challenged Washington State's prohibition on assisted suicide by arguing that it violated a fundamental liberty interest protected by the Due Process Clause of the Fourteenth Amendment to the Constitution of the United States.

The Court's decision turned, in part, on the definition of a fundamental liberty interest as one that is deeply rooted in a nation's history. Given that definition, the Justices rightly point out that suicide, assisted or not, has been a punishable offense for centuries. They also argued that the state has a compelling interest in preserving human life and protecting vulnerable populations, such as the mentally ill and the disabled, from coercion, medical neglect, and error. The Court expressed concern that declaring assisted suicide a constitutionally protected right would lay

Correspondence to: Francine Rainone, Our Lady of Lourdes Memorial Hospital, 169 Riverside Drive, Binghamton NY 13903, USA.
Email: frainone@lourdes.com

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the groundwork for approving voluntary and involuntary euthanasia.

In a related case, after New York State enacted a ban on PAS, three physicians and three terminally ill patients challenged its constitutionality. They argued that the law violated the Equal Protection Clause of the Fourteenth Amendment, because it allowed terminally ill patients to refuse life-sustaining treatment and even to ask that it be withdrawn, but did not allow patients to ask for and receive assistance in suicide. They argued that the right to withdraw life-sustaining treatment and the right to ask a physician to end life is the same right, because they both concern competent adults wanting to die.

In its majority opinion, the Supreme Court ruled that there is no fundamental 'right to die'. The Court held that refusing treatment and asking that a physician end life are distinct practices that can be distinguished by intent and outcome. Refusing unwanted treatment is allowed within the rights to bodily integrity and autonomy. Therefore, ending unwanted treatment at a patient's request requires only the intent to respect the patient's wishes. In contrast, honoring a request to end life necessarily requires the intent to kill the patient. Importantly, the Court held that stopping treatment may cause the patient to die from underlying causes, but administering lethal drugs causes the patient to die by the actions of the physician. In other words, the outcome of letting die is death by underlying disease, whereas the outcome of intentionally killing someone is death by physician action. The Court also held that the NY state law in fact treated all patients in the same way: they are all allowed to refuse unwanted treatments, but not to request assistance in suicide.

When we turn from the majority opinion to the concurring opinions, we find PS introduced, but not named.[8,9] Justice O'Connor (joined by Justice Ginsburg) specifically wrote that there were no legal barriers to terminally ill patients in great pain requesting and receiving medications to alleviate their suffering, even if the medications render patients unconscious and hasten their death. They also wrote that states were not prohibited from enacting legislation that carefully balanced the rights of terminally ill patients with the interests of society. Legislatures, they held, were the more appropriate forum for dealing with the issue of the right to die. The opinions of Justices Stevens, Breyer, and Souter also refer to a person's right to pain medication for the purpose of alleviating suffering. Stevens noted that there might be circumstances in which patients' interest in hastening death, when central to their liberty, outweighed the state's interest in preserving life. Justice Breyer recommended that the right to die should be renamed the right-to-die with dignity. He articulated the view that this right encompassed the right of a competent individual to determine the manner of death, the degree of professional intervention, and the amount of physical pain and suffering that was acceptable.

In their concurring opinions, the Justices conflate, or at least fail to distinguish among, different practices. PAS[10] has come to be defined as a situation in which a physician provides the means and/or information for ending life but the patient employs the means. In light of this definition, PS cannot be PAS, because the patient is not self-administering the drugs. Euthanasia[11] has come to be defined as the act of a physician ordering and administering or causing to be administered medications that end a patient's life in order to relieve intolerable and incurable suffering. By specifically saying that relieving suffering caused by intractable symptoms is permissible even if it hastens death, the Justices raised the issue of whether those performing PS were in fact practicing euthanasia.

Palliative care clinicians were also struggling to name PS in a way that distinguished it from other practices. In 1991, Enck reviewed two articles about symptom control at end of life and called the use of drug-induced sedation for symptom control in the dying 'terminal sedation'.[12] (Interestingly, these papers indicated that as many as 52% of dying cancer patients had symptoms so refractory that sedation was the only way to control them.)[1,13] Unfortunately, the term 'terminal sedation' was confusing, because some interpreted the adjective 'terminal' to mean the purpose of the sedation, rather than the time frame in which it is used. In other words, 'terminal sedation' was confused or conflated with euthanasia.

In response to the confusion numerous alternatives to 'terminal sedation' were proposed. Quill *et al.* argued that there are actually three categories of sedation: ordinary sedation, proportionate palliative sedation (PPS), and palliative sedation to unconsciousness.[14] Cellarius and Blair[15] recommended that all PS be referred to as PPS, because it affirms the principle that the degree of sedation should be proportionate to the intensity of the symptoms. Perhaps because of its simplicity, PS has become the most widely used term. However, whether PS can be distinguished from euthanasia continues to be a topic of debate.[16]

Guidelines and definition

We saw above that the Court relied on intent and outcome to distinguish PS from euthanasia. The definitions of PS endorsed by major medical societies implicitly rely on the same factors, and are broadly congruent. There is agreement that PS involves the use of sedative drugs to reduce the level of consciousness of a terminally ill patient in order to relieve

intractable suffering within the context of total care. Major U.S., Canadian and Western European medical societies endorse PS as a valuable part of normal medical practice.

Despite the superficial agreement among professional societies with respect to the definition of PS, there is disagreement about the terms used within the definition and about the prerequisites for implementation of the process. If we compare, for example, the guidelines issued by the Royal Dutch Medical Association (RDMA),[17] the European Association of Palliative Care (EAPC),[18] the National Hospice and Palliative Care Organization (NHPCO),[19] and the National Ethics Committee of the Veterans Health Administration (NEC-VHA),[20] we find discrepancies about the definitions of 'terminally ill' and 'reduced level of consciousness'. The necessity of a 'do not resuscitate' (DNR) order also divides the major guidelines. Additionally, as we shall see below, the definition of 'intractable' may not match usual clinical practice (Table 1).

The NHPCO guidelines define the patients appropriate for PS as terminally ill when they are expected to die within 14 days, which is close to the RDMA guideline that prognosis is death within 1–2 weeks. For the EAPC, the prognosis should be hours to days. Leaving the determination more broadly up to clinicians, the NEC-VHA says PS is indicated for patients who have entered the 'final phase of the dying process'. When we examine what is known about clinical practice, the importance of the difference between days and weeks will be clearer.

A reduced level of consciousness includes light and deep sedation, continuous and intermittent sedation. EAPC, RDMA, and NHPCO all explicitly state that the level of sedation should be the lowest necessary to relieve the intractable symptom being treated. EAPC explicitly states that intermittent or mild sedation should generally be attempted first. However, they do not go on to recommend that policies should codify this preference.

There is overwhelming agreement that intractable or refractory symptoms are those for which conventional treatments have not provided relief, further interventions are unable to provide relief, or further interventions will create excessive or intolerable side effects, or will not provide relief within a reasonable time frame. However, the guidelines assume that other methods of relief will have been tried first and failed prior to initiation of PS. Whether this is so will be discussed below in reviewing studies of clinical practice. Some have argued that there are situations that fall outside these guidelines, such as sedating patients before terminally extubating them. However, these situations fall under the proviso that other treatments would not provide relief in a reasonable time frame. Similarly, while guidelines and discussions repeatedly state that PS is a rare procedure used as a 'last resort', examining clinical practice calls these statements into question.

While many US guidelines explicitly require that patients undergoing PS have a DNR order, the EAPC guidelines do not. We saw above that U.S. courts indicated that balancing the competing interests of the state and the individual are at the crux of the decision to initiate PS. It may, therefore, be surprising to note that although all guidelines recommend consultation with patients and families, only the NEC-VHA explicitly requires consent. In contrast, the RDMA guideline explicitly states that the ultimate decision is in the hands of the physician.

Close examination reveals, therefore, that guidelines about PS differ with respect to the specific patients for whom it is indicated, the limitations implied about other treatments, and the mechanics of beginning and continuing the practice.

Ethical issues

There are three main ethical issues related to PS. The first is whether PS is euthanasia, or whether it is the routine medical practice of symptom relief, which satisfies the principle of beneficence. The second is whether the practice supports patient autonomy, a central ethical principle in American bioethics. The third is whether sufficient safeguards are or could be in place to prevent its abuse, thereby satisfying the principle of non-maleficence.

Beneficence, PS and euthanasia and euthanasia

If PS does not hasten death, there is no reason to charge that it is a form of euthanasia. Whether it hastens death is largely an empirical question. A 2012 systematic review of eleven studies (seven retrospective and four prospective) that involved 1837 patients in the USA, the UK, Europe, South Africa, and Asia revealed wide variations in percentage of patients sedated, indications for sedation, medications used, and duration of sedation.[21] All studies were characterized by the reviewers as either fair or fair–-poor in quality. Only four studies reported relief of distress, and only two studies reported survival from start of sedation. Despite these limitations, the review found that there was no statistically significant difference in mean or median survival between sedated and non-sedated groups. Confirmation of these data is provided by a prospective study comparing two cohorts of hospice patients, one of which was sedated and the other of which was not.[22] The authors concluded that PS had no overall effect on length of life in otherwise terminally ill patients.

A retrospective study of 124 cancer patients admitted to a palliative care unit of a hospital in

Table 1

organization→Definition↓	RDMA	EAPC	NHPCO	NEC-VHA
Terminal=death in	1–2 weeks	Hours to days	14 days	Patients have entered the final phase of dying
Reduced level of consciousness	Lowest level necessary to relieve symptom	Intermittent or mild sedation usually should be tried first	Lowest level necessary to relieve symptom	Lowest level necessary to relieve symptom
Decision rests with patient/surrogates	No. rests with physician	Consultation with Patient/surrogates recommended	Consultation with Patient/surrogates recommended	Patient/surrogate consent required
DNR in place	Yes	No	Yes	Yes

Japan showed that one half of them had at least one uncontrolled symptom for which they were sedated. They found no significant difference in time to death between those who were and were not sedated.[23] Three older studies examined degree of sedation and impact on survival after withdrawal of ventilatory support. None of them found a correlation between survival and use or dosage of sedating drugs.[24–26] In all three studies, morphine and benzodiazepines, not sedative drugs, were used to sedate patients.

In contrast, a Japanese study found there was a small increase in risk of respiratory depression or aspiration in individual patients.[27] Sykes and Thorns[28,29] also published two review articles examining use of PS. As in the Japanese study, there were very few cases in which it could be argued that sedation hastened death, but they did exist.

The data about hastening death are not incontrovertible. Needless to say, no randomized controlled trials have been or even could be done. Methodological heterogeneity and variations in prevalence, medications, and doses used weakens the conclusions reached based on existing studies. Claessens *et al.*[30] concluded that more research was needed to determine whether PS shortened life. However, the balance of evidence currently seems weighted to the conclusion that PS does not hasten the death of most terminally ill individuals.

Although the empirical issue is still open to question, the moral question of whether PS is justifiable can be adjudicated. Even if PS shortens life in the terminally ill, many ethicists argue that it can be justifiable – and can reliably be distinguished from euthanasia. In making this distinction, they appeal to the doctrine of double effect (DDE). The Court's reliance on intent and outcome to make the distinction also implicitly appealed to the DDE.

What is now called the DDE was first articulated by Aquinas[31] in a discussion of the morality of killing in self-defense. To justify an act on the principle of double effect, at least four conditions must be met.[32]

1. The act itself must be either good or at least indifferent.
2. The agent may not intend the bad effect, but may permit it if he cannot attain the good effect without the bad.
3. The good effect must be produced directly by the action, not by the bad effect, because using a bad means to a good end is never allowed.
4. The good effect must be sufficiently desirable to compensate for the allowing of the bad effect.

With regard to the first condition above, PS can be considered a good act, because the act of relieving intractable suffering fulfills the principle of beneficence. With regard to the second and third conditions, physicians performing PS intend to relieve suffering, and the relief is caused by the sedation, not by the person's death. To express this in the language of intent and outcome, the intent and purpose of PS are to relieve suffering, whereas the intent and purpose of euthanasia are to induce death. The successful outcome of PS is measured by whether suffering is relieved, whereas the success of euthanasia is whether the patient dies. In euthanasia, the bad effect (death) produces the good effect (end of suffering), in violation of the third condition. With regard to the fourth condition, if PS shortens life, death (the bad effect) is allowed for the purpose of relieving suffering (the good effect).

Some have challenged the DDE,[33] mainly on the grounds that intentions are complex, nuanced, and distinguishable from motive or purpose. Furthermore, intentions are difficult to determine, and multiple, contradictory intentions may accompany a single act. There are several weaknesses in this train of thought. First, whether or not we can objectively assess intentions, and whether or not they may be contradictory, we can agree that to practice euthanasia a physician selects types and doses of drugs expected to be lethal. It is *prima facie* reasonable to believe that physicians who choose lethal doses of lethal drugs intend the death of the patient to whom they are given. Second, right intention is only one of the four conditions that must be satisfied to justify an act under the DDE. The issue of balancing competing interests, which the Court addressed at length, is equally important and not identical to the issue of intentions. Third,

proportionality, which is discussed below, is central to the morality of an action. It may or may not be implicit in the third condition, but it is essential to the traditions that invoke the DDE.

Aquinas explains proportionality as follows: '...though proceeding from a good intention, an act may be rendered unlawful if it be out of proportion to the end. Wherefore, if a man in self-defense uses more than necessary violence, it will be unlawful, whereas, if he repel force with moderation, his defense will be lawful'.[34] In other words, it is one thing for someone to shoot back at someone shooting; it is another to pump 15 rounds into the person after they are on the ground, unarmed, and disabled. Satisfying the principle of proportionality bears directly on determining the choice and doses of drugs, the depth of sedation, and whether it is continuous or intermittent. Proportionality plays no role in euthanasia. Euthanasia drugs are not titrated – unless the provider mistakenly gives a dose that is not lethal.

In summary, if PS is a proportionate act that meets the four conditions required to invoke the DDE, it is not euthanasia, and can be ethically justified as an act of beneficence, even if it hastens the death of some terminally ill individuals.

Beneficence and continuing artificial nutrition and hydration

Some ethicists regard stopping artificial nutrition and hydration (ANH) as a decision independent of the decision to begin PS. Withholding or withdrawing ANH is subject to the ethical principles of beneficence and non-maleficence. Many families believe that ANH is beneficial, either because it provides comfort or because it extends life. Little evidence supports either belief. It is helpful to separate artificial nutrition (AN) from artificial hydration (AH) when examining the evidence. Studies in multiple different populations show neither survival benefit nor improved quality of life from AN, among those with advanced illness.[35–37] Similarly, multiple studies indicate that hydration does not contribute to survival or improved Quality of Life (QOL) in patients near death.[38,39] Palliative care teams are committed to providing care that is congruent with patients' and families' desires, values, and beliefs, whenever possible. If the goal is to prolong survival or improve QOL, then many people will agree to stop ANH after exposure to the evidence against its contributing to those goals. If the goal is to uphold cultural or religious imperatives, then it may be appropriate to continue ANH.[40,41]

Non-maleficence requires that we do no harm. If we accept the evidence that comfort is not reduced by withholding ANH, then we are not harming the patient by withholding it. However, if withholding ANH hastens death, then we are practicing euthanasia. If terminal sedation is employed in the last hours or days of life, then stopping ANH will not shorten life. If the patient lives beyond one week, then the decision to withhold ANH may need to be reexamined.

Autonomy

While autonomy is a core principle of bioethics, it is no more absolute than any of the others. It would be difficult to argue that respect for patient autonomy enjoins physicians to do whatever a person asks freely and sincerely. For example, we are not obligated (but are permitted) to give chemotherapy to a person for whom no medical or survival benefit will ensue, simply because the patient wants to 'go out fighting'. The fact that fulfilling the patient's request is within our power is not sufficient to render it ethically justified.

Autonomy by proxy is even more problematic. Although proponents cast the decision to start PS as an exercise of a competent patient's autonomy, once continuous sedation is begun the person loses autonomy.[42] If sedation is deep and continuous, a person is unable to change her or his mind and stop it, and there may be no way for those around the sedated person to gauge its effectiveness. When surrogates make the decision, it is even more difficult to argue that PS supports autonomy. Unless the patient made wishes clear prior to losing medical decision-making capacity, there is the potential to deprive patients of their autonomy against their will. In clinical practice, more often than not decisions about beginning and continuing sedation are not made by autonomous patients.

If it were easy to assess suffering in unconscious patients, then their inability to communicate would not be as problematic. Scales such as the Critical Care Pain Observational Tool, the Behavioral Pain Scale, and the Richmond Agitation–Sedation Scale have been, at most, only partially validated for use in the dying. All of them are limited by the fact that they infer level of awareness and pain from motor responsiveness, which is suppressed in deeply sedated patients. If we cannot rely on objective measures, to whom do we turn? Are family members' and surrogates' perceptions of their loved ones' comfort always truer to the patient's experience than the perceptions of medical staff? Are the perceptions of the medical staff more reliable than those of the patient and family?

The ethical principle of autonomy affirms that a competent person has the right to determine what happens in and to his/her body. Legitimate practical issues arise when trying to determine how to protect the interests of a suffering person who no longer has

medical decision-making capacity. As we saw above, the NEC-VHA requires consent of the patient or surrogate, but the Dutch have opted for leaving the decision in the hands of physicians. It is not clear that either requirement necessarily protects patients without capacity.

Non-Maleficence

There are two types of ethical argument against PS that relate to the ethical principle of non-maleficence, the obligation to do no harm. The first type is that the practice is often, if not always, potentially harmful. The second type is that the practice of PS is likely to lead to abuse. First, we discuss whether PS can be harmful, referring in part to advances in neuroscience. While the benefits of PS sometimes are easy to see – an agitated person becomes calm, a person no longer struggles to breathe – the fact that sedated patients are powerless to alter their life conditions places them in a uniquely vulnerable state that makes it all the more important for us to protect them from harm. As we saw above, the Courts have interpreted the fourth condition needed for an act to be justifiable under the DDE to mean that the patient's interest in relieving suffering must outweigh the state's interest in protecting the vulnerable from coercion, neglect, and medical error. The condition that the person must be terminally ill from a known cause of death is important in balancing these competing interests.

Some have argued that the harm inflicted by PS stems from the fact that it induces 'social death', the loss of ability to experience the world or interact with others. Last words may be unspoken. Last looks may not be seen. Continuous deep sedation renders the person isolated in a way that precludes connectedness, belonging, and community.[1,2,43–47] Insofar as connectedness and interdependence are essential qualities of human beings, PS takes away something of the humanity of the person. Harm also extends to the family, and others keeping vigil by the bedside of someone palliatively sedated, who may feel prevented from providing a meaningful presence to their loved ones.[1,19,31]

Another potential harm to the individual is that continuous deep sedation prevents further growth and development, and precludes the opportunity for transcendence. Arguments for the benefit of PS seem to arise from a static view of suffering,[1] the view that once suffering is intractable it becomes unbearable. However, the experience of suffering is variable and dynamic. What is intolerable at one point may later become acceptable, or even routine. Moreover, what is seen as a burden at one point may stimulate personal growth that leads to peace and closure.

Questions about non-maleficence raised by advances in neuroscience

Empirical data now challenge the assumption that, whatever our intentions, PS always relieves suffering. Only a few researchers have commented on the efficacy and safety of the practice. Morita *et al.*[28] reported that PS adequately relieved symptoms in 83% of the cases. They noted serious complications, including respiratory suppression without arrest, aspiration, and paradoxical reaction, in 22% of patients. Chater *et al.*[48] reported a perceived success rate of 90%, and Chiu *et al.*[49] reported that in 71% of the cases, physicians were satisfied with the treatment of PS, and 67% of families were satisfied. Despite that rather low level of satisfaction, 90% of the families in this study agreed that this treatment was the best option for the patient. The data we have, therefore, indicate PS is not unfailingly effective. Its potential failure means that informed consent for PS is fraught with more than the usual problems. Unless it is intermittent, there is no opportunity for the patient to communicate to the health care team whether or not the process has achieved its goal. The unconscious patient is no longer able to indicate that s/he is being harmed, is suffering.[47]

Developments in neuroscience are challenging our conceptions of consciousness, awareness, and even personhood. Our ability to determine a person's level of awareness – and consequently their suffering – remains extremely imprecise. Deeprose *et al.*[50] demonstrated that patients under general anesthesia may still experience noxious stimuli. Deschepper *et al.*[51] cite research studies establishing that 40% of patients in unresponsive wakefulness syndrome show minimal signs of conscious awareness, that some purportedly unconscious patients generated appropriate responses to two distinct commands on electroencephalographs, and at least sometimes, some patients could communicate 'yes' and 'no' answers using functional magnetic resonance imaging. Patients with locked-in syndrome may be mistakenly taken to be unconscious. Rarely, patients under general anesthesia experience pain. Descheppers *et al.* conclude that '[d]ying uncommunicative patients are a vulnerable population'. They recommend 'a triangulation of methods in which existing observational scales, subjective assessments of caregivers and family, and neuroimaging and/or electrophysiological techniques are combined'. At this point in time, the technology needed is not widely enough available to ensure that such triangulation becomes standard of care, but without further research there remain questions about how to prevent harm from PS.

If some sedated patients continue to suffer without being able to communicate that suffering, and we are unable to distinguish them from those whose suffering is relieved, the potential for PS to cause harm has to be admitted.

While the first type of argument against PS is based on the potential for harm, the second type is based on the potential for abuse. Concerns about abuses related to PS arise from reviewing what is known about its implementation. The incidence of continuous deep sedation until death varies dramatically from facility to facility and country to country, and appears to be increasing. In the USA, it is probably at least 34%,[21] in Flanders, Belgium (BE) about 15% (data from 2007), in the Netherlands (NL) about 8% (data from 2005), and in the UK about 17% (data from 2007 to 2008).[52] We do not currently have analyses that explain these wide variations. When the Supreme Court ruled that relief of interminable suffering was justified in certain circumstances and professional societies endorsed PS, the explicit assumption was that such circumstances would rarely occur. Even if the rate of PS were, on average, 10%, it would be difficult to continue to maintain it is a 'last resort' option used rarely.

The NL provides some potentially troubling data about the spread of PS.[53] In 2001, the percentage of patients undergoing PS was 5.6. By 2005, it reached 8%, and by 2010, PS was used in 12.3% of all deaths in the NL. At the same time, euthanasia rates declined. The authors of the study that revealed these rates are not alone in questioning (a) whether PS is seen as an alternative to euthanasia; (b) whether it is always used with patient consent; and (c) whether it is used without the careful titration of medications required by guidelines. Evidence supporting these concerns is found in another study,[54] which documented that in 21.6% of cases described by physicians as PS, the physicians had an explicit life-shortening intent, explicit patient request was present only in about 20% of cases, and physicians estimated that life was shortened by more than 24 hours in 51% of cases. One reason for the growth of the practice is suggested by a study of Dutch physicians' experiences of the influence of the family on PS.[55] This study indicates that the longer the patient stays alive, the more the family feels burdened. They may begin to question whether movements, moaning, or dyspnea indicate suffering. They may worry that lying helplessly in a bed is not, in fact, a dignified way to die. Not uncommonly, families pressure physicians to speed up the process, and at times physicians do so.

This author, and many co-workers with whom I have spoken, not uncommonly receive requests from families to 'just give her/him something'. Typical questions are 'Can't you just give him something so that he doesn't know what's going on?'; 'How long is this going to take? I have to get back to work'; and 'Can't you just put him out?' Many family members say 'I can't stand to see her/him suffer'. This author has begun to ask people why they think the patient is suffering. The reasons for these requests and their actual content are an area ripe for further exploration.

Existential suffering and the slippery slope

The 'slippery slope' refers to the argument that deciding to allow an action or practice that seems justifiable may begin a trend that ends in the unintentional promotion and acceptance of a morally unacceptable action or practice. With respect to PS, the question is whether allowing PS will result in it use for people who do not fit the carefully constructed guidelines. Specifically, the worry is that people who are not terminally ill, intractably suffering, and freely requesting PS will be subject to it. These worried are embodied in the issue of whether PS could be indicated for intractable *existential suffering* in the terminally ill. The arguments in favor of this view arise from the very definition of PS as indicated for intractable suffering. If the criterion is refractoriness, the reasoning goes, then why cannot anxiety, depression, demoralization, or moral distress qualify as a symptom for which PS is available? The EAPC guideline acknowledges that there is no consensus on the issue, but says there may be rare circumstances in which PS is appropriate for intractable existential suffering, and offers a set of guidelines severely restricting its use. To the objection that existential distress is not objectively quantifiable, and therefore cannot be judged to be refractory or not, the rejoinder is that the judge of refractoriness is properly and ultimately the individual. More strikingly, proponents accuse those who exclude PS for existential suffering of assuming a dichotomy between body and mind, delegitimizing patient experience, and operating from a somatic reductionist view of palliative care. If we are attending to the whole person, then how is it, they ask, that we should refrain from alleviating only certain kinds of suffering?[56]

The NEC-VHA report[21] summarizes three main arguments against the view that existential suffering is a valid indication for PS. They concern defining existential suffering, determining what a 'proportionate' response to it would be, and deciding whether relief of existential suffering is within the scope of medical practice. To begin with, there is no agreed on definition of existential suffering that provides concrete guidance on its diagnosis. Far from being somatic reductionism, it is recognition of the interdependence of body, mind, and spirit that leads to the conclusion it may be impossible to tease out the contributions of physical, psychological and spiritual distress to existential suffering. If the patient's distress is – even in part – from an underlying treatable physical or mental disorder, surely we are required to address that component of the suffering before calling it intractable.

What constitutes a proportionate response to existential suffering is also difficult to determine. Usual treatments for psychological distress have very low morbidity compared with sedation. Moreover, levels of existential distress vary significantly over time, and individuals may be capable of overcoming them at some point, without knowing at the moment that they have that capability. There also is no way for physicians to determine which individuals will be able to overcome existential suffering. Given that existential suffering is not, in itself, a lethal condition, it would be difficult to meaningfully distinguish PS from euthanasia in these cases.

On a practical level, the issue of proportionality concerns whether allowing practitioners to make subjective decisions about levels of suffering without objective confirmation opens the door to abusive practices. Allowing PS for existential suffering raises questions about how to guard against abuse. Opponents point out that if PS is indicated for intractable existential suffering, it is hard to know why it should be restricted to the dying. Why should it be withheld from, for example, schizophrenics who are suffering and not responding to treatment? If surrogates are permitted to make the request for PS, should we sedate until death severely mentally retarded children whose parents say their children have 'suffered enough'? Critics are concerned that approving PS for existential suffering will lead down the slippery slope to voluntary and non-voluntary euthanasia, regardless of whether or not a person is terminally ill.

In light of this concern, the EAPC recommends safeguards against abuse of PS for existential suffering, including having skilled clinicians make repeated assessments over time, convening a multidisciplinary care conference that includes bedside caregivers, psychiatry, chaplaincy, and ethics, initiating sedation on a respite basis for 6–24 hours and considering continuous sedation only after repeated trials of respite sedation with intensive intermittent therapy. It is not at all clear that these guidelines would prevent patients, families, or unbefriended patients from feeling pressure to request an end to life.

The issue of whether relief of existential suffering is within the scope of medical practice may be beyond the bounds of this paper. At stake is the relationship between patient and physician, and the limits of what we ought to do, even if we can.

In a variation on the slippery slope argument, ten Have and Welie[1] argue that increased use of PS is an example of 'mission creep'. Use of PS has followed a pattern typical of most medical interventions, which begin by being limited to particular indications in a particular set of patients and gradually evolve to being applied for other indications in other patients. In addition to the NL study cited above, other data from Europe indicate that PS has spread to use by non-specialists.[2] In Belgium, specialized palliative care units use PS at a rate almost 50% lower than its use in general care settings (7.5 vs 14.5%).[57] An Italian study showed that 13.2% of patients cared for at home received PS.[58]

Sedation for symptom control is not a new procedure. Many patients in trauma and burn units are sedated. Patients on ventilators in the intensive care unit are almost all sedated at some point. In dying patients whose intubation is being withdrawn, sedation to unconsciousness is used to prevent the patient from dying with symptoms of suffocation.[59] Sedation is also routine before minor surgical procedures, such as esophago-gastro-duodenoscopies, colonoscopies, vasectomies, some reconstructive and cosmetic surgeries, and some dental procedures – especially in patients who are highly anxious. What is new about PS is that it is being practiced increasingly widely, with no requirement for training in the procedure. Gastroenterologists are specifically trained to sedate patients before, for example, colonoscopies. There is no guarantee, and little reason to believe that hospitalists have been trained in PS. While there are no specific studies of the prevalence of different drugs used to sedate people in the USA, conversations with many of my co-workers have confirmed my belief that opioids are the most common drugs used to sedate patients. The author's hospital, and many others, has an order set for 'comfort care' used by all medical staff, whether or not they have been trained in PS. When a family requests PS because they deem the patient to be 'suffering', the doses of opioids are simply increased until the patient is no longer conscious. As more physicians with less training order PS, the probability of departing from the guidelines – or being ignorant of the guidelines – increases. If there is no adherence to guidelines, the potential for abuse increases.

Conclusions and wider implications

ten Have and Welie[1] argue that the widespread use of PS has important ethical consequences for the larger community and for the field of palliative care as a whole. First, they state that it signals a return to silence: it promotes a kind of dying in which connectedness, communication, and presence take a back seat to absence of signs of distress. Second, it represents a further medicalization of death. Third, it risks placing the kind of focus on treating the physical dimension of suffering with physical, pharmaceutical responses that characterized the kind of medicine palliative care was supposed to replace. They conclude that present-day palliative care replicates the traditional approach to end of life care:

> 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.

These authors are writing specifically about medical practice in the NL. They are not commenting directly on the practice of palliative care specialists, and their conclusions do not apply to the palliative care professionals this author knows, but there are certainly other physicians, some of whom practice PS, to whom they apply.

If PS were used for terminally ill patients with intractable suffering, using carefully titrated sedative drugs – i.e., were it done according to the guidelines developed by professional societies – it might well be used rarely, and its benefits might be incontrovertible. In such cases, few concerns (but not none) would arise about violating autonomy or committing harm. As it stands, the empirical data suggest that PS is used by generalists and by specialists without a palliative care orientation, that it is not uncommon, that titration is not the norm, and that often there has been no specific patient request. Under these circumstances, the potential to violate autonomy and cause harm is real and present.

Palliative care as a field is already undergoing a major convulsion stemming from the widespread use of opioids for chronic non-malignant pain. Specialists and non-specialists alike have been stunned by the unintended consequences of this effort to relieve suffering. While it is now clear that only a fraction of those with chronic non-malignant pain benefit from chronic opioid therapy, abuse remains rampant, and to date neither legal nor professional bodies have devised effective plans to remedy the harm being done. Could we be in a similar situation with PS? Are we unwittingly creating a culture in which all struggle is seen as suffering, and absence of feeling equated with peace? Our profession needs to continue to attend to these questions. More empirical data from the USA and Canada are critical to determine whether/what changes palliative care professionals should support. As a preliminary measure, PS should be more tightly regulated to ensure that the principles of palliative care, including the need for a multidisciplinary approach and repeated assessments of symptoms and their management, are required rather than just recommended, before and during PS.

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