

Palliative sedation: A controversial end-of-life practice

Overview

- What is palliative sedation (PS)?
- Indications for PS
- Case presentation
- Types of PS
- Existing ethics analyses
- Comparison of:
 - PS and voluntary active euthanasia
 - PS for physical distress and PS for psycho-existential distress
- Under-explored PS ethics issues
- Questions & comments

Palliative sedation

- Deep & continuous palliative sedation (sometimes called terminal sedation):
 - Induction and maintenance of a coma-like level of unconsciousness until death
 - Typically performed in a specialized palliative care setting
 - Usually achieved through the sustained intravenous administration of a potent sedative agent

Palliative sedation

- Where is PS practiced?
 - In many developed world countries (in particular, Europe and the East)
 - Used in the management of 4 to 10% of all deaths in the Netherlands (early 2000s data)
 - Variable use in North America – “apparently depending more on the values and practice patterns of the practitioners than [on] the patients.” (T. Quill, 2008)



Palliative sedation

- Clinical indications for PS – the ‘3Is’:
 - Imminent death
 - Distress/suffering that is:
 - Intolerable
 - Intractable (failure of multiple treatment modalities including standard ‘optimal integrated palliative care’)
 - Can be used for physical and/or psycho-existential distress...



The Case of Mrs. Thompson



Types of palliative sedation

- PS for physical distress, e.g.,
 - Pain
 - Nausea & vomiting
 - Terminal shortness of breath



Physical distress

- Does PS for physical distress hasten death?
 - Probably not much – in most circumstances PS is initiated after nutrition and hydration has been discontinued...
 - Patients died an average of 3.4 days after initiation [of PS] ... the length of terminal admission to the palliative care unit ... was not significantly different than that of patients not requiring sedation." (G. Cooney, 2005)



Psycho-existential distress

- PS for psycho-existential distress, e.g.,
 - Severe anxiety/fear
 - Agitation
 - Severe depressive dysphoria
 - Intense spiritual angst



Psycho-existential distress

- "The use of sedation to treat uncontrolled psychosocial or existential suffering is much more controversial [than to treat physical distress]." (G. Cooney, 2005)
- The frequency of use of PS for psycho-existential distress is unknown – suspicion that this practice is under-reported as the common co-morbidity of physical distress may be privileged in the recording



PS for psycho-existential distress

- Types of psycho-existential suffering treated with PS identified in a study performed in Japan...
 - 61% - feeling of meaningless/worthlessness
 - 48% - feeling of being a burden to others
 - 33% - death anxiety/fear/panic
 - 24% - wish to control time of death
 - 22% - isolation/lack of social support

Morita et al., 2004



Existing ethics analyses of PS

- Considerations of:
 - Respect for persons (autonomy)
 - Patient welfare
 - 'Double effect' principle (including proportionality, which is sometimes considered separately)



Respect for persons

- Concept of individual autonomy (self-determination):
 - A person has the right and should have the opportunity to choose his/her life plans including the making of decisions about his/her health care and treatment
 - In this context, a person and/or substitute decision maker (SDM) has the right to request and be offered PS when it is appropriate and available



Autonomy

- Potential problems:
 - Is informed choice possible in the context of intolerable, intractable suffering? – “reflective unimpaired consent may no longer be possible.” (M. Battin, 2008)
 - No opportunity to ‘change your mind’ (as opposed to the practice of intermittently lightening sedation in order to re-assess the patient’s status)



Patient welfare

- Beneficence
 - PS provides benefits to patients in the form of relief of their profound distress
- Nonmaleficence
 - PS eliminates harms/burdens related to the experience of intolerable, intractable suffering



Patient welfare

➤ Potential problems:

- In the view of some, PS poses a harm/burden in that it forecloses an important experiential life option – “suffering is a dynamic and transforming process that offers the opportunity for healing at the end of life.” (W. Shaver, 2005)
 - Usually accompanied by a ‘sanctity of life’ claim – a religious, absolute respect for life that is held to entail the wrongness of suicide and killing; life is sacred and should not be artificially manipulated



Double effect principle

➤ It is morally permissible to administer high doses of narcotics and/or sedative medications to patients if the only **intent** is to relieve suffering, even though the risk of death is foreseeable

- Derived from Roman Catholic moral theology
- Kantian ethics focus on intention



Double effect

- For the purpose of considering whether double effect justifies the practice of PS, it may be useful to compare the relevance of this principle to: 1) PS, and 2) the existing, standard palliative care practice of escalating dosages of narcotics to relieve severe distress in circumstances where this could lead to death



Double effect

- Four conditions that need to be met for this principle to justify an end-of-life practice:
 - The nature of the act must be 'good' independent of its consequences (or at least morally neutral and not in a category of that is absolutely prohibited)
 - Kantian ethics focus on the nature of actions taken by individual actors
 - The 'act' for both practices – the administration of medication to a patient



Double effect

- Necessary conditions, cont'd:
 - The secondary bad effect must not be the means to accomplish the primary good effect
 - Re. escalating dosages of narcotics: the bad effect is death and the administration of narcotic medication is the means to the good effect (relief of suffering)
 - Re. PS: the bad effect is a 'non-experiential state of being' and administration of sedative medication is the means to the good effect (relief of suffering)



Double effect

- Necessary conditions, cont'd:
 - There must be **proportionality** between the intended good effect and the foreseen potential bad effect – it is anticipated that the benefits of the good effect will significantly outweigh the harms/burdens of the bad effect
 - The crucial notion of proportionality ... is really at the heart of the concept of palliative sedation." (P. Claessens, 2008)



Double effect

- Necessary conditions, cont'd:
 - There must be a no less harmful option(s) for achieving the intended good effect
 - Typically, in circumstances in which PS is considered and offered, all other possible palliative care modalities have been tried and failed, including escalating dosages of narcotics



Double effect

- Potential problem in justifying PS through the principle of double effect:
 - In the practice of PS, “whether [the bad effect] is intended or merely foreseen is less clear.” (Quill, Dresser & Brock, 1997) – considering the standard definition of the principle of double effect
 - “Human intention is multilayered, ambiguous, subjective, and often contradictory.” (Quill, Dresser & Brock, 1997)
 - Some of this uncertainty/complexity about causation, intent and shared responsibility is ‘desirable’ and “all [research] respondents resisted this disambiguation...” (Douglas, Kerridge & Ankeny, 2008)



Comparison of PS & VAE

- Voluntary active euthanasia (VAE) – end-of-life practice in which a health care provider (HCP) deliberately ends the life of a patient in the fulfillment of a request to do so by a capable patient
 - Illegal in Canada; practiced openly in the Netherlands for 30+ years and now legally accepted under certain conditions in Dutch law
- Critics of PS have attempted to conflate these two practices for the purposes of casting aspersions on the moral legitimacy of PS; PS “is seen by some as euthanasia in disguise or as slow euthanasia...” (A. Rietjens et al., 2006)



PS vs. VAE

- Let's compare these two EOL practices by considering four selected domains of ethics analysis:
 - Autonomous choice
 - Motives
 - Actions
 - Consequences



Autonomous choice

- Both VAE and PS respect individual autonomy
 - VAE – must occur within the context of a fully informed consent/choice process; requires the direct consent of a capable patient
 - PS – the decision to initiate the practice may be substituted in some circumstances when the patient lacks capacity



Motives

- The motives may be somewhat different
 - PS – usually the motive is relief of profound, intractable suffering
 - VAE – there is some research to show that “requests for euthanasia are often inspired by a sense of loss of dignity ... euthanasia seems to be used as a response to a crucial loss of dignity.” (A. Rietjens et al., 2006)



Actions

VAE	PS
<p>➤ Typically, intravenous injection of a lethal cocktail containing potassium chloride by a solitary HCP in a home or hospital setting</p>	<p>➤ A potent sedative agent is administered over time in a hospital setting by a group of attending nurses who are following an attending physician's formal treatment order</p>

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Consequences

VAE	PS
<p>➤ Direct and relatively immediate ending of the life of the patient; often the time between VAE and <i>anticipated death without the intervention</i> is not accurately predictable – death is potentially hastened</p>	<p>➤ Induction of a 'non-experiential state of being' which typically lasts for days (and most often does not interfere with the timing of death from the underlying health condition)</p>

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Consequences

➤ Controversial claim – VAE produces less harmful consequences than PS on the basis of:

- Relative reduction in the prolonged anticipatory grief of family members
- Reduced burden of hospitalization costs to challenged health care systems

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Using the same four domains of ethics analysis, compare the practices of PS for physical distress (PS-px) and PS for psycho-existential distress (PS-p/e)



Autonomous choice

➤ Both practices require:


- Fully informed direct consent of a capable patient or indirect consent of the legitimate substitute decision maker (SDM)
- Given the extreme nature of the clinical circumstances in which PS is typically considered and offered, informed consent of a SDM is often (but not always) required



Autonomous choice

➤ Assessment of the degree of suffering:

- There are known, readable clinical signs of severe physical distress, e.g., withdrawal responses to pain, facial grimacing, increased cardiac and breathing rates, etc.
- Psycho-existential distress may not manifest itself externally in a quantifiable way – “no simple and clinically oriented evaluative and therapeutic method exists for the many spiritual and psychosocial concerns encompassing existential suffering.” (P. Rousseau, 2001)



Motives

- Motives – ?essentially the same for PS-px and PS-p/e
 - The intention of the capable patient/SDM/HCPs is to relieve intolerable, intractable suffering...
 - ...and *suffering is suffering*, right??
 - WHO definition of palliative care: "An approach that improves the quality of life of patients ... through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."



Actions

- The acts performed by HCPs are the same for PS-px and PS-p/e, i.e., intravenous administration of a potent sedative agent to induce a sustained deep level unconsciousness



Consequences

For PS-px	For PS-p/e
➤ Usually initiated after nutrition & hydration have been discontinued; according to research, death is not usually hastened	➤ More likely to be initiated when the patient is still receiving nutrition & hydration; likely more variability in the period of time from induction of PS to death; claim that life is possibly foreshortened



Consequences

- From a relational perspective,
 - In circumstances where the patient is capable, there may be differences in the psychological responses of family members (and attending HCPs), e.g., they could experience greater emotional difficulty accepting the patient's choice in PS-p/e than in PS-px



Under-explored ethics issues of relevance to the practice of palliative sedation



Under-explored issues

- Who should decide? – potential HCP bias
 - PS is usually first considered by the patient's attending health care team and, if there is a consensus among them that PS is appropriate and should be offered, the option is presented to the patient/SDM
 - Potential for the personal values, beliefs and biases of individual team members to act as a veto regarding the offering of PS



Under-explored issues

- Who should decide? – patient vs. family
 - In circumstances in which the patient has capacity, PS is usually only provided where dual consent has been obtained from the patient and his/her family, presumably in an attempt to reduce the psychological distress of family members (and HCPs) during the variable period of time that the patient remains in an unconscious state before his/her death



Under-explored issues

- Should the current accepted '3Is' criteria for PS be relaxed?
 - Projected time to death
 - Degree of suffering/distress
 - Treatment refractoriness of the underlying medical condition



Questions & Comments