PALLIATIVE SEDATION THERAPY - MOVING FROM CONTENTION TO CONSENSUS

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Outline

History of PST within EOL care
  - Published findings on its prevalence
  - Controversies surround its use
  - Observations and findings from this history

Clinical Guideline
  - What are the established mechanisms to standardize medical practice?
  - History (to date) of guideline/policy development for PST
  - Essential components to standardization of practice

Conclusion
  - Beyond clinical guidelines
  - Future research needs
“We are now always able to control pain in terminal cancer patients sent to us, and only very rarely indeed do we have to make them continually sleep”

1961

Dame Cicely Saunders

“More than 50% of these patients die with physical suffering that is controlled only by means of sedation”

1990

Dr Vittorio Ventafridda
What’s in a Name?

In the past, alternative names/descriptions have been suggested to describe the practice of sedation at the end of life—some of the less appreciated terms have included:

- Opioid Coma
- Anesthetic Coma
- Slow Euthanasia (still in use by some!)
## Contemporary terms/descriptors

<table>
<thead>
<tr>
<th>Conscious</th>
<th>Continuous</th>
<th>Intermittent</th>
<th>Terminal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deep</td>
<td>Light</td>
<td>Reduced</td>
<td>Proportionate</td>
<td></td>
</tr>
<tr>
<td>Palliative</td>
<td>End of Life</td>
<td>In the imminently dying</td>
<td></td>
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</tr>
<tr>
<td>Sedation</td>
<td>Sedation Therapy</td>
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</tbody>
</table>
PST vs. “Terminal” Sedation

The use of prefix “terminal” is ambiguous and potentially controversial.

- Sedation for patients with a terminal prognosis.
- Sedation until the patient’s life terminates.
- Sedation which causes/contributes to patient’s death.
- Sedation intended to cause a patient’s death.
History does not refer merely or even principally to the past- on the contrary the great force of history comes from the fact that we carry it within us…..

- James Baldwin, Civil Rights Leader
The pull

- History has a strong effect upon us morally
- History shapes our core identity
- We “occur” within a story –of the past
- There can be many histories- but we suffer from the great optical illusion that assumes there is one monolithic historical reality
So

- What then is the appropriate role of history in human life?
- To what extent should we allow history to shape our identity and action?
- Do I have an ethical duty to fulfill this role?

Response to these questions have varied anywhere from total amnesia to what can be called “fractured time”
Answers have generally evolved around four central themes

- Pluralism
- Forgetting
- Social dualism
- Sectarianism
Pluralism

- Ultimate philosophy of diversity
- Pluralist say it’s the hegemony of one “history” over others that has caused much grief
- It says there is no one “truth” in the world
- One account of history is as good as the other

Problems

Epistemological problem of no consistent set of truths
- All views of history are not equal
- Sometimes identity forms history
Forgetting

- Memories make us act in immoral ways- ergo forgetting should work well!

Problem/Concerns
- Yes history helps create our identity- but does it force people to do things for good or ill?
- Human nature dictate people do things not because history makes them do it- they do it because they want to achieve some goal or value
Social Dualism

- Says certain moral interpretations of events can be sacrificed for the good of the whole
- Focus on social cooperation and action- a greater social welfare is identified to bring people out of their own personal history to serve a common good

Concern

-how good are one’s personal ethical stance if they fail to address life as it is? If we can abandon some goods for the greater good- then how good are the views that we hold???
Sectarianism

- Oftentimes refutes the basic tenets of pluralism
- Find a community where your own views are accepted
- Don’t try and impose our views on others

Concerns
Not easily supported if you assert that you have an ethical responsibility to those around you and more generally to humanity...
A 5\textsuperscript{th} way?

- Need a proper way to understand history in human life
- “Those who forget history are doomed to repeat it” (G Santayana)
  - Educative role that is fundamentally moral in nature.
  - History can teach us much but it must be from a history that is rooted in objective truth
A 5th way

- Need to look back and see the inherent dichotomy between myth and history
- Myth carries the moral message and history accounts what actually happened
- Myth fosters identity, culture, and belonging—these self-serving narratives are myths—even if it does contain facts
HOW DOES THE ROLE OF HISTORY AND ITS ENSUING EFFECT ON ETHICS IMPACT EOL CARE AND THE USE OF PST?
Goal of medicine - historical contemporary

- Medical aphorism: Cure sometime; Relieve often; Comfort always

- The alleviation of pain and suffering is an important goal of medicine, especially in the care of the dying.
Historical Timeline- palliative sedation

1959 Benzodiazepines introduced
1961 Marks the start of the modern hospice movement

* (1990) Dr Enck’s article on “Terminal Sedation”
* (1990) Cruzan v MDH
  * 1994 Cherney & Portney
  * (1994) Oregon DWDA passed
  * (1997)Vacco v Quill

* Legalization of euthanasia in Holland (2001)
* (2001) ACPEHRC position paper
  * “terminal” gets dropped from common reference to sedation

(2002 to 2010) 9 National/International guidelines are published

<table>
<thead>
<tr>
<th>1990 to 1999</th>
<th>2000-2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decade of Differentiation</td>
<td>Decade of Standardization</td>
</tr>
</tbody>
</table>
**Washington v. Glucksberg**

- The Court asserted that because assisted-suicide is not a fundamental liberty interest, it was therefore not protected under the 14th Amendment. As previously decided in *Moore v. East Cleveland*, liberty interests not "deeply rooted in the nation's history" do not qualify as being a protected liberty interest. Assisted-suicide had been frowned upon for centuries and majority of the States had similar bans on assisted suicide.
Averages by country

- Japan in 4 reports 40% (8-60)
- Italy in 7 reports 24% (3-52)
- USA in 4 reports 17% (2–25)
- Belgium and Netherlands in 9 reports 11% (5-43)
- Canada in 3 reports 8% (1-16)
Why the variation?

- Lack of a standard definition for palliative sedation
- Are some reporting only deep versus light
- Are some talking about sedation as a secondary but not intended outcome
- Levels of acuity seen by the reporting centre
- Culture of acceptance or culture of concern
What is Palliative Sedation Therapy (PST)?

- The use of a pharmacological agent(s) which can induce sedation (i.e. diminished consciousness).
- The presence of intractable distress (pain/suffering).
- Distress is refractory to standard non-sedative palliative treatment.
Ethics of Pharmacotherapeutics

- Medicine has traditionally been a balance between art and science.
- Trends in medicine have seen the focus and power of science being brought forward, and less focus on the art of the craft.
- Impersonal treatment meets personal care.
- Actions of probability when certainty is absent or missing.
- Challenges the goal: “right drug, right patient, right dose, right time.”
Diagnostic information is becoming more scientifically sophisticated- and yet therapeutic decisions aimed at treatment are often based on impressions and traditions.
Professionalism and Pharmacotherapy

- Have a clear indication for the administration of any drug
- Use medications you know (beneficial effects and possible side effects)
- Judgment of a drug's superiority should be justified by the evidence at hand (not just from a pharma sales rep)
- Employ sound pharmacological principles in the administration of any drug
Professionalism and Pharmacotherapy

- Possess knowledge of drug-drug interactions. Many hospitalized patients are on at least 6 different medications.

- Knowing when to adjust, stop a medication is as important as when to start.
Pharmacotherapy seeks safety and efficacy of a drug on an individual.

All patients differ in their response to drugs.

Each therapeutic encounter must in part be considered an experiment... (N of 1)

- Need well-defined clinical endpoints.
- Needs in some cases surrogate markers.
Individualized therapy requires pharmacokinetic and pharmacodynamic knowledge

- Age
- Underlying Disease
- Status of organs of elimination (kidney, liver)
- Concurrent use of other medications
- Hydration and nutritional status
- Previous exposure
Important considerations…

- Large patient to patient variability exists and needs to be applied to all aspects of therapeutic drug monitoring
- Monitoring of pharmacodynamics requires the use of indicators for acceptable efficacy and toxicity
The art of medicine

... The secret of the care of the patient is in caring for the patient.

- Francis Peabody in his 1927 essay entitled: The Care of the Patient
...clinical picture(s)......

Knowing what’s wrong.... And what treatment (drug) is most effective
Art and Science

- Therapeutics must be dominated by an objective evaluation of an adequate base of factual knowledge.
- The need to be attuned to the emotional life of the patient… “the significance of the intimate relationship between a clinician and patient cannot be overemphasized” (F. Peabody)
How does ethics of pharmacotherapeutics impact palliative sedation?

- How is refractory understood by you
- What are the clear cut indications for sedation?
- What additional medications are needed in conjunction with the sedative?
- Which drug will you use?
- What administrative dosage rate will you prescribe?
- What plans are in place for monitoring your “sedated patient”
- What is the “relationship” you have with the patient/family?
Quality of care issues for PST

- Clear understanding of what constitutes a refractory symptom- (i.e. mgt of delirium protocols)
- Variation of determination of refractoriness by skill level- use of consult services
- Documentation of consent
- Proximity to death wrt use of PST
- Clinical audits of CPG’s (training, order sheets)
### Significant Publications that have impacted guideline development and creation for PST

<table>
<thead>
<tr>
<th>Title</th>
<th>Type</th>
<th>Year</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Sedation Therapy: Therapy in the last weeks of life: A literature review and recommendations for standards</td>
<td>Formative review</td>
<td>2007</td>
<td>De Graeff and Dean</td>
</tr>
<tr>
<td>Existential Suffering and palliative sedation: A brief commentary with a proposal for clinical guidelines</td>
<td>Formative article</td>
<td>2001</td>
<td>P. Rousseau</td>
</tr>
<tr>
<td>Responding to Intractable Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids</td>
<td>Formative paper</td>
<td>2000</td>
<td>American Society of Internal Medicine EOL Consensus Panel (I Byock and T Quill authors)</td>
</tr>
</tbody>
</table>
# Palliative Sedation Therapy - Guidelines, Frameworks and Consensus Statements

<table>
<thead>
<tr>
<th>Name</th>
<th>Type</th>
<th>Original Date/Rev.</th>
<th>Originator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous Palliative Sedation Therapy</td>
<td>Framework</td>
<td>Fall 2011(*being reviewed)</td>
<td>Canada- sponsored by Canadian Society of Palliative Care Physicians</td>
</tr>
<tr>
<td>Palliative Sedation Guidelines</td>
<td>Guideline</td>
<td>2010</td>
<td>Federation of Palliative Care Flanders [in Dutch]</td>
</tr>
<tr>
<td>Use of Palliative Sedation in Imminently Dying Terminally Ill Patients</td>
<td>Position Statement</td>
<td>2010</td>
<td>National Hospice and Palliative Care Organization (NHPCO)</td>
</tr>
<tr>
<td>European Association for Palliative Care recommended framework for the use of sedation in palliative care</td>
<td>Framework</td>
<td>2009</td>
<td>European Association for Palliative Care (EAPC) Cherny et al.</td>
</tr>
<tr>
<td>Title</td>
<td>Type</td>
<td>Date</td>
<td>Author/Source</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
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<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Guidelines for Palliative Sedation</td>
<td>Clinical Practice Guideline (CPG)</td>
<td>Dec 2005 (Revised 2010)</td>
<td>Royal Dutch Medical Association</td>
</tr>
<tr>
<td>Clinical Practice Guidelines for Palliative Sedation</td>
<td>Clinical Guideline</td>
<td>2005 (Revised 2009)</td>
<td>Alberta Health Services (Calgary Regional Health Authority CPG 1999)</td>
</tr>
<tr>
<td>Guidelines on Palliative Sedation</td>
<td>Guidelines</td>
<td>2001</td>
<td>Norwegian Medical Association</td>
</tr>
<tr>
<td>Name</td>
<td>Recommended Prognosis</td>
<td>Consideration for Existential Distress</td>
<td>Proportionate sedation</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-----------------------</td>
<td>----------------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Canadian CPST (2011)</td>
<td>&lt; 2 weeks</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Belgium Palliative Sedation Guidelines (2010)</td>
<td>&lt; 1 week</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>National Hospice and Palliative Care Organization (Position Statement) (2010)</td>
<td>&lt; 2 weeks</td>
<td>Unable to recommend</td>
<td>Yes</td>
</tr>
<tr>
<td>Dutch Guidelines for Palliative Sedation (2010)</td>
<td>1-2 weeks</td>
<td>Inclusive but never just for existential distress</td>
<td>Yes</td>
</tr>
<tr>
<td>European Palliative Care recommended framework for the use of sedation in palliative care (2009)</td>
<td>Hours/days</td>
<td>Special consideration</td>
<td>Yes</td>
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<tr>
<td>Alberta Health Services- Clinical Practice Guidelines for Palliative Sedation (2009)</td>
<td>Few days</td>
<td>Controversial</td>
<td>Induce, maintain deep sleep</td>
</tr>
<tr>
<td>AMA Special Report of the Council on Ethical and Judicial Affairs* Subject: Sedation to Unconsciousness in End-of-Life Care (2008)</td>
<td>Final stages</td>
<td>Not appropriate only for existential distress</td>
<td>Sedation to unconsciousness</td>
</tr>
<tr>
<td>AAHPM Position Statement on Palliative Sedation (2006)</td>
<td>Very advanced (would not alter time of death)</td>
<td>Not mentioned</td>
<td>Yes</td>
</tr>
<tr>
<td>Japan CPG for Palliative Sedation Therapy (2005)</td>
<td>2-3 weeks</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Norwegian Medical Association Guidelines on Palliative Sedation (2008)</td>
<td>Few days</td>
<td>Not appropriate for only existential distress</td>
<td>Yes</td>
</tr>
<tr>
<td>Sedation in the management of refractory symptoms: Guidelines for evaluation and treatment (1994)</td>
<td>Not specified- “end of life”</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Consensus on Clinical Indication

- Intolerable symptom(s)
  - Patient, family and professionals agree that the physical symptoms is (or appears) profoundly distressing

- Refractory symptom(s)
  - Patient and professionals have tried all reasonable available options and found them to be unsatisfactory

- Imminently dying (days-week)
Patient or substitute has requested:
- that no resuscitation be attempted in event of death (DNR, No CPR order)

Patient or substitute has given:
- informed consent for sedation
Consensus on Clinical Administration

- Titration of sedation (Proportionality)
  - Depth – just enough to control symptoms
  - Continuity – intermittent trial

- Monitoring of effect of sedation
  - As palliation – [symptom scales]
  - Overall status – e.g. respiratory status, hydration status, etc.
Contention

- Indications for CPST
  - Psychological/existential distress alone

- Imminence
  - How close to death is the administration of CPST justifiable
Psychological/Existential Distress

- Conceptual understanding of total pain
  Is pain: what the patient says it is?
- Is medical therapy the answer to spiritual or existential suffering?
- What is existential suffering refractory to?
- Conflicting psycho-spiritual and cultural meanings of “suffering”
- Can decision-making in the context of anguish be compatible with rational thinking
Imminence

- When is it ok to hasten death?
- Limits to the Principle of Double Effect
- Intent/Causation: withholding nutrition and hydration in CPST for patients with a prognosis greater than days to a week(s) versus hours to days.
Ethical Issues Central to CPST

- Can a patient’s free and informed consent (free from undue situational coercion) ever be obtained in the context of intolerable suffering?

- Is the use of PST in the face of Existential Suffering ethically justified?
  - Is a treatment that relies on the decrease/absence of consciousness— not just another means to remove suffering by removing the sufferer (euthanasia)?

- What are the appropriate prognostic criteria for the use of CPST?
  - Does PST hasten death?
  - How is the withholding of artificial nutrition and hydration in CPST different from a practice of slow euthanasia?

- Can any policy related to CPST incorporate sufficient safeguards to stop abuse?
Principles at Play

- Autonomy
  - Consent
- Beneficence
  - Mercy
- Non Maleficence
  - Integrity of medicine
  - Increased vulnerability
- Sanctity of life
  - Sentient
  - Biological
- Proportionality
- Intentionality
- Causation
- Imminence
How do we answer this question?

- Need to have an understanding of what existential distress (suffering) is
- Need to have an understanding of what the role and duty of a clinician is in the context of care at the end of life
- Need to know what the argument is that presents a conflicting perspective—why do people say we ought not use sedation for this indication
Human suffering

- Rely here on the work of Eric Cassell
- Suffering experienced by person’s is unique precisely because of their essential features
- So- if it’s the nature of the human person that suffers- we need to understand what is the core nature of human beings
Topology of a person

- Life Experiences
- Cultural and Social background
- Body
- Family
- Roles
- Political Rights
- Private Lives
- Transcendent Nature
- Personality and character
- Behavioral patterns
- Temporal status (Past, Present, Future)
Defining suffering-- now

“A state of severe distress associated with events that threaten the intactness of the person”

Topology of a person
Define Existential Suffering

“The experience of agony or distress that results from living in an unbearable state of existence, including for example—death anxiety, isolation, and loss of control”
What can we say about suffering

- Suffering has many potential sources
- Suffering has many dimensions
- The body (qua body) does not suffer; persons suffer
- Based on Cassell’s definitions- all suffering experienced by the human person is inevitably existential
Critics……

- Seek to distinguish between “clinical” and “nonclinical” forms of suffering.
- Believing then that palliative sedation should only be reserved for refractory clinical suffering.
- Nonclinical suffering is viewed as being beyond the scope of clinical care [and better addressed by other interventions]
Diagnosing suffering?

- Clinical suffering is neuro-cognitive in derivation in that it has a direct causal relationship to the patient’s underlying medical condition (i.e. physical pain in the body causes anxiety).

- Nonclinical suffering is agent-narrative in derivation and has only an indirect causal relationship to the patient’s underlying medical condition (related to the patient’s beliefs about their underlying terminal condition).

Scientific reductionism

- System
- Organ
- Cell
What is the goal of medicine? Role of the physician and clinician?

- Ultimately whatever definition we arrive at, it will entail- at its heart, a call of duty for all clinicians to relieve pain and suffering in the actualization of their role as healers

I. Byock. The Best Care Possible 2012
Life [in and of itself] as a human value (Good)

Traditionally there have been three competing approaches to looking at the inherent value in human life:

- Vitalism
- Quality of Life
- Inviolability of life
Vitalism

- Life is considered a supreme good
- It should be preserved in each patient at all cost
Quality of life

- Life in and of itself isn’t inherently valuable
- It’s the dignity with which one lives their life that defines its value
- This reduces life to being only an instrumental good - life is simply the essential platform for defining a worthwhile life
- Implies a “threshold” quality is needed
Inviolability of life

- Life here is viewed as a basic or intrinsic good.
- All human beings by virtue of their being human possess an inherent, inalienable, ineliminable dignity.
- It is this dignity that grounds one a “right to life.”
- Core principle- it is always wrong to try and extinguish the life of another.
Argument from autonomy to justify or prohibit the taking of life

- In a QoL value-based system, it would be the (subjective) self assessment of how dignified or indignant life is that determines if life can ended voluntarily (intent).

- Within a Sanctity of life value-based system, it is acknowledged that personal choice is an essential human capacity (by exercising this choice, we shape our lives and influence the lives of those around us). However, it comes with an obligation-that we use this capacity reasonably: choose good and not ill
Inviolability of life

- Sees an important distinction between intending death and foreseeing death as a side effect of one’s conduct
- Foreseen causation ought not be conflated with intention
- Intention implies foresight and causation
- To grapple with the challenges of life- the principle of double effect came into being
<table>
<thead>
<tr>
<th>Arguments supporting a moral difference</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Intention</td>
<td>In sedation shortening of life in never the intended goal</td>
</tr>
<tr>
<td>Withholding AHN</td>
<td>Sedated patients die from their underlying disease- not from withholding AHN</td>
</tr>
<tr>
<td>Proportionality</td>
<td>Sedation medications are titrated to effect</td>
</tr>
</tbody>
</table>
| Sanctity of life                       | Sedated patients die from their underlying disease-
|                                        | Patient is allowed to die passively |
| Removal of consciousness               | Unconscious patients are not dead |

Does PST effect survival?

- Recent paper published in the Journal of Clinical Oncology “Palliative sedation in end of life care and survival: a systematic review" from Italy (J. Ckin. Onc; Vol 30, No 12, April 20, 2012).
- Provides some interesting evidence
Literature search between 1980 and 2010
Excluded case studies, guidelines, reviews, surveys, letters, ethical articles, studies without survival data recorded
Total articles reviewed 11 (out of 59 found)
7 of these were retrospective and 4 were prospective studies
Total patients 1807 of which 34.4% were sedated
Findings

Main refractory symptoms requiring sedation in 774 sedated patients:
- Delirium 30%
- Psychological distress 19%
- Dyspnea 14%
- Pain 7%
Findings

- Median time of sedation: 0.8 to 12.6 days

- Median impact on survival
  - Sedated: 7 to 36.5 days
  - Unsedated: 4 to 39.5 days
  (no statistical difference)

- Cases where sedation may have negatively impacted survival time: 3.9%
Though PC has improved significantly, there are still many reported cases of treatments that are either ineffective or intolerable at the end of life.

7 of 10 studies reported that psychological distress was the primary cause for using sedation.

Overall sedation when appropriately indicated and correctly used does not shorten life.

In a small (3.9% of reported cases) where it did impact survival, there remains a role for the PDE.
History of the Principle of Double Effect

- Attributed to St. Thomas Aquinas
- 13th Century Dominican Priest
- Articulated in his discussion of killing in self defense
- Formulated a clean distinction between means and side effects
The human condition observed

- We can control or choose not to perform an intentional action

BUT

- We cannot always avoid doing something what has a bad side effect
The principle of double effect (PDE)

- PDE specifies that an action with two possible effects – one good and one bad is morally permitted if the action:
  - Is not in itself immoral
  - Is undertaken only with the intention of achieving the possible good effect, without intending the possible bad effect, even if it was foreseen
  - Does not bring about the possible good effect by means of the possible bad effect
  - Is undertaken for a proportionately grave reason
In defense of using PDE

- One needs to clearly specify the “effect” being aimed at by the intervention proposed. Some would say that having “relief of suffering” in and of itself as the desired effect would be too broad.

- Once the aim is identified, the clinician needs to be reasonably sure the intervention can achieve the effect (see ethics of pharmacotherapeutics).
Canadian CPST Framework

Process

1) CSPCP call for development of a PST Guideline (Spring 2008)
2) Working group created (4 PC Physicians + 1 Ethicist)
3) Detailed literature review and preliminary framework created
4) Review by 30 experts in PC, Ethics, Law (Canada and US)
5) Revision 1
6) Conference presentations (2 major CHPCA and 1 Canadian Bioethics Society)
7) Revision 2
8) Detailed survey of the CSPCP membership for consensus
9) Revision 3 with consensus notation and unaddressed comments to CSPCP
10) CSPCP endorsement of the framework
11) Journal publication (JPM August 2012)
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Terminology and Definitions</td>
<td>Aim statement</td>
</tr>
<tr>
<td>2 Aim statement</td>
<td>Indicators and Conditions</td>
</tr>
<tr>
<td>3 Communications</td>
<td>Decision-making and Informed Consent</td>
</tr>
<tr>
<td>4 Cultural considerations</td>
<td>Type of sedation</td>
</tr>
<tr>
<td>5 Drug selection, dosing and titration</td>
<td>Hydration, nutrition and concurrent medications</td>
</tr>
<tr>
<td>6 Ethical considerations</td>
<td>Outcome and monitoring</td>
</tr>
<tr>
<td>7 Family Supports</td>
<td>Staff Supports</td>
</tr>
</tbody>
</table>
How effective are guidelines for PST?

- Literature suggesting protocolization of medicine can help (i.e. The Checklist Manifesto, etc)
- Not a lot of research on this from the standpoint of palliative sedation
  - Published Dutch study 2009 (J Hasselaar in Arch Int. Medicine)
  - Unpublished Canadian study 2004? (T Braun, Calgary Chart Audit study)
### Table 1. Presumed Changes in Dutch Practice Regarding the Royal Dutch Medical Association Guideline for Palliative Sedation

<table>
<thead>
<tr>
<th>Guideline Recommendation</th>
<th>Research Variable</th>
<th>Expected Direction of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>The indication is a refractory symptom with a mostly somatic nature.</td>
<td>Presence of somatic (vs nonsomatic) symptoms as an indication for palliative sedation</td>
<td>Increase</td>
</tr>
<tr>
<td>Patient should be involved in decision making before sedation as much as possible.</td>
<td>Patient involvement in decision making for palliative sedation</td>
<td>Increase</td>
</tr>
<tr>
<td>Symptom management should be continued during sedation.</td>
<td>Use of morphine in case of physical pain and/or dyspnea plus use of antipsychotic medication in case of delirium</td>
<td>Increase</td>
</tr>
<tr>
<td>Benzodiazepine should be used as a sedative.</td>
<td>Use of midazolam, clonazepam, and diazepam</td>
<td>Increase</td>
</tr>
<tr>
<td>Morphine should not be used as a sedative.</td>
<td>Use of morphine without benzodiazepine</td>
<td>Decrease</td>
</tr>
<tr>
<td>Artificial hydration during sedation is not recommended.</td>
<td>No. of physicians who decided to forsake artificial hydration</td>
<td>Increase</td>
</tr>
<tr>
<td>Sedation should not be used as slow euthanasia.</td>
<td>a. No. of patients who formulated a request for euthanasia before sedation</td>
<td>Decrease</td>
</tr>
<tr>
<td>Patient life-expectancy prognosis should not exceed 1 or 2 weeks before the start of sedation.</td>
<td>Patient prognosis: &lt;1 week, 1-2 weeks, &gt;2 weeks</td>
<td>NA: only asked in 2007</td>
</tr>
<tr>
<td>Patients with oral intake should explicitly refuse artificial hydration. In other cases, artificial fluids are regarded as medically futile.</td>
<td>a. Oral intake before sedation: yes, ≥0.5 L/d; yes, &lt;0.5 L/d; no</td>
<td>NA: only asked in 2007</td>
</tr>
<tr>
<td></td>
<td>b. Percentage of patients with oral intake with whom artificial hydration was discussed</td>
<td></td>
</tr>
</tbody>
</table>

**Abbreviation:** NA, not applicable.

Dutch findings

- Patient involvement in decision making 72 to 82%
- Use of Benzo’s as sedative 70 to 90%
- Decrease in morphine for sedation 21 to 8%
- Request for euthanasia dropped 14 to 6%
- 1/3 of Physicians still felt that withholding hydration with sedation resulted in shortening of life, however, no change in median survival time was noted
CAN GOOD CLINICAL GUIDELINES OR POLICIES MITIGATE ETHICAL CONCERNS RAISED BY THE USE OF CPST?

- POOR DATA EXIST TO BASE CONCLUSION
- DATA SUGGESTS SOME CONCERNS ARE ADDRESSED BUT MANY CONCERNS REMAIN
- IS THERE A ROLE OF INTEGRATED CARE PATHWAYS?