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Hospice Palliative Care Program
Symptom Guidelines

Refractory Symptoms and Palliative Sedation Therapy Guideline

How can Palliative Care help you manage difficult symptoms? What about refractory symptoms?

Palliative care aims to relieve suffering and to help patients and families with life limiting illness live as actively as possible with good quality of life, neither hastening nor postponing death. Although many palliative patients experience symptoms, most are well managed when appropriate medications and treatments are used. **The FH Hospice Palliative Care (HPC) Symptom Guidelines** are valuable evidence based resources to help manage symptoms. http://www.fraserhealth.ca/EN/hospice_palliative_care_symptom_guidelines/

At times, symptoms prove more difficult to manage or do not respond to commonly used medications. In these cases, palliative care consultation can provide a key interdisciplinary resource. Admission to a FH Tertiary HPC unit is available through contact with your Hospice Palliative Care (HPC) consultation team or Palliative Care physician. HPC team consultation is available 24/7 in Fraser Health. During the day – HPC consult team contacts http://fhpulse/clinical_programs/end_of_life/Pages/Default.aspx After 5pm and weekend – HPC Physician http://oncall/oncall/BrowseSchedules/Groups.aspx?TeamId=103

The NEW HPC Symptom Guideline ***'Refractory Symptoms and Palliative Sedation Therapy'*** will help health care teams determine when a symptom is **refractory** versus **difficult** to manage. Refractory symptoms are those where "all possible treatments have failed, or it has been determined that there is no method within the time frame and risk: benefit ratio the patient can tolerate". (Levy & Cohen, 2005) **Consultation is strongly recommended to determine if a physical symptom is refractory. Consultation MUST be sought when the refractory symptom is 'existential' e.g. non-physical suffering.**

The guideline provides criteria and direction for when the extraordinary intervention of **Palliative Sedation Therapy (PST)** is an appropriate therapy. **PST may only be considered for a patient with terminal illness in the last days of life experiencing refractory symptoms.** Although sedative medications and brief periods of sedation may be the *unintended but predictable* adverse effect of mediation used in aggressive symptom management, this is different than PST. **PST aims to relieve intolerable suffering from refractory symptoms by the *intentional lowering* of a patient's level of consciousness in the last days of life by the *proportional and monitored* use of non-opioid sedative medications.** Opioids alone do not provide adequate sedation and should never used for that purpose. Pharmacological treatment choices appropriate for PST are outlined in detail in the guideline including anti-anxiolytics, neuroleptics, and sedative anti-epileptics.

Users are guided through a process of informed consent with active involvement of the patient and substitute decision maker(s) and interdisciplinary health team. Recommendations for discussions, documentation, and patient and family support are included. Guidelines for initiating and adjusting sedation proportional for symptom relief are outlined.

PST is an extraordinary intervention requiring expertise in clinical care, communication and interdisciplinary team process. When used appropriately, the patient experiences symptom relief until death occurs through the natural course of the underlying disease, usually within hours to days .(deGraff & Dean, 2007) HPC Consultation team is available for support and guidance. **If palliative sedation therapy is initiated in FH, please follow the link to access a tool intended to obtain your feedback and assess the utility of the guideline.** http://fhpulse/clinical_programs/end_of_life/End of Life Document Library/Refractory Symptoms and Palliative Sedation Therapy Clinician Feedback Form Nov 3 2011.pdf

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Refractory Symptoms and Palliative Sedation Therapy

☐ Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Fraser Health, British Columbia.

☐ Scope

This guideline provides recommendations for the ongoing assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing refractory symptoms in the last days of life. For the management of a specific symptom, see *Fraser Health Hospice Palliative Care Symptom Guidelines on the relevant symptom.*

This guideline does not include or suggest any support for practice of physician assisted suicide (PAS) or euthanasia. It does not cover emergency sedation for crises such as exsanguinations and respiratory crisis in the last minutes of life.

☐ Background

Palliative care aims to relieve suffering and to help patients live as actively as possible, neither hastening nor postponing death. FH HPC Symptom Guidelines are valuable evidence based resources for managing symptoms. Although many patients with life threatening illness experience symptoms, most are well managed when appropriate medications and treatment approaches are used.

When symptoms are difficult to manage, HPC consultation provides a key interdisciplinary resource for providers, patients & families. Admission to the FH Tertiary HPC unit may be needed and is available through contact with FH HPC physicians.

In rare circumstances, thorough interdisciplinary assessment and treatment of a palliative patient's symptoms may not result in sufficient relief. When all possible treatments have failed, or no methods are available for palliation within an acceptable time frame, the symptom is determined to be refractory.

The incidence and type of refractory symptoms vary significantly according to patient demographics, regional access to adequate pain management and palliative care, and the availability of interventions, health care professional treatment patterns and the standards of care.[1,2] The most common refractory symptoms are: delirium, dyspnea, pain, nausea and vomiting.[1,3-5]

Determining that a physical symptom is refractory often requires consultation. Consultation must be sought when the refractory symptom is existential suffering. HPC team consultation is available 24/7 in Fraser Health.

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Palliative Sedation Therapy (PST) is an infrequent and extraordinary intervention that requires inter-professional expertise and effective communication skills of the caregivers involved.[5,6]

☐ Definition of terms

Palliative Care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, 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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."[20]

Refractory Symptoms (also "Intractable", "Unbearable") are physical and emotional symptoms for which "all possible treatments have failed, or it is determined that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate".[2] Often geography and the relative availability of interventions influence the determination of refractoriness.[1]

Difficult Symptoms, by contrast could possibly respond within a tolerable time frame, to aggressive interventions that yield adequate relief and preserve consciousness, without excessive adverse results.[2, 6]

Suffering (also "Distress", "Anguish") is "a sense of helplessness or loss in the face of a seemingly relentless and unendurable threat to quality of life or integrity of self".[21] Although pain, dyspnea, delirium, nausea and vomiting are frequent causes of suffering at the end of life, hopelessness, remorse, anxiety, loneliness, and loss of meaning also cause suffering. Suffering involves the whole person in physical, psychological, and spiritual ways and can also affect family, friends, and caregivers.[22]

Existential Suffering (also "Psychic" or "Spiritual" Suffering, Distress or Anguish) describes the experience of patients facing terminal illness who may or may not have physical symptoms but report

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distress that is related to "the meaninglessness in present life", hopelessness, being a burden on others, feeling emotionally irrelevant, dependant, isolated or grieving, that is unrelated to a psychiatric disorder or social isolation.[23,24] Existential distress specifically develops as a result of facing one's own mortality.

Moral Distress occurs as an "emotional and spiritual response when an individual is obligated to act in a manner which breaches their personal belief and value system" and/or "arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action."[25-27]

Natural Sedation or drowsiness occurs as part of the dying process. Progressive drowsiness or sedation is expected and occurs as part of reduced consciousness leading through coma to death. This is due to a combination of renal/hepatic/septic/neurologic processes resulting in body shutdown.[28]

Consequential (ordinary/mild) **Sedation** is the unintended but predictable adverse effect of some drugs used for symptom control in patients who are not actively dying. This type of sedation may be transient and is often reduced or eliminated with dose adjustment, or as tolerance develops. Brief periods of sedation may be used in the general management of pain, dyspnea or delirium. This is not PST.[28]

Respite Sedation (intermittent) is intended to be temporary. The patient is sedated, then awakened after an agreed upon period (usually 24-48 hours) to assess whether or not the symptom remains refractory.[3,5,6,14,38-40] "The practice of respite sedation recognizes that either a symptom might respond to continued or future therapy or that the patient's ability to tolerate the symptom may be improved following the rest and stress reduction provided by sedation."[6]

Family is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be "like" a family member, regardless of blood relations.[31]

Assisted Suicide is the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both. In **Physician Assisted Suicide**, the other person is a physician.[32]

Physician Assisted Suicide means knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.[32]

Euthanasia means knowingly and intentionally performing an act that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition, AND commits the act with the primary intention of ending the life of that person.[32]

Palliative Sedation Therapy (PST) (also "Terminal Sedation", "Controlled Sedation", "Total Sedation", "Deep Sedation", "Continuous Sedation") is the intentional lowering of a patient's level of consciousness in the last days of life. It involves the proportional and monitored "use of sedative medications to relieve intolerable suffering from refractory symptoms by a reduction

in patient consciousness".[5] The patient experiences symptom relief until death occurs by the natural course of the underlying disease, usually within hours to days.[5]

Decision-making is focused on relieving the patient's suffering and creating a more tolerable situation by adjusting the combination and doses of drugs administered.

PST can also be regarded as inducing and maintaining "sleep" in very specific circumstances:

- for the relief of refractory suffering, when all other possible interventions have failed, and
- when the underlying disease is irreversible and death is expected in hours to several days.[3,4,5,8,12,24, 33-38]

In clinical practice, PST usually does not alter the timing or mechanism of a patient's death, as refractory symptoms are most often associated with very advanced terminal illness.[37-45]

In using Palliative Sedation Therapy (PST) the intention is symptom relief by proportional use of sedative medications to lower consciousness only as much as is necessary to obtain symptom relief. In euthanasia or physician assisted suicide (PAS), there is no proportional use of medications as the primary intent is the death of the patient.[46]

☐ Standard of Care

1. Determine symptoms are Refractory
2. Determine criteria for implementing PST are met
3. Guidelines for Decision-Making
4. Documentation of Decision-Making
5. Initiating, Assessment and Care Provision
6. Supportive Care
   A. Supporting the Family and Friends
   B. Supporting the Care Team
   C. Care after Death
7. Pharmacological Interventions - Initiating and Maintaining PST

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Recommendation 1 Determine symptoms are Refractory

As mentioned under definitions, a refractory symptom is a symptom that has not been adequately relieved despite attempts to do so, using a variety of intervention strategies. A symptom or symptoms are considered refractory when "all possible treatment has failed, or it is estimated that no methods are available for palliation within a time frame and risk-benefit ratio that the patient can tolerate".[3]

The **patient** must be the one suffering from refractory symptoms. It is not uncommon for families to request PST on behalf of their loved one, citing a perception of suffering, when in fact it is the family that is suffering.[47]

In order to ensure that thorough assessment of and intervention for one or more difficult symptoms has been attempted, the reader is referred to the relevant symptom section in the FH Hospice Palliative Care Symptom Guidelines. To determine if the criteria are met for a refractory symptom, consider the following questions regarding possible interventions, time frame and tolerability.[3,8,16,18,22,28,59]

- Are further interventions capable of providing adequate relief?
- Are interventions likely to provide relief within a tolerable time frame?
- Will the intervention itself increase physical or emotional suffering?

A useful framework for assessing whether or not PST should be considered is the Latimer Ethical Decision Making Model.[5,7-9,11-13,14,16,19,28-30, 60-61]

- Patient's Illness - extent of disease, prognosis, and nearness to death
- Patient's Experience - symptom intensity, impact on quality of life, suffering, demoralization, and lack of dignity
- Patient as a Person - goals, hopes, and plans in light of current symptom, and wishes as contained in an advance care plan (if one has been completed)

Explore other options and supports for the patient and family. Meaning based interventions, dignity conserving therapy and other spiritually based approaches have been useful to help patients and families find meaning in the dying process.[62-73] *See Fraser Health Hospice Palliative Care Symptom Guideline on Psychosocial Care.*

The treating physician should also assess the patient for any conditions which may benefit from psychiatric consultation.[5, 22,74]

It is important not to label difficult symptoms as refractory because of a lack of skill or knowledge on the part of the health care provider, or because of an unwillingness to request a consultation. **Consultation is strongly recommended in cases of refractory symptoms to ensure that all possible options have been explored.** Such consultation may be with a more experienced colleague, the patient's family physician, a local hospice-palliative physician, or on call hospice-palliative consultant, even if this can only be done via telephone.[5,7-9,11-13,14,16,19,28-31,33]

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Within Fraser Health, 24/7 on-call palliative care physician input is available and as above, is strongly recommended. Admission to a specialized Tertiary Hospice Palliative Care Unit (TPCU) may be required in order to determine that symptoms are refractory; this can be arranged by the palliative care physician.

Fraser Health palliative physician consultation can be obtained weekdays during the day from the local teams and after 1700 hours weekdays, and on weekends from the Medical On Call Availability Hospice Palliative Care (MOCAP) physician. The schedule and pager numbers for the MOCAP Palliative Care Physicians can be reached at: http://oncall/oncall/BrowseSchedules/

Recommendation 2 Determine criteria for implementing PST are met

Health care professionals providing end of life care have a responsibility to offer sedatives in appropriate circumstances, usually targeted at specific symptoms (ordinary sedation). Palliative Sedation Therapy (PST) is occasionally necessary to relieve otherwise refractory symptoms, with the degree of sedation proportional to the severity of the target symptom. PST is an extraordinary intervention, but can be viewed as part of the continuum of palliative care.[47,59,75-77]

PST should only be considered in the rare circumstance that thorough interdisciplinary assessment and treatment of a patient's refractory symptoms has not resulted in sufficient relief (or is associated with unacceptable side effects), and when sedation is needed to meet the patient's goal of relief from refractory symptoms.[3,8,16,18,22,28,59,65,74]

In cases of refractory symptoms, ethical principles and legal rulings support the use of palliative sedation therapy to relieve otherwise refractory symptoms.[46,78] In Canada, the enactment of the Criminal Code is under federal jurisdiction, but the administration of justice is a provincial responsibility. The Attorney General of each province has discretion as to whether charges are laid. In accordance with these responsibilities, in November 1993, the British Columbia Ministry of the Attorney General issued guidelines for Crown Counsel (Policy 11-3-93, File no. 56880-01 Eut 1).[46] According to these guidelines, palliative care and withholding or withdrawing medical treatment will not be subject to criminal prosecution when provided or administered according to accepted ethical medical standards.

The factors considered by Crown Counsel as to whether the acts of a qualified medical practitioner, or a person acting under the general supervision of a qualified medical practitioner, constitute "palliative care" include:

- Whether the patient was terminally ill and near death with no hope of recovery
- Whether the patient's condition was associated with severe and unrelenting suffering
- Whether accepted ethical medical practices were followed, and
- Whether the patient was participating in a palliative program or palliative care treatment plan.

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Criteria for implementing PST are as follows: [5,6,33]

- The patient is terminally ill and near death with no hope of recovery
- In all but the most unusual circumstances, death is anticipated within hours to days [8,17,18,24,28,33-34,77,79]
- A "Do Not Resuscitate" order is in effect
- The patient is in a palliative program or has a palliative care treatment plan
- The patient has refractory symptoms
- The clinician's intent is to relieve refractory symptoms
- The planned degree of sedation is proportionate to the severity of refractory symptoms
- The patient is fully informed and involved in the decision making. When the patient is not able to participate, consent needs to be provided by the patient's substitute decision maker or legal representative who is acting in accordance with the patient's values and beliefs. *See Recommendation 3 B for further discussion of consent. Refer to Appendix A for process of selection and duties of temporary decision makers.*

Management of **existential suffering** is controversial. Requests for sedation because of existential suffering are the most challenging and difficult to address.[2,9,30,48-58]

PST for the management of refractory existential suffering should never be undertaken without consultation. Such consultation may be obtained from a member of an interdisciplinary hospice palliative team with knowledge and understanding of the patient's belief system. This may be a hospice-palliative physician or a psychiatrist/clinical psychologist, in addition to a social worker, a medical ethicist, or a spiritual care practitioner.

Recommendation 3 Guidelines for Decision-Making

The question of providing palliative sedation therapy may be raised by the patient or family/loved ones, either explicitly or indirectly, in the form of a request to relieve suffering. However, in deciding whether or not to initiate PST (or another plan of care that can still address the refractory symptoms of the patient), a formal discussion should take place. Most often, this is a family meeting with all relevant family/loved ones and health care professionals present to review the patient's condition and explore options.

Principles to Guide Decision-Making

A. Keep an open mind. The decision may be "For", "Against", or "Wait and See".

Use a systematic and inclusive process for determining whether to use sedation for refractory symptoms and how sedation is to be used, such as this process outlined by deGraeff and Dean.[5]

1. Actively involve the patient and ideally substitute decision maker(s) (SDM)

- Elicit patient's values, beliefs and goals

- Determine preferences for information and involvement in the decision
- If unable to participate, refer to previous discussions or advance care planning documentation
- Discuss with patient and family that there is no chance of recovery and life expectancy is very limited
- Discuss the therapeutic options, including potential benefits and risks
- Make clear the intent of PST is comfort and symptom management, not hastening death
- Facilitate patient-family discussion
- If necessary, remind the substitute decision maker of the duty to uphold the patient's wishes, or to express what is known about the patient's previously expressed preferences
- Provide support to family members finding it difficult to make critical decisions for a loved one

2. Involve all members of the team providing care for the patient. Those who should be present include:

- The patient and ideally the SDM(s) - give the patient an opportunity to specify who s/he would like to be present at the meeting, and don't make assumptions about who should or shouldn't be there;
- The physician who will be documenting the meeting and writing the orders;
- A nursing team member with knowledge of the patient's condition and care needs;
- A psychosocial practitioner with knowledge of the patient and/or experience in palliative care or end-of-life decision-making, such as a palliative social worker, spiritual care practitioner, clinical psychologist, or medical ethicist;
- A clinical pharmacist with knowledge of the patient, and/or experience in palliative care, especially in medically complex situations.

  - Agree on the goals of care and proportionality of PST
  - Elicit practical and ethical/moral concerns of the team about the use of PST in this case
  - Tailor the specific sedating interventions to the patient's values and clinical goal of care

3. Whenever possible, consider the needs of all those involved in choosing the time for initiating sedation.

B. Ensure informed consent. Actively involve the patient or the substitute decision maker.

As with all treatment, the use of PST requires informed consent.[8,28,33] Under Provincial law, in deciding whether an adult is incapable of making a particular health care decision, the decision must be based on whether the adult demonstrates that he or she:

1. understands the information being given about his or her health conditions;
2. understands the nature of the proposed health care, including the risks, benefits and alternatives and
3. understands as well that the information applies to his or her situation

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If a patient is not able to understand the above, then a substitute decision maker needs to be identified. The treating physician or other Health Care professional should first determine whether there are any formally appointed substitute decision makers (Committee of Personal/Personal Guardian or Representative; as well as if advance care planning conversations or documents (including an Advance Directive) have been made or discussed. Copies of documents should be provided and reviewed by the health care team. Previously expressed wishes or instructions of the adult patient must be followed and carried out through consent by the substitute decision maker(s) (SDM), unless they are appointed as Committee of Personal/Personal Guardian. If such documents are not in place or information available is not sufficient/applicable, in British Columbia, the requirements for temporary substitute decision making are set out in The Health Care (Consent) and Care Facility (Admission) Act.[80] See Appendix A for further information about selecting the SDM and his or her duties. Contact a social work department to consult with the Office of the Public Guardian (PGT) if no one is available to act as SDM or there is conflict about who should be the SDM. The PGT can appoint someone or act as SDM.

The care team should confirm that the patient's decision is not being affected by psychological or social pressure.[12]

C. Develop a plan. If the plan is "For PST", consider and plan for:

- timing the initiation of sedation, consider the physical, emotional and physical needs of patient and family
- sedation to be proportional to the symptom distress/requirement for symptom relief
- whether to provide artificial hydration
- need for Foley catheter, continued bowel care
- concurrent medications for control of other symptoms
- how to support family and staff if the patient does not die within the expected time frame
- whether the sedation therapy will be discontinued or reversed after a period of time

D. If the plan is "No PST", or "Wait and See", determine when this decision might be reviewed.

E. In cases where no agreement about a plan can be reached, consider referral to an Ethics Committee or an independent patient advocate. In Fraser Health, Ethics Services can be accessed via 604-587-4486. http://fhpulse/clinical_resources/ethics_services/Pages/Default.aspx

Recommendation 4 Documentation of Decision Making

Careful documentation of the team/family meeting, who was present, and the decision made is essential. It could be done by any member of the team, such as the social worker, clinical nurse specialist, spiritual care practitioner, or physician and should be made in the permanent patient record.

The attending physician as a minimum,* must *document in the permanent record:

- A DNR / No CPR order and signed document is in place.[17-18, 33]
- The criteria and rationale used to determine that the symptom is refractory.[17-18, 33]
- The consultation process between the attending physician, palliative care consultants, patient and family.
- A summary of the discussion(s):
  - The people involved in the decision making.
  - The information provided.
  - The decision reached.
  - Record the patient's expressed wishes, in his or her own words, as much as possible, or refer to prior documented conversations between the patient and other healthcare worker(s).
  - Informed consent for PST has been given by the patient, substitute decision maker, or legal representative.
- A summary of the plan:
  - If NO sedation is desired, document the agreed upon care plan. Is there a plan for further discussions? Are further consultations to be requested? Is an ethical review required?
  - Document the plan in relation to:
    - Timing of initiation.
    - Medical orders for sedation and for concurrent therapies, as needed.
    - Hydration/Nutrition.
    - Plan for managing foreseeable events
    - Anticipate possible crises, and how they will be managed[5]

Recommendation 5 Initiating, Assessment and Care Provision

Initiating palliative sedation may be an emotionally charged time, not only for the patient and family but also for health care providers. This is particularly true in situations in which the level of consciousness is rapidly lowered, rendering it difficult or impossible to communicate with the patient. It is beneficial to have the family and/or loved ones integrated into the plan of care as much as possible. Inform them of what to expect, reassure about expected changes in their loved one's condition, what practical things they can do while their loved one is sedated, and provide opportunities to express their emotions.[22]

Once the patient is sedated:

- Ensure frequent communication with the family for reassurance, support, feedback, and ongoing decision-making.

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- Ensure support is in place for patient and family, including palliative services, social work and spiritual care as desired by the patient or family.
- Through presence, intent, words, and touch, convey compassion for the patient and family.[22]
- Assume the patient can hear, and encourage visitors to talk or read to the patient, or play his or her favorite music if appropriate.
- Provide meticulous physical care because the patient will have reduced movement (e.g. loss of ability to blink, and other protective reflexes).[22]
- Encourage family to continue to touch their loved one.
- Discuss with family if they wish to participate in providing care. If desired, show them how to provide mouth care, eye care, hand or foot massage, or skin care as appropriate. If desired, include the family in repositioning the patient.
- Monitor for symptom relief.
- Assess for bladder emptying and place a urinary catheter when needed. Continue with bowel care.[22]

Assessments & Care Provision

The patient should be **monitored on a regular basis** to be sure that the goal of relief of refractory symptoms is being met.

After PST has been initiated, the following care should be provided and documented in the permanent record by the team members who are caring for the patient **regularly throughout the shift:**

- Response to PST - signs of symptom relief, Richmond Agitation Sedation Scale (RASS) *See Appendix B*[121]
- Assessment of the balance between symptom relief and level of sedation, along with appropriate drug and/or dosage changes
- Assessment of physical care needs and provision of care – skin care, mouth care, repositioning, bowel care, other care as needed
- Family coping and interventions to support the family
- Indicators for need to re-assess continuation of PST
- Outcome and care after death

Recommendation 6 Supportive care

A. Supporting the family and friends

Palliative care includes comforting and supporting the patient's family and friends, who play an important role both when palliative sedation is being considered and while it is being carried out. They often serve as caregivers, observers, informants and representatives in addition to their role as partner, child, relative or friend. They each pass through their own emotional / spiritual

journey which may include feelings of doubt, guilt, fear, sorrow, and mourning. They may also feel relief that the suffering of their loved one has come to an end. Information, explanation, cooperation and ongoing evaluation of the situation are essential if the palliative sedation is to work to good advantage and those involved can bid a meaningful farewell. The health care team should communicate with the patient's family using language they can understand.[15]

Family members can be an important source of information about the well-being of the patient. It is helpful to meet with them at set times for periodic updates or to discuss new circumstances that may arise. It also allows the health care providers to watch for signs of stress or burn-out in the family, and encourage them to care for themselves with adequate rest and nutrition.[25]

Ascertain the level of involvement that the family wants in the process. Provide an opportunity for the patient, if possible, to express what s/he may want from their loved ones, or would find comforting, during the time they are sedated. Obtain information on anything that the patient would want or need before sedation is initiated, i.e., rituals, spiritual or religious rites, saying good-byes or expressing their feelings to family or team members. Conversely, is there anything that a family member or loved one needs to say to the patient prior to the initiation of PST?

B. Supporting the care team

In cases where PST is being initiated, a profound empathy for the patient's suffering is common. To bear witness and still be professionally present and supportive for a patient and family can be an emotionally exhausting experience. Therefore, it is helpful that the team members caring for a patient and family discussing and possibly initiating PST be offered opportunities to discuss their own personal feelings. This may include formal or informal debriefings before or during the initiation of PST or after the death of the patient or individual meetings with team members.[4,15,51,59]

A more organized debriefing session for involved team members may be considered whenever:

- Management of refractory symptoms was especially challenging.
- The decision to initiate PST was difficult.
- Death was unusually arduous.
- Significant complications arose.
- Death occurred during intended respite sedation.

The debriefing session(s) should be facilitated by an experienced social worker, clinical counselor, psychologist or spiritual care practitioner, who may or may not have been involved in the care of the patient. Most importantly, such offering of support can positively impact or offset any moral distress experienced by health care providers. It also serves as an opportunity for increased team cohesion, overall team functioning, and learning opportunities for what was done well or could have been done differently.

C. Care after death

A patient receiving PST will eventually show some or all of the indicators of impending death (mottling and cooling of the periphery, irregular and/or noisy respirations) and death will occur as a natural outcome of the underlying disease within hours or days.[118] Palliative Sedation Therapy has not been shown to hasten death: there is no difference between the length of stay of those patients who receive palliative sedation and

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those who do not.[39,40,43,45,119] Death can occur sooner or later than the family or team had expected, although more than 85% of patients receiving PST die within 3 days and 98% do so within 7 days.

The family may need advice about burial, cremation, financial arrangements etc. They may have cultural beliefs about who may touch or wash the body, and how it is to be laid out. During this time, they should be given a chance to express their feelings about the way the patient died. Some families might appreciate the opportunity to debrief with the care team following the patient's death. This can encourage expression of their emotions and their feelings about the role they played and the support they received from others and the professionals involved in the case.[15] The family may find it particularly helpful to have the attending physician present during such a session.

Family and friends should be asked whether they would like to receive information about bereavement support. Bereavement support and follow up is available through local hospice societies or other community resources, and on various websites.

Recommendation 7 Pharmacological Interventions – Initiating and Maintaining PST

The patient's care location (home, hospice residence, acute medical unit, tertiary palliative unit, critical care unit) and the availability of medication administration routes, such as intravenous, primarily guide the PST medication used. The goal of pharmacological treatment is proportional reduction of consciousness to a level sufficient to relieve symptoms.

If a patient is already being treated with opioids and/or antipsychotics, these medications should be continued during sedation in accordance with the patient's needs. When an existing medication is being administered continuously via the parenteral route, it is preferable to administer the sedative drugs via a separate site. This avoids an undesirable increase in the existing medication when the doses of sedatives are increased, and avoids potential drug incompatibilities when mixed together.

There is no strong evidence to support a ranking of medications. Choices depend on the experience of the physician, drug availability, institutional policy, and location.

Anxiolytic Sedatives

The most common initial choice of PST medication in the literature is a benzodiazepine, such as midazolam or lorazepam. They provide a high potential for sedation, a low risk of respiratory depression at sedative doses, and a wide safety margin. Where feasible, the use of midazolam by continuous subcutaneous infusion (CSCI) is preferred, to permit responsive titration. In general, subcutaneous administration is preferable to intravenous administration because of the practical advantages of subcutaneous infusion and the greater risk of apnea when bolus injections are administered intravenously. Where continuous infusions are not possible, consider using longer acting lorazepam by intermittent injection or sublingual administration. In general, midazolam is preferred over lorazepam because of its more immediate titration responsiveness, although lorazepam SL or buccally might be the simplest method in the home.

When the patient has delirium, benzodiazepines are not recommended as sole agents for PST, and should be combined with a neuroleptic[5, 81-82] or phenobarbital.

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Midazolam Initiation	• 1 to 5 mg subcut or IV q 5 minutes until settled. • In emergencies, when a very rapid lowering of consciousness is required, bolus injections can be given more frequently. In other situations, a quiet atmosphere and gradual changes in consciousness are more important than speed.
Midazolam Maintenance	• Follow bolus initiation dosing with 1 mg per hour CSCI or continuous IV infusion (CIVI)[105] and titrate every 15 minutes until adequately sedated. • For elderly patients with a low body weight, no previous treatment with benzodiazepines, and no urgent need for rapid sedation, a low initial dose of 0.5 mg per hour is preferable. • Usual dose is 30 to 100 mg per day, yet range is broad from 3 to 1200 mg per day.[81]
Midazolam Titration	• Individualized titration of midazolam is required. • Provide p.r.n. intermittent doses q1h p.r.n. equal to the hourly maintenance infusion rate. • Adjust the maintenance dose every 1 to 2 hours,[105] based on number of p.r.n. boluses needed. If sedation is insufficient, the dose of midazolam can be doubled every 1 to 2 hours in combination with a bolus until an adequate effect has been achieved. • At dosages greater than 20 mg/hour (480 mg/day) consider adding, or switching to, second line treatment.[105]
Dosing Special Populations	• Use lower initial doses in patients with no previous treatment with benzodiazepines, cachexia, age over 60 years, renal, hepatic or cardiac impairment, and concomitant opioid administration. • Higher doses may be needed in patients with significant previous benzodiazepine exposure, patients requiring a long duration of sedation, or in young patients.[83]
Precautions	• Tolerance may develop to the sedative effects of midazolam, sometimes to the point where the patient may unexpectedly recover consciousness. The dosage of midazolam may have to be increased over time, watching for this tolerance effect, mainly in younger patients.[5] • Delirium is a rare complication (seen especially in elderly patients and children) on the initiation of sedation, and if occurs, it is advisable to increase the dosage rapidly.

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Midazolam - *cont*	
Precautions - *cont*	• Paradoxical excitation reactions to midazolam, including hyperactive or aggressive behavior, have been reported (2% incidence). The reversal drug flumazenil, and haloperidol or ketamine have been used successfully in non-PST use.[84-89] **As the goal of PST is to sedate to symptom relief, flumazenil would not be the best choice. Stop the midazolam, to prevent further episodes, sedate with an alternate drug.**
Infusion Solution	• Compatible in solutions of normal saline, D5W or Lactated Ringers.[35-37] • Compatible with morphine and hydromorphone in the same syringe or mini-bag,[94] but does not allow for individual titration of medications.

Lorazepam Initiation	• 0.5 to 1 mg subcut or IV q 15 minutes. • Alternatively: start with 1 to 4 mg sublingually or buccally.
Lorazepam Maintenance	• Continue with 1 to 4 mg subcut or IV q 2 to 4h regularly or 1 to 8 mg sublingually or buccally. Usual dose is 4 to 40 mg per day.[74]
Titration	• Titrate with intermittent doses of 0.5 to 2 mg q 2h p.r.n.[74]
Dosing Special Populations	• Lorazepam pharmacokinetics remain unaltered with age,[90] but elderly may be more sensitive.[91] • Renal impairment may require dosage adjustment, guidelines unavailable.[90] • Liver impairment – no dosage adjustment generally necessary.[90] Pharmacokinetics altered less in hepatic dysfunction versus most other benzodiazepines.[90] Cirrhotic patients may require lower dosing.[91] Obese patients may need greater doses.[91]
Precautions	• Volume becomes a problem if used subcut at higher doses.
Infusion Solution	• D5W, NS, D5W preferred[90] but compatibility is concentration dependent, time limited and temperature sensitive.[90-92] • Lorazepam is best avoided for infusion due to risk of precipitation.

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Midazolam is the most commonly used drug for palliative sedation[83] yet if it, or lorazepam, is inadequate to provide the desired effect, consider proceeding to, or adding, the following alternatives.

Neuroleptics

Methotrimeprazine is a useful second-line choice for PST. It acts on multiple receptors and has some antiemetic and analgesia effects.[113] It provides significant sedation, can be administered intravenously, subcutaneously, continuously or intermittently. It can be used in combination with midazolam. Other neuroleptics have been used for PST, but experience with them is much more limited. Haloperidol does not provide the degree of sedation necessary for PST, however, it remains useful as an adjuvant treatment for nausea and vomiting.

Methotrimeprazine Initiation	• 10 to 25 mg subcut or IV q 15 to 30 minutes until settled. • No dilution necessary for subcut intermittent administration, however for IV intermittent doses or continuous infusion consult parenteral manual for dilution instructions.[96]
Methotrimeprazine Maintenance	• 10 to 50 mg subcut q 4h or 0.5 to 8 mg per hour infusion subcut or IV.[105] • Dose range is 25 to 250 mg per day.[81,95]
Methotrimeprazine Titration	• Use p.r.n. doses up to q 1h p.r.n.[114] Once settled, adjust regular doses every 8 hours until stable. May accumulate due to its long half-life, dosage reduction may be needed, especially after a few days.[15]
Dosing Special Populations	• Coadminstration in patients on opioids or phenobarbital may need dose reduction by one-half.[93,96] • Subcut administration reported to be twice as potent as oral.[93,97] • Prostatic hypertrophy patients may be more sensitive to anticholinergic effects. • Phenothiazines can lower seizure threshold, avoid in patients in whom cerebral irritation is a potential problem.[99] • Hepatic and renal impairment – use with caution, no specific dosing available.
Precautions	• Extrapyramidal side effects may appear with high doses of any neuroleptic and may limit the dose of methotrimeprazine.[107] • Used alone, a neuroleptic can reduce the seizure threshold or induce myoclonus in severely ill patients.

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Methotrimeprazine- *cont*	
Precautions - *cont*	• May cause skin irritation and require site rotation based on patient tolerance. Rotation at least every 72 hours suggested.[94]
Infusion Solution	• D5W 93,94,96 NS has also been used.[94,96] • IV: Maximum 100 mg per 250 mL.[96]

Tolerance to methotrimeprazine is rare (unlike the benzodiazepines and barbiturates).[107] If the benzodiazepine and methotrimeprazine have insufficient effect, stop both and start phenobarbital.

Sedative Antiepileptics

Some clinicians consider phenobarbital a first-line PST medication, while others use it as a third line option that provides sedation in cases of inadequate response to anxiolytic sedatives and/or methotrimeprazine. Phenobarbital has a long duration of action with a rapid onset, reportedly faster than midazolam. It can be administered intravenously, by CSCI, or intermittent subcutaneous injection. Its antiepileptic properties may be of additional anticonvulsant value.

Phenobarbital Initiation	• 1 to 10 mg per kg induction bolus subcut or IV or 100 to 200 mg subcut.[99, 116] • May repeat induction bolus dose every 1 to 4 hours x 2 doses to maximum of 30 mg per kg total in first 24 hours.[116]
Phenobarbital Maintenance	• Use induction dose q 8h regularly or 5 to 100 mg per hour CSCI. • Usual dose is 600 to 1600 mg per day.[74] Range is 200 to 2500 mg per day.[81]
Phenobarbital Titration	• p.r.n. dose should be q 4 to 8h at half or the full amount of the induction dose. • If symptoms uncontrolled after 10mg/kg Loading Dose, may repeat q 2h to max of 30 mg/kg; after loaded to 30 mg/kg, may titrate CSCI rate if symptoms uncontrolled.[116] • Requires individualized dosing due to considerable variability in pharmacokinetics.[99] • Can accumulate due to its long half-life, of 1.5 to 4.9 days,[34] and dosage reduction may be needed, especially after a few days.

Phenobarbital - *cont*	
Dosing Special Populations	• Adjustments may be necessary in elderly patients or those with hepatic or renal dysfunction.[101] • Review concurrent medications for potential drug interactions, as several exist.
Precautions	• Extravasation can cause skin irritation[98] ranging from slight to frank tissue necrosis[100] due to its alkaline pH (9.2-10.2)[102] However, CSCI usually well tolerated.[94] • Abrupt withdrawal after prolonged use may precipitate seizures.[98]
Infusion Solution	• NS, D5W. May have complex mixing requirements in combination with other drugs.[94,110] • Mix just prior to use, visually inspect and do not use solution if precipitate forms.[101]

Generally, phenobarbital should be used in preference to propofol because it is less complicated for clinical staff to titrate and monitor.[122] However, if phenobarbital does not meet the goal of symptom relief, discontinue it and try another option.

General Anaesthetics

Propofol is generally regarded as a fourth line PST medication, when symptom relief has not been achieved by the above medications. However in a hospital setting, where intravenous access is readily attainable and an anesthesiologist is available, it may be preferable to consider as a second line agent.[105] It requires intravenous access, and should be administered only by a physician with experience using this drug. Administration should preferably be done under supervision of an anaesthesiologist.[105] It provides immediate onset, rapid titratability due to an ultra-short duration of action, and possesses antiemetic activity.

Propofol Initiation	• Induction bolus dose of 0.25 to 0.5 mg per kg IV. Give over 3 to 5 minutes.[112] May repeat q 5 to 10 minutes until settled. • Slow infusion techniques preferable over rapid bolus administration.
Propofol Maintenance	• Maintenance by infusion should immediately follow the induction dose.[109] A variable rate infusion is preferable over intermittent bolus dose administration.[109]

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Propofol- *cont*

Propofol Maintenance - *cont*	• Continuous IV infusion (CIVI) at 0.25 mg per kg per hour to a maximum of 4 mg per kg per hour (4 mcg/kg/min to 67 mcg/kg/min).[81] • Generally start with 0.5 mg/kg/hr (8 mcg/kg/min) for refractory nausea and vomiting or 1 mg/kg/hr (17 mcg/kg/min) for agitated delirium or intolerable distress.[122] • Usual dose is 500 to 1100 mg per day. Dose range is between 400 to 9,600 mg/day.[81] • Doses greater than 4 mg/kg/hr (67 mcg/kg/min) are associated with increased risk of adverse effects.[121,123]
Propofol Titration	• May repeat boluses q 5 to15 minutes p.r.n. and increase CIVI by 0.25 to 0.5 mg/kg/hr q 30 to 60 minutes.[81,108] If patient is too sedated, turn off infusion for 2 to 3 minutes and restart at lower rate.[122] • May require p.r.n. bolus doses before turns, dressing changes, or potentially painful procedures.[106]
Dosing Special Populations	• May require dosage reduction of 20 to 30% in elderly, debilitated, or hypovolemic.[103] • Concurrent opioids may lower BP, reduce heart rate and cardiac output.[103] • Interpatient variability in dosage requirements may occur over time.[103] Accumulation may occur with long-term use.[111] Tolerance can develop, necessitating a dose increase, but generally not within one week.[122]
Precautions	• Potential bradycardia, hypotension. Also apnea during induction.[112] • Hypotension more likely with rapid bolus or in elderly patients or those with compromised myocardial function, intravascular volume depletion or abnormally low vascular tone (e.g. sepsis).[103,109] • High incidence of injection skin reaction (18%), and immediate or delayed discomfort may occur in 90% of adults.[24] Occurs more frequently when small veins are used. Extravasations may cause local pain, swelling, blisters and tissue damage.[24] • Transient local pain during injection may be reduced by prior injection of 10 mg of IV lidocaine (preservative and epinephrine free).[103,109,122]

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Propofol - *cont*	
Precautions- *cont*	• Propofol infusion syndrome (one or more symptoms of bradycardia, metabolic acidosis, renal failure, cardiac failure, cardiopulmonary arrest) is rare, but may occur at high doses over 4 mg/kg/hr, or in patients with refractory status epilepticus.[104,123] • Do not use subcutaneously.[112]
Infusion Solution	• Shake well before use as propofol is mixed in an egg lecithin and soybean oil vehicle. • Replenish infusion quickly when a container empties,[108] as effect wears off in 10-30 min.[122] • Pain at infusion site can be minimized by using a large vein and adding a maximum of 20 mg of preservative and epinephrine free lidocaine per 200 mg propofol immediately prior to starting infusion.[122]

If propofol alone does not provide adequate symptom relief, supplement with midazolam by CSCI.[122]

Palliative Sedation Treatment Dosing

If the patient recovers consciousness after initially being adequately sedated, it is important to check whether the indications for PST are still present.

If the patient is not appropriately sedated to the point of symptom relief, ensure that the mode of administration and the medications are in order. Ensure there is no drug extravasation, blocked or kinked lines, or equipment malfunction. Check that delivered therapy matches intended prescribed dose.

When a patient is being cared for in the home, the use of a pump for continuous subcutaneous administration may not be logistically feasible. This is particularly the case where life expectancy is extremely short (1 to 2 days). In such circumstances, intermittent administration of sedatives is an acceptable alternative. Depending on the situation, any of the following drugs can be used for this purpose:

- Midazolam: 5 to 10 mg subcut q 4h regularly, and PRN
- Lorazepam: 1 to 4 mg SL or subcut q 4h regularly, and PRN
- With or without Methotrimeprazine: 10 to 50 mg subcut q 4h, and PRN

Drugs NOT RECOMMENDED for Palliative Sedation Therapy

Opioids alone do not provide adequate sedation. Trying to achieve sedation with opioids is very likely to produce neuroexcitatory adverse effects such as myoclonus or agitated delirium.

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They **do have a role as analgesics** and are frequently used concurrently with PST.[74] During PST, as with patients under general anaesthesia, pain is still registered within the central nervous system, even if the patient is not consciously aware of, or able to indicate it. Thus, previously prescribed opioid medications must be continued once PST is initiated.

Increasing pain and analgesic requirement may be expected due to disease progression and drug tolerance. However, any increase of opioid doses in a sedated patient should be supported by careful document of signs of pain.[117] Signs of pain in the sedated patient may include, tearing, moaning, tachycardia, tachypnea, hypertension, and movement.

Thiopental is not recommended as it is a common drug used for physician-assisted suicide in those jurisdictions where it is practiced. Its use in PST could be misinterpreted.

References:

Information was compiled using the CINAHL, Medline (1996 to December 2009) and Cochrane DSR, ACP Journal Club, DARE and CCTR databases, limiting to reviews / systematic reviews, clinical trials, case studies and guidelines / protocols using 'refractory / intractable symptoms / suffering' terms, as well as 'palliative / terminal sedation' terms in conjunction with palliative / hospice / end of life / dying. Palliative care textbooks mentioned in generated articles were hand searched. Articles not written in English were excluded.

1. Beel A. McClement SE. Harlos M. Palliative sedation therapy: a review of definitions and usage. Int J Palliat Nurs. 2002; 8(4):190-9.
2. Levy MH. Cohen SD. Sedation for the relief of refractory symptoms in the imminently dying: a fine intentional line. Seminars in Oncology. 2005; 32(2):237-46.
3. Cherny NI. Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care. 1994; 10(2):31-8.
4. Chater S. Viola R. Paterson J. Jarvis V. Sedation for intractable distress in the dying--a survey of experts. Palliat Med. 1998; 12(4):255-69.
5. de Graeff A. Dean M. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. J Palliat Med. 2007;10(1):67-85.
6. Cherny NI. Palliative sedation for the relief of refractory physical symptoms. Prog in Pall Care. 2008; 16(1):51-62.
7. Quill TE. Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. Annals of Internal Medicine. 2000; 132(5):408-14.
8. Braun TC. Hagen NA. Clark T. Development of a clinical practice guideline for palliative sedation. J Palliat Med. 2003; 6(3):345-50.
9. Cherny NI. Sedation: Uses, abuses and ethics at the end of life. Jerusalem: Shaare Zedek Medical Centre; 2003.
10. Cowan JD. Palmer TW. Practical guide to palliative sedation. Curr Oncol Rep. 2002; 4(3):242-9.
11. Hawryluck LA. Harvey WR. Lemieux-Charles L. Singer PA. Consensus guidelines on analgesia and sedation in dying intensive care unit patients. BMC Medical Ethics [Internet]. 2002 Aug 12 [cited 2008 Sep 20]; 3(3).
Available from: http://www.biomedcentral.com/1472-6939/3/3.
12. Morita T. Bito S. Kurihara Y. Uchitomi Y. Development of a clinical guideline for palliative sedation therapy using the Delphi method. J Palliat Med. 2005; 8(4):716-29.
13. Rousseau PC. Ross E. Use of palliative sedation. Carl T. Hayden VA Medical Center, Phoenix Arizona; 2000.
14. Rousseau PC. Existential suffering and palliative sedation: a brief commentary with a proposal for clinical guidelines. Am J Hosp Palliat Care. 2001; 18(3):151-3.
15. Committee on National Guideline for Palliative Sedation, Royal Dutch Medical Association (KNMG). National Guideline for Palliative Sedation. Utrecht, The Netherlands, December 2005.
16. Schuman ZD. Lynch M. Abrahm JL. Implementing institutional change: an institutional case study of palliative sedation. J Palliat Med. 2005; 8(3):666-76.
17. Palliative Sedation Subcommittee, Hospice & Palliative Care Federation of Massachusetts: Palliative Sedation Protocol: A report of the Standards and Best Practices Committee Hospice & Palliative Care Federation of MA; April 2004.

Approved by: End of Life Care, Quality Performance Council. January 13, 2011.
End of Life Care, Practice Advisory Council, May 9, 2011

18. Palliative Care Clinical Practice Guideline Committee. Community Services, Regional Palliative Care Program, Capital Health (Edmonton AB). Palliative Sedation. [Internet] 2006[cited 2008 Sept 21].
Available from: http://www.palliative.org/PC/ClinicalInfo/Clinical%20Practice%20Guidelines/PDF%20files/3A6%20Palliative%20Sedation%20and%20Addendum.pdf

19. Wein S. Sedation in the imminently dying patient. Oncology (Williston Park). 2000; 14(4):585-92; discussion 592, 597-8, 601.

20. World Health Organization. WHO Definition of Palliative Care. [cited 2008 Sep 20].
Available from: http://www.who.int/cancer/palliative/definition/en/print.html

21. Cassell EJ. Diagnosing suffering: a perspective. Annals of Internal Medicine. 199; 9131(7):531-4.

22. Lynch M. Palliative Sedation. Clin J Oncol Nurs. 2003; 7(6):653-67.

23. Morita T: Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients. J Pain Symptom Manage 2004;28:445–450.

24. Rousseau PC. Palliative sedation. Am J Hosp Palliat Care. 2002; 19(5):295-7.

25. Jameton A. Nursing Practice: The Ethical Issues. [book] Englewood Cliffs (NJ): Prentice-Hall; 1984.

26. MacPhail S. Recognizing moral distress and moral residue in practice. Health Ethics Today, 2003; 13(2): 5-7.

27. Hamric AB. Davis WS. Childress MD. Moral distress in health care professionals: What is it and what can we do about it? Pharos of Alpha Omega Alpha Honor Medical Society. 2006; 69(1):16-23.

28. Braithwaite D, Downing M. Death and Dying - Palliative Sedation (PS) Framework and Guideline. In: Downing GM, Wainwright W, editors. Medical Care of the Dying. 4th ed. Victoria, B.C. Canada: Victoria Hospice Society Learning Centre for Palliative Care; 2006. p. 605-15.

29. Morita T. Inoue S. Chihara S. Sedation for symptom control in Japan: the importance of intermittent use and communication with family members. J Pain Symptom Manage. 1996; 12(1):32-8l.

30. Rousseau PC. Existential distress and palliative sedation. Anesthesia & Analgesia. 2005; 101(2):611-2.

31. Service Canada. Unemployment benefits: compassionate care benefits definition [homepage on the Internet]. In: Employment Insurance Act – Part I – Unemployment Benefits. Ottawa: Service Canada; [Internet] 2008 [cited 2008 Jan 30].
Available from: http://www.hrsdc.gc.ca/eng/ei/legislation/ei_act_part1_7.shtml#a23_1

32. Canadian Medical Association. CMA Policy: Euthanasia and Assisted Suicide. [Internet] Update 2007. [cited 2009 Jun 29].
Available from: http://policybase.cma.ca/dbtw-wpd/Policypdf/PD07-01.pdf

33. Clinical Practice Committee of the Regional Palliative and Hospice Care Service, Calgary Health Region. Clinical Practice Guideline for: Palliative Sedation. December 2005.

34. Verkerk M. van Wijlick E. Legemaate J. de Graeff A. A national guideline for palliative sedation in the Netherlands. J Pain Symptom Manage. 2007; 34(6):666-70.

35. Fainsinger RL. De Moissac D. Mancini I. Oneschuk D. Sedation for delirium and other symptoms in terminally ill patients in Edmonton. J of Palliat Care. 2000; 16(2):5-10.

36. Fainsinger RL. Waller A. Bercovici M. Bengtson K. Landman W. Hosking M. Nunez-Olarte JM. deMoissac D. A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. Palliat Med. 2000; 14(4):257-65.

37. Muller-Busch HC. Andres I. Jehser T. Sedation in palliative care – a critical analysis of 7 years experience. BMC Palliative Care. [Internet] 2003 [cited 2008 Sep 20] 2:2.
Available from: http://www.biomedcentral.com/1472-684X/2/2

38. Sykes N. Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. Archives of Internal Medicine. 2003; 163(3):341-4.

39. Kohara H. Ueoka H. Takeyama H. Murakami T. Morita T. Sedation for terminally ill patients with cancer with uncontrollable physical distress. J Palliat Med. 2005; 8(1):20-5.

40. Stone P. Phillips C. Spruyt O. Waight C. A comparison of the use of sedatives in a hospital support team and in a hospice. Palliat Med. 1997; 11(2):140-4.

41. Ventafridda V. Ripamonti C. De Conno F. Tamburini M. Cassileth BR. Symptom prevalence and control during cancer patients' last days of life. J Palliat Care. 1990; 6(3):7-11.

42. Sykes N. Thorns A. The use of opioids and sedatives at the end of life. Lancet Oncology. 2003; 4(5):312-8.

43. Chiu TY. Hu WY. Lue BH. Cheng SY. Chen CY. Sedation for refractory symptoms of terminal cancer patients in Taiwan. J Pain Symptom Manage. 2001; 21(6):467-72.

44. Vitetta L. Kenner D. Sali A. Sedation and analgesia-prescribing patterns in terminally ill patients at the end of life. Am J Hosp Palliat Care. 2005; 22(6):465-73.

45. Morita T. Tsunoda J. Inoue S. Chihara S. Effects of high dose opioids and sedatives on survival in terminally ill cancer patients. J Pain Symptom Manage. 2001; 21(4):282-9.

46. BC Crown Counsel Policy Guidelines. Appendix 1: Active Euthanasia and Assisted Suicide, Crown Counsel Policy Manual, Province of British Columbia, Ministry of Attorney General, Criminal Justice Branch (Policy 11-3-93, File no. 56880-01 Eut 1).

47. Claessens P. Genbrugge E. Vannuffelen R. Broeckaert B. Schotsmans P. Menten J. Palliative sedation and nursing: the place of palliative sedation within palliative nursing care. J Hosp Palliat Nurs. [Internet] 2007 [cited 2008 Sep 20]; 9(2):100-106. Available from: http://www.medscape.com/viewarticle/558051.

48. Taylor BR. McCann RM. Controlled sedation for physical and existential suffering? J Palliat Med. 2005; 8(1):144-7.

49. Rousseau PC. Existential suffering and palliative sedation in terminal illness. Prog Palliat Care 2002; 10:222-224.

50. Cherny NI. Commentary: sedation in response to refractory existential distress: walking the fine line. J Pain Symptom Manage. 1998; 16(6):404-6.

51. Morita T. Tsunoda J. Inoue S. Chihara S. Terminal sedation for existential distress. Am J Hosp Palliat Care. 2000; 17(3):189-95.

52. Blondeau D. Roy L. Dumont S. Godin G. Martineau I. Physicians' and pharmacists' attitudes toward the use of sedation at the end of life: influence of prognosis and type of suffering. J Palliat Care. 2005; 21(4):238-45.

53. Eckerdal G. Sedation in palliative care—The doctor's perspective. In: Tannsjo T, editor. Terminal Sedation: Euthanasia in Disguise? Dordrecht: Kluwer Academic Publishers, 2004. pp. 37–41.

54. Rosen EJ. A case of "terminal sedation" in the family. J Pain Symptom Manage 1998; 16:406–407.

55. Davis MP. Ford PA. Palliative sedation definition, practice, outcomes and ethics. [Letter] J Palliat Med. 2005; 8:699–701.

56. Nunez Olarte JM. Guillen DG. Cultural issues and ethical dilemmas in palliative and end-of-life care in Spain. Cancer Control. 2001; 8:46–54.

57. Shaiova L. Case presentation: Terminal sedation and existential distress. J Pain Symptom Manage. 1998;16:403–404.

58. Mount BM. Hamilton P. When palliative care fails to control suffering. J Palliat Care. 1994; 10(2):24-6; discussion 27-30.

59. Lo B. Rubenfeld G. Palliative sedation in dying patients. "We turn to it when everything else hasn't worked". JAMA. 2005; 294:1810-1816.

60. Latimer EJ. Ethical care at the end of life. CMAJ. 1998; 158(13): 1741-47.

61. Latimer EJ. Ethical decision-making in the care of the dying and its applications to clinical practice. J Pain Symptom Manage. 1991; 6(5):329-36.

62. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ. 2007; 335(7612):184-7.

63. Chochinov HM. Krisjanson LJ. Hack TF. Hassard T. McClement S. Harlos M. Dignity in the terminally ill: revisited. Journal of Palliative Medicine. 2006; 9(3):666-72.

64. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. CA: a Cancer Journal for Clinicians. 2006; 56(2):84-103; quiz 104-5.

65. Chochinov HM. Cann BJ. Interventions to enhance the spiritual aspects of dying. J Palliat Med. 2005; 8 Suppl 1:S103-15.

66. Chochinov HM. Hack T. Hassard T. Kristjanson LJ. McClement S. Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. J Clin Onc. 2005; 23(24):5520-5.

67. Chochinov HM. Hack T. Hassard T. Kristjanson LJ. McClement S. Harlos M. Dignity and psychotherapeutic considerations in end-of-life care. J Palliat Care. 2004; 20(3):134-42.

68. Chochinov HM. Dignity-conserving care--a new model for palliative care: helping the patient feel valued. JAMA. 2002; 287(17):2253-60.

69. Breitbart W. Gibson C. Poppito SR. Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie. 2004; 49(6):366-72.

70. Daniels J. Kissane DW. Psychosocial interventions for cancer patients. Current Opinion in Oncology. 2008; 20(4):367-71.

71. Kissane DW. The contribution of demoralization to end of life decisionmaking. Hastings Center Report. 2004; 34(4):21-31.

72. Street AF. Kissane DW. Constructions of dignity in end-of-life care. J of Palliat Care. 2001; 17(2):93-101.

73. Kissane DW. Psychospiritual and existential distress. The challenge for palliative care. Australian Family Physician. 2000; 29(11):1022-5.

74. Rousseau PC. Palliative sedation in the management of refractory symptoms. J Support Oncol. 2004; 2(2):181-186.

75. Rousseau PC. Dying and terminal sedation. Clin Geriatr 1999; 7:19-20.

76. Carr MF. Mohr GJ. Palliative sedation as part of a continuum of palliative care. J Palliat Med. 2008; 11(1):76-81.

77. Statement on Palliative Sedation. American Academy of Hospice Palliative Medicine Position Statements. [Internet]. 15 Sep 2006. [cited 2008 Sep 21].
Available from: http://www.aahpm.org/positions/default/sedation.html

78. Dunsmuir M. Smith M. Alter S. Harder S. Euthanasia and Assisted Suicide in Canada. Current Issue Review 91-9E, Parliamentary Information and Research Service, Library of Parliament; revised 23 Feb 2006.

79. Morita T. Chinone Y. Ikenaga M. et al. Japan Pain, Palliative Medicine, Rehabilitation, and Psycho-Oncology Study Group. Ethical validity of palliative sedation therapy: a multicenter, prospective, observational study conducted on specialized palliative care units in Japan. J Pain Symptom Manage. 2005; 30(4):308-19.

80. The health care (consent) and care facility (admission) act [Internet]. 2011 [updated 2011 Oct 19; cited 2011 Oct 27].
Available from: http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96181_01.

81. Twycross R. Wilcock A. Hospice and Palliative Care Formulary USA 2nd Edition. Palliativedrugs.com Nottingham, United Kingdom; 2008.

82. Pandharipande P. Ely EW. Sedative and analgesic medications: risk factors for delirium and sleep disturbances in the critically ill. Critical Care Clinics. 2006; 22:313-37.

83. Claessens P. Menten J, Schotsmans P, Broechaert B. Palliative sedation: a review of the research literature. Journal of Pain and Symptom Management. 2008; 36(3):310-33.

84. Thurston TA Williams CGA, Foshee SL. Reversal of a paradoxical reaction to midazolam with flumanzenil. Anaesthesia Analgesia. 1996; 83:192.

85. Khan, LC, Lustic SJ. Treatment of a paradoxical reaction to midazolam with haloperidol. Anaesthesia Analgesia. 1997; 85:213-5.

86. Weinbroum A. Geller E. The respiratory effects of reversing midazolam sedation with flumanzenil in the presence or absence of narcotics. Acta Anesthesiol Scand. 1990; 92 (Suppl.):65-69.

87. Weinbroum A. Szold O. Ogorek D. Flaison A. The midazolam induced paradox phenomenon is reversible by flumanzenil. European Journal of Anaesthesiology. 2001; 18:789-97.

88. Sanders JC. Flumazenil reverses a paradoxical reaction to intravenous midazolam in a child with uneventful prior exposure to midazolam. Paediatric Anaesthesia. 2003; 13;366-71.

89. Golparvar M, Saghaei M. Sajedi P. Razavi S. Paradoxical reaction following intravenous midazolam premedication in pediatric patients: A randomized placebo controlled trial of ketamine for rapid tranquilization. Pediatric Anaesthesia. 2004; 14:924-30.

90. Lorazepam Monograph, Clinical Pharmacology. [Internet] [cited 2006 June 30].
Available from: http//:cp.gms (subscription required).

91. Lorazepam product monograph Micromedex. [Internet] [cited 2006 June 30].
Available from: www.thompsonhealthcare.com (subscription required).

92. Lorazepam Parenteral Admixtures King Guide to Parenteral Admixtures. [Internet[[cited 2008 Jan 4].
Available from: http://www.kingguide.com/kgpa/slog/select_1.asp

93. Nozinan product monograph. Sanofi-Aventis. [Internet]. May 18, 2007 [cited 2008 Jan 11].
Available from: www.sanofi-aventis.ca

94. Dickman A. Schneider J. Varga J. The Syringe Driver continuous subcutaneous infusions in palliative care. 2nd Edition. Oxford University Press Inc. New York; 2005.

95. Methotrimeprazine product monograph Micromedex. [Internet]. [cited 2005 Oct 11].
Available from: www.thompsonhealthcare.com (subscription required)

96. Methotrimeprazine Parenteral Drug Therapy Manual monograph. Fraser Health [Internet} [cited 2008 Dec 29].
Available from: http://fhpulse/clinical_support_services/pharmacy/policies_pdtm_ppos_forms/PDTM%20Drug%20Monographs%20Adult/methotrimeprazine%20Jul08.pdf

97. Watson M. Lucas C. Joy A. Back I. Oxford Handbook of Palliative Care. Oxford University Press New York; 2005.

98. Phenobarbital Parenteral Drug Therapy Manual monograph, Fraser Health. [Internet]. [cited 2008 Dec 29].
Available from: http://fhpulse/clinical_support_services/pharmacy/policies_pdtm_ppos_forms/PDTM%20Drug%20Monographs%20Adult/phenobarbitalFeb09.pdf

99. Stirling CL, Kurowska A. Tookman A. Management of agitation and seizures at the end of life. Journal of Pain and Symptom Management. 1999; 17:363-8.

100. Phenobarb Monograph Clinical Pharmacology. [Internet] [cited 2006 May 16].
Accessed from: http//:cp.gms (subscription required)

101. Phenobarb product monograph Micromedex. [Internet]. [cited June 30, 2006]
Available from: www.thompsonhealthcare.com (subscription required)

102. Personal communication Vita Barakova Sandoz Medical Information Specialist March 5; 2008.

103. Propofol monograph Canadian Pharmaceutical Association. [Internet]. [Cited 2008 Jan 20]. electronic Compendium of Pharmaceutical Specialties.

104. Kerr M. Lie D. Propofol could cause fatal reaction in refractory status epilepticus. [Internet]. Medscape Medical News. October 29, 2008. [Cited 2008 Nov 5].
Available from: http://www.medscape.org/viewarticle/582756

105. Vissers KCP. Hasselaar J. Verhagen AHHVM. Sedation in palliative care. Current Opinion in Anaesthesiology. 2007; 20:137-42.

106. Moyle J. The use of propofol in palliative medicine. Journal of Pain and Symptom Management. 1995; 10(8);643-6.

107. Tisdale C. Woloschuk DM. Terminal sedation: is there a role for the pharmacist? Canadian Pharmaceutical Journal. 1999; 132(6):28-33.

108. Lundstrom S. Zachrisson U. Furst CJ. When nothing helps: propofol as sedative and antiemetic in palliative cancer care. Journal of Pain and Symptom Management. 2005; 30(6):570-7.

109. Pms-Propofol product monograph. Pharmascience. Nov 15, 2002.

110. Fraser Health Hospice Palliative Care. Guidelines for the use of continuous subcutaneous infusions (CSCI) and the medications and combinations that can be administered via CSCI. [Internet]. 2007 [cited 2009 Jan 2].
Available from: http://fhpulse/clinical_support_services/pharmacy/policies_pdtm_ppos_forms/Documents/palliative%20care%20guideline%20csci.pdf

111. Propofol monograph. Clinical Pharmacology. [Internet]. [cited 2007 Jan 4].
Available from: http//:cp.gms (subscription required)

112. Fraser Health. Propofol parenteral drug therapy monograph. [Internet] 2005 [cited 2009 Jan 2].
Available from: http://fhpulse/clinical_support_services/pharmacy/policies_pdtm_ppos_forms/PDTM%20Drug%20Monographs%20Adult/propofol%20Apr09.pdf

113. O'Neill J. Fountain A. Levomepromazine (methotrimeprazine) and the last 48 hours. Hospital Medicine (London). 1999; 60(8):564-7.

114. Cherny NI. Sedation for the care of patients with advanced cancer. Nature Clinical Practice Oncology. 2006; 3(9):492-500.

115. Cosgrove JF. Nesbitt ID. Bartley C. Palliative care on the intensive care unit. Current Anaesthesia and Critical Care. 2006; 17:283-88.

116. Pirrello RD et al: Phenobarbital Protocol, The Institute for Palliative Medicine at San Diego Hospice. San Diego, CA; 2010.

117. Rousseau P. Palliative sedation in the control of refractory symptoms. J Palliative Medicine. 2005; 8(1):10-2.

118. Müüller-Busch HC. Outcome with sedation in palliative care – Some ideas for the Sedation group. Forum. European Association for Palliative Care. [Internet]. [cited 2009 Jul 27].
Available from: http://www.eapcnet.org/forum/default.asp?category=Outcome%20with%20sedation%20in%20palliative%20care

119. Sykes N. Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. Archives of Internal Medicine. 2003; 163(3):341-4.

120. Maltoni M. Pittureri C. Scarpi E. et al: Palliative Sedation Therapy does not hasten death: results from a prospective multicentre study. Annals Oncology. 2009; 20:1163-9.

121. Ely EW. Truman B. Shintani A. et al: Monitoring sedation status over time in ICU patients: Reliability and validity of the Richmond Agitation Sedation Scale (RASS). JAMA. 2003; 289:2983-2991.

122. Twycross R. Wilcock A. Dean M. Kennedy B. Hospice and Palliative Care Formulary Canadian Edition. Palliativedrugs.com. Nottingham, United Kingdom; 2010.

123. Kam PCA. Cardone D. Propofol infusion syndrome. Anaesthesia. 2007;62:690-701

124. The patient property act [Internet]. 2011 [updated 2011 October 19; cited 2011 Oct 27]. Available from: http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96349_01

125. The representation agreement act [Internet]. 2011 [updated 2011 October 19; cited 2011 Oct 27]. Available from: http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96405_01

126. Sessler C. Grap M. Brophy G. Multidisciplinary management of sedation and analgesia in critical care. Seminars in Respiratory and Critical Care Medicine. 2001;22:211-225.

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Selection and Duties of the Substitute Decision Maker[80]

To obtain substitute consent to provide major or minor health care to an adult, a health care provider must choose the first, in listed order, of the following who is available and qualifies (see below).

(1) **A court-appointed Committee of Person/Personal Guardian:** Under the *Patients Property Act*[124] (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96349_01), the court may have appointed a committee for an adult who is incapable of making health care decisions.

(2) **A representative:** An adult may, when able to do so, have planned for their future by making a Representation Agreement (section 9 agreement is required for consent to life sustaining treatment) under the *Representation Agreement Act*[125] (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96405_01) authorizing a representative to make health care decisions on their behalf if they were unable to make their own decisions.

(3) **Advance Directive:** This needs to be valid and relevant to the health care. If no Representative is appointed, it can stand alone and no TSDM needs to be appointed.

(4) **A Temporary Substitute Decision Maker:** If there is no representative or court-appointed committee of Person/personal guardian, under the *Health Care (Consent) and Care Facility (Admission) Act*[80] (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96181_01) a health care provider must choose the nearest relative as ranked below:

- The adult's spouse (common law, same gender);
- The adult's children (equally ranked);
- The adult's parents (equally ranked);
- The adult's brothers or sisters (equally ranked);
- The adult's grandparent (equally ranked)
- The adult's grandchild (equally ranked)
- Anyone else related by birth or adoption to the adult
- A close friend of the adult
- A person related immediately to the adult by marriage
- Another person appointed by Public Guardian and Trustee

When no one from the ranked list of substitute decision makers is available or qualified, or there is a dispute between who to appoint that cannot be resolved, the health care provider must contact a **Health Care Decisions Consultant at the Public Guardian and Trustee** who will appoint or act as TSDM.

To qualify to give, refuse or revoke substitute consent to health care for an adult, a person must

(a) be at least 19 years of age,

(b) have been in contact with the adult during the preceding 12 months,

(c) have no dispute with the adult,

(d) be capable of giving, refusing or revoking substitute consent, and

(e) be willing to comply with the duties below.

Duties of Representatives:

Representatives must:

- Act honestly and in good faith;
- Exercise the care, diligence and skill of a reasonable prudent person; and
- Act within the authority given in the Representation Agreement
- Consult, to a reasonable extent, with the adult to determinate his or her current wishes and
- Comply with those wishes if it is reasonable to do so. Please note, however, that in a section 9 Representation Agreement an adult may provide that the Representative need only comply with any instructions or wishes the adult expressed while capable.

Duties of Temporary Substitute Decision Makers:

- A person chosen to give or refuse substitute consent to health care for an adult must be 19 years of age or older, have had communication within the last 12 months with the patient and not be in dispute with the patient. Before giving or refusing substitute consent, the TSDM(s) must consult to the greatest extent possible:
  i. with the adult, and
  ii. if the person chosen under section 16 is a person authorized by the Public Guardian and Trustee, with any friend or relative of the adult who asks to assist, and
  iii. comply with any instructions or wishes the adult expressed while he or she was capable.
- If the adult's instructions or wishes are not known, the person chosen must decide to give or refuse consent:
  a. on the basis of the adult's known beliefs and values, or
  b. in the adult's best interests, if his or her beliefs and values are not known.
- When deciding whether it is in the adult's best interests to give, refuse or revoke substitute consent, the person chosen must consider
  a. the adult's current wishes,
  b. whether the adult's condition or well-being is likely to be improved by the proposed health care,
  c. whether the adult's condition or well-being is likely to improve without the proposed health care,
  d. whether the benefit the adult is expected to obtain from the proposed health care is greater than the risk of harm, and
  e. whether a less restrictive or or less intrusive form of health care would be as beneficial as the proposed health care

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Richmond Agitation Sedation Scale (RASS)

TERM	SCORE	DESCRIPTION
+4	*Combative*	• Overly combative or violent. Immediate danger to staff
+3	*Very agitated*	• Pulls/removes tubes or catheters. Has aggressive behaviour toward staff
+2	*Agitated*	• Frequent non-purposeful movement.
+1	*Restless*	• Anxious or apprehensive but movements not aggressive or vigorous
0	*Alert and calm*	
-1	*Drowsy*	• Not fully alert, but has sustained (>10 sec) awakening with eye contact to voice
-2	*Light sedation*	• Briefly (<10 sec) awakens with eye contact to voice
-3	*Moderate sedation*	• Any movement (but no eye contact) to voice
-4	*Deep sedation*	• No response to voice, but any movement to physical stimulation
-5	*Unrousable*	• No response to voice or physical stimulation

Procedure for RASS Assessment

STEP	PROCEDURE	SCORE
1	**Observe patient** • Patient is alert , restless, or agitated	**0 to +4**
2	**If not alert, state patient's name and say to open eyes and look at speaker.** • Patient awakens with sustained eye opening and eye contact • Patient awakens with eye opening and eye contact, but not sustained • Patient has any movement in response to voice but no eye contact	**-1** **-2** **-3**
3	**If patient does not respond to voice, physically stimulate patient by shaking shoulder and/or rubbing sternum*.** • Patient has any movement to physical stimulation • Patient has no response to any stimulation	**-4** **-5**

***Rubbing the sternum is not appropriate for palliative care patient assessment, and is not recommended.**

Adapted from Ely EW, Truman B, Shintani A, et al: Monitoring sedation status over time in ICU patients: Reliability and validity of the Richmond Agitation Sedation Scale (RASS). JAMA 289:2983-2991, 2003.[121]

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