

Framework for Continuous Palliative Sedation Therapy (CPST) in Canada

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Abstract

Background: Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy (CPST). Although a number of institutional and regional guidelines exist, Canadian practice varies. Given the lack of international and national consensus on CPST, the Canadian Society for Palliative Care Physicians (CSPCP) formed a special task force to develop a consensus-based framework for CPST.

Objective: Through a preliminary review of sedation practices nationally and internationally, it was determined that although considerable consensus was emerging on this topic, there remained both areas of contention and a lack of credible scientific evidence to support a definitive clinical practice guideline. This led to the creation of a framework to help guide policy, practice, and research.

Methods: This framework was developed through the following steps: 1) literature review; 2) identification of issues; 3) preparation of a draft framework; 4) expert consultation and revision; 5) presentation at conferences and further revision; and 6) further revision and national consensus building.

Results: A thorough literature review, including gray literature, of sedation therapy at the end of life was conducted from which an initial framework was drafted. This document was reviewed by 30 multidisciplinary experts in Canada and internationally, revised several times, and then submitted to CSPCP members for review. Consensus was high on most parts of the framework.

Conclusion: The framework for CPST will provide a basis for the development of safe, effective, and ethical use of CPST for patients in palliative care and at the end of life.

Introduction

SEDATION IS USED as a palliative treatment at the end of life, sometimes qualified as palliative, terminal, or deep continuous sedation.¹ Palliative sedation therapy was first described in the early 1990s as an existing practice but little is known about its development.^{2,3} Many definitions have been put forward for various types of sedation used in palliative practice, but at the core they share the ideas that palliative sedation is: 1) the use of (a) pharmacological agent(s) to reduce consciousness; 2) reserved for treatment of intolerable and refractory symptoms; and 3) only considered in a patient who has been diagnosed with an advanced progressive ill-

ness. Continuous palliative sedation therapy (CPST) is the use of ongoing sedation continued until the patient's death. There remains concern over the misuse or abuse of sedation in general and CPST in particular.⁴⁻⁹

Some countries have frameworks or guidelines that standardize CPST,¹⁰⁻¹³ but Canada does not and, although many institutional and regional guidelines exist, Canadian practice varies.¹⁴⁻¹⁸ Under the mandate of the Canadian Society for Palliative Care Physicians (CSPCP) the authors propose here a national framework within which to consider CPST. Given the lack of international consensus in many areas of CPST, for example, terminology, prognostic criteria, CPST in existential distress, and preferred medications, we do not seek to

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propose practice guidelines but instead propose a framework to standardize new and existing policies on CPST.

Methods

This framework was developed through five steps:

- 1) Literature review: The literature review was exploratory and not fully systematic, intending not to summarize the literature but to aid the development of a position statement. The review of sedation therapy at the end of life was conducted using Ovid Medline® from 1970 to December 2008 (Ovid Technologies Inc., New York, NY) and EMBASE® from 1980 to 2008 (Elsevier, New York, NY) search engines with the terms “terminal sedation,” “palliative sedation,” and “end of life care.” A review of gray literature including related national and international policies and protocols supplemented the review.^{11–16}
- 2) Identification of issues: From the papers retrieved the authors noted issues relevant to CPST, which were then developed into a framework.
- 3) Expert consultation and revision: The first draft of the framework was sent for review to 30 multi-disciplinary experts in Canada and internationally, and the framework was redrafted based on their feedback.
- 4) Presentation and revision: The framework was presented at three national conferences in workshop format and revised in light of feedback from these sessions.
- 5) Consensus and revision: The framework was submitted to the membership of the CSPCP and the recommendations assessed using an electronic survey (5-point Likert scale and comments). From the response the framework required minimal adjustment. The response rate was 29.3% for the 304 members (6 weeks response time, two reminder emails), and consensus was high on almost all parts of the framework (<30% “disagree” or “disagree strongly”). The framework was thereafter formally endorsed by the CSPCS.

Results

From the literature five broad issues appeared for inclusion in this framework. Below are the recommendations, appearing first in summary, and discussed in greater detail thereafter. Appendix 1 provides a diagrammatic algorithm that incorporates these recommendations.

Indications

1. CPST is indicated only for refractory and intolerable suffering, usually in the last 2 weeks of life.
2. The care team should have or seek expertise to determine that the symptoms are refractory and intolerable.
3. CPST for purely existential symptoms should be initiated only in rare cases of severe existential distress and after careful consultation with experts in the area.

The indication for CPST is refractory *and* intolerable suffering. Determining refractoriness and intolerability requires careful assessment by a multidisciplinary team attentive to the physical, psychological, social, emotional, and existential/spiritual dimensions of the symptom(s).^{16,17}

Before CPST is offered all other available symptom-targeted medications, procedures or interventions should have been considered, offered if appropriate, and either continued or declined. If the healthcare team lacks the ability to make these assessments the team should seek consultation with a clinician more experienced in CPST. This consultation should be in-person, but may use other means if no such option exists. The setting of care and the relative availability of interventions may affect refractoriness.¹⁸ When considering CPST in a patient who cannot communicate his/her wishes, discussion with the patient’s substitute decision maker (SDM) is required.

CPST should be considered only when death is expected within 1 to 2 weeks. Although prognosis remains sometimes challenging, the longer the anticipated time before death the greater the ethical challenges and the more controversial the procedure, especially regarding decisions around nutrition and hydration during sedation.

CPST for existential suffering alone is controversial.^{19–25} Existential suffering describes the experience of patients who may or may not have physical symptoms, but suffer in part from their understanding of their position. It can be related to one or more of: meaninglessness in present life; sense of hopelessness; perceiving oneself as a burden on others; feeling emotionally irrelevant; being dependent; feeling isolated; grieving; loss of dignity and purpose; (fear of) death of self; or fear of the unknown.^{26,27} Existential suffering can exacerbate suffering from refractory physical symptoms,²⁸ or can be significant in its own right and should not be disregarded. However, CPST for purely existential symptoms should only be initiated in rare cases of severe existential distress and after skilled multidimensional management directed at the physical, psychological, and existential dimensions has been attempted, preferably in consultation with relevant experts in this area, such as, for example, a psychologist or psychiatrist, chaplain, ethicist, or palliative care physician.²⁹

Aim

1. The aim of CPST is to relieve refractory and intolerable suffering of the patient.
2. Sedation should be carefully titrated to adequately relieve suffering.
3. CPST correctly practiced is not a form of euthanasia, but an appropriate palliation.

The aim or intention of CPST should be the relief of suffering due to refractory and intolerable symptoms^{30–32} and not the sedation itself. There should be no intention to shorten life and no intention to bring about complete loss of consciousness, although the latter may sometimes be necessary. The level of consciousness should be lowered only as far as is necessary to relieve the suffering. The implication of a decision to use CPST is that symptom relief could not be obtained without intentionally clouding consciousness (proportionate reason). There should be consensus that the harm of suffering warrants the harm of reduced consciousness and sedation should only be deep enough to palliate (proportionate response)—no further sedation is required.

There remains some concern that CPST might constitute euthanasia, understood as knowingly performing an act that, with the motive of mercy, intentionally ends another person’s life. In bioethics, the principle of double effect has served as

traditional justification for the use of palliative sedation—wherein a moral distinction is made between one's initial intentions and the foreseen and unintended consequences of the act.^{33–38} However, the data published to date indicates that the appropriate use of CPST does not shorten life.^{42–44} Clinicians continue to dispute the relationship between CPST and the hastening of death, but most often this concerns cases in which sedation is given outside the scope recommended in this framework, such as sedation given well beyond levels needed to palliate suffering and sedation given before death is imminent.

Decision making

1. Decisions regarding CPST should conform to the accepted national, provincial, and institutional policies for decision making and informed consent in law and medical ethics.
2. Decisions regarding CPST and concurrent treatments should be considered separately as well as together.
3. Decisions regarding CPST should involve all relevant members of a health care team, one of whom should, preferably, be a clinician experienced in CPST.
4. Decisions regarding CPST should be revisited periodically with the family, health care providers, and, where possible, the patient.
5. CPST-related decision making should incorporate specific cultural and religious/spiritual values and practices into the plan of care for patients and families, and should involve language interpreters if needed.

Decisions about CPST should be made in a manner that is clinically, ethically, and legally appropriate, requiring attention to both the process of arriving at decisions and to the substance of what is to be decided upon. At a minimum, common law precedence and statutory law provide a framework to direct and evaluate medical decision making.⁴² For decisions to be legally valid the patient must (1) be capable of making the decision; (2) make his/her choices voluntarily; (3) be informed; and (4) the choice must be specific to the proposed procedure. If the patient is not capable, a SDM must be sought.

The process ensuring these conditions in the case of CPST is the same as for other medical procedures. Where there is concern about a patient's capacity to make a decision, capacity

must be assessed using a recognized approach⁴³ and/or in consultation with appropriate professionals and a SDM sought if necessary. As in all cases of medical decision making, the patient or SDM should understand the patient's condition, the treatments available, and the potential harms and benefits of those treatments versus no treatment. Discussion of CPST should address issues pertinent to CPST in particular (see Table 1). The SDM should be aware of the patient's values, goals, preferences and wishes, and make any decisions based on these, especially if expressed in an advance directive. Discussions regarding medical treatment should be clearly documented in the patient's records. Even if a decision for CPST is reached, a healthcare provider can refuse to administer CPST if he/she views it as ethically unacceptable, but the provider must then transfer care to someone who will deliver it.

Given that CPST is by definition indicated in cases of intolerable suffering, one can ask whether some persons suffering in this way might be incapable of giving truly voluntary or fully capable consent. This framework accepts that to some degree such concerns cannot be eliminated. However, two considerations justify CPST in spite of these concerns. First, by insisting before initiating CPST that all other reasonable alternatives have failed or were reasonably rejected, the framework precludes the opportunity to choose CPST "prematurely" or under duress of suffering. Second, by encouraging teams to follow accepted consent procedures the framework supports the kind of voluntary and capable decision making that these procedures seek to promote.

Providing CPST while withholding or withdrawing other treatments, particularly nutrition and hydration (N&H), continues to cause concern.⁴⁴ Withdrawal or withholding of hydration, for example, need not be an element of CPST,²⁹ but there is insufficient evidence about either the beneficial or harmful effects of fluid administration to terminally ill patients to permit recommendations.⁴⁵ Decision making regarding the use of concurrent treatments needs to be made both in light of CPST and independently, with clear reasons given for the use or not of each.^{42,46,47} An institution involved in the provision of end-of-life care should consider having policies and/or practice guidelines to assist decision making involving the withholding and/or removal of life supportive therapies, for example, ventilatory support and N&H. The psychological, ethical, cultural, religious, and/or legal implications of N&H management in palliative patients also need consideration.⁴⁸

Decisions about CPST should involve as many persons as it is likely to impact, including, for example, the patient (if able to participate), the family of the patient and the patient's healthcare team, and sometimes others important in the patient's life. Notwithstanding this inclusiveness, the appropriate ethical and legal norms of confidentiality must be respected. Decisions about CPST should be made with the aid of a health care team that includes an experienced palliative care clinician. Where this is not feasible, the attending physician should attempt to obtain a second opinion from a clinician experienced in CPST, if not in person then by video-conference or telephone. Because decisions about CPST may affect so many persons, there is potential for disagreement and uncertainty, and therefore discussions concerning CPST should begin early, take place repeatedly, and be documented on each occasion. If disagreement does arise, others beyond

TABLE 1. DECISION-MAKING CONSIDERATIONS
SPECIFIC TO CPST

That the patient's disease will result in the patient's death, and how imminent this might be.
That there should be consensus that the patient has refractory and intolerable suffering.
That the aim of CPST is to reduce suffering, not hasten death.
That the sedation will be titrated to the relief of suffering.
That the patient will have a reduced or nonexistent ability to communicate after initiation of CPST.
That the patient will be monitored for relief of suffering and the adverse effects of sedation.
That if CPST is stopped, the patient's symptoms and suffering may recur.
That decisions about concurrent treatments need to be made (e.g., fluid and nutrition, medication review).

TABLE 2. CULTURAL CONSIDERATIONS FOR THE USE OF CPST

Value and meaning given to pain and suffering.
Importance of consciousness in the dying process.
How decisions are made by the patient and family.
Value and meaning placed on food and hydration.
Death rituals/spiritual beliefs and practices.
Communication pattern and systems (truth telling, disclosure, and hope system).
Meaning of death and dying.
Perception by the patient/family of the role of the health care practitioners.
Cultural understanding of illness versus disease, and health care practices used for treatment (traditional and medical models).

the immediate care team may need to be consulted to help resolve the issues and to provide support, for example, an ethicist or chaplain. (See the algorithm in Appendix 1.)

Professional cultural and linguistic translators should be used if language or cultural differences present uncertainty, with awareness that a person may have a background in a culture without sharing all of that culture's aspects. Table 2 outlines some of the significant cultural aspects pertaining specifically to CPST.⁴⁹ Training and proficiency in cultural competency can help facilitate the health care team in the important role of determining team members' own and the patient's and family's attitudes toward and underlying beliefs about CPST.⁵⁰

These discussions should take as much time, patience, and understanding as is necessary, but be balanced against the urgency to relieve the patient's suffering. Professionals should recognize that patients, their family and friends, and the professionals involved, including themselves, might be distraught, stressed, and overwhelmed. As far as possible, the health care professionals involved in the discussions should remain sensitive to the patient's culture, feelings, and traditions; the institutional culture and policy; and the hopes on all sides that will underlie these discussions. Disagreements and tensions should be addressed with all the experience and resources available, and sometimes require support from those with extra expertise but who are outside the institutions involved.

Drugs and their administration

1. Benzodiazepines or sedating antipsychotics are used most often for palliative sedation.
2. Drugs used for CPST should be titrated to relieve suffering through sedation.
3. Opioids and haloperidol should not be used for CPST, although when appropriate opioids may continue to be administered to a patient receiving CPST.

No good evidence exists to strongly recommend one medication over any other of those commonly used in CPST. However, several reviews do describe the medications that are preferred by practitioners,^{15,18,22,26,31,46,51} and those are briefly discussed next. The actual choice of one sedative over another should depend on the clinical experience of practitioners and institutional policies.

Benzodiazepines are the most commonly used medications for CPST, and of them midazolam is most frequently used.³¹

Because it is administered parenterally, midazolam can be used in all stages of sedation and due to its short half-life it can be more easily titrated than other benzodiazepines. It also possesses anxiolytic, anticonvulsant, and muscle relaxant properties. In some patients, benzodiazepines may have a paradoxical excitatory effect.

Antipsychotics are also frequently used, although sedating antipsychotics are less commonly used for CPST than benzodiazepines. Of the sedating antipsychotics, chlorpromazine and methotrimeprazine are preferred by practitioners because both medications can be administered parenterally and both have neuroleptic properties that may be helpful in cases where CPST is used for a patient with profound terminal delirium. Haloperidol is another antipsychotic medication that has been used for CPST, but it has weaker sedative properties than both chlorpromazine and methotrimeprazine and is a poor choice. Extrapyramidal effects and cardiac arrhythmias are possible side effects associated with antipsychotics, but they are rare in the brief use typical of CPST.

Barbiturates, for example phenobarbital,⁵² and propofol are also occasionally used for CPST.⁵¹ Phenobarbital may be used as an adjunct to midazolam or an antipsychotic, or it may be used alone. It may rarely cause paradoxical excitation, or respiratory depression in high doses. Propofol has a rapid onset and short half-life but can cause respiratory depression and profound hypotension, and it should be used only by an experienced practitioner. Opioids are a poor choice for CPST because deep sedation will occur only when toxic doses are used, risking neuroexcitatory effects and respiratory depression leading to hastened death. However, it may be appropriate to continue to provide opioid therapy for symptom management, for example, pain or dyspnea in a sedated patient.

The use of palliative sedation presents a conceptual challenge in the case of delirium. Pharmacological treatments directed at easing delirium may also cause sedation as a side effect, that is, *secondary* or *consequential* sedation, but this differs from CPST, in which sedation is a directly intended treatment. For example, less-sedating antipsychotics such as haloperidol may be used to manage delirium, but haloperidol is not typically used as a first-line sedative drug. Other antipsychotics that are sedating, for example, methotrimeprazine, may in lower doses treat delirium with little sedation and in larger doses cause obvious sedation. Ultimately, however, these conceptual nuances do not affect the principles outlined elsewhere in this framework. It remains the case that sedation should be titrated to relieve suffering and therefore that deep and continuous sedation for (terminal) delirium is a last resort, used when suffering remains intolerable and refractory despite other treatments.

Monitoring and outcomes

1. A patient receiving CPST should be monitored for:
 - a. Relief of suffering
 - b. Level of consciousness (depth of sedation)
 - c. Potential adverse effects of sedation
2. Family and healthcare professionals should be monitored for:
 - a. Psychological distress
 - b. Spiritual distress

CPST should be provided with attention to the desired effects and also with an eye to unwanted pharmacological side

TABLE 3. ASPECTS OF CPST REQUIRING MONITORING

Relief of suffering as assessed by verbal comments of the patient or the caregiver(s), facial expressions, and/or body movements or posture.
Level of consciousness (depth of sedation) as assessed by responses to verbal or nonpainful physical (mechanical) stimuli.
Adverse effects related to sedation. Depending on the depth of sedation, this might include susceptibility to limb/joint injury, skin breakdown, respiratory depression, etc.

effects, for example, apnea, and possible unwanted consequences arising from the patient's decreased awareness of his/her body, for example, skin breakdown, joint injury, or aspiration. All patients receiving CPST should have documented monitoring of suffering, consciousness, side effects and unfavorable consequences, and other palliative measures (see Table 3).

Patients should be assessed frequently until adequate sedation has been achieved and then at least once a day. Although little consensus appears in the literature on CPST, monitoring has been suggested every 20 minutes until adequate sedation has been achieved, and thereafter should occur at a minimum of three times a day.^{15,17} The pharmacokinetics of the drug used for sedation should influence the frequency of monitoring and dose adjustment; therefore, consultation with a pharmacist may be helpful. Frequency of monitoring will also vary based on the location of care, for example, home or institution.

Monitoring should include patient comfort, so any scale devised for this patient population should have this orientation. Monitoring scales exist to assess communication,⁵⁶ level of sedation,^{54,55} motor activity,⁵⁶ and agitation^{54,56} of sedated patients, as do scales assessing level of consciousness due to trauma or disease, but the usefulness of these scales in CPST patients has not been proven.⁵⁷ Scales involving administration of painful stimuli are not acceptable within the palliative care context. Those scales oriented toward agitation may not be appropriate for monitoring a patient sedated for reasons other than agitation, for example, pain or dyspnea. A scale for use in CPST has been proposed, but it addresses only the level of sedation, not comfort, relief of suffering, or adverse effects, and at one level requires a moderately painful stimulus (pinching of the trapezius muscle).⁵⁸ Presently, no particular scale can be recommended for monitoring.

Although, ideally, monitoring of symptom control would include patient self-report, the patient's depth of sedation may preclude this. Some authors have advocated either an initial trial of sedation^{19,59} or a lightening of sedation at a predetermined time (intermittent sedation),^{29,31,60,61} the aim being in either case to allow the patient to report on the benefit or not of the sedation. One author suggests that the relief from stress during sedation may be therapeutic and further sedation will not be needed.²³ The contrary concern is that the patient will awaken to intense suffering and there may even be a risk that adequate sedation cannot be obtained without far more aggressive drug administration. Although intermittent sedation may be indicated when the patient is not close to death, for the imminently dying patient intermittent sedation is unlikely to be beneficial to patient or family, and so is not considered an option within the context of this framework.

Patients receiving continuous sedation during the last few days of life do not require measurements of "vital signs" unless such monitoring would contribute to the comfort of the patient and/or family.^{17,18} Dose reduction should be considered if adverse effects attributable to the sedation occur (e.g. breathing pattern, tachycardia, sweating), unless such changes are thought to be part of the disease or dying process.

The experience of having a patient sedated is usually stressful for family and caregivers, and the emotional state of both should be monitored informally. It is important to provide psychosocial and spiritual support for the patient's family, and care teams should address and support each other with respect to the emotional burdens of the HCPs involved. Interprofessional debriefing conferences should be held if necessary.

As with all aspects of care, the results of monitoring should be recorded.

Conclusion

Under the mandate of the Canadian Society for Palliative Care Physicians, the authors have proposed a national framework within which to consider CPST. The potential for abuse does exist in CPST, and this framework attempts to provide foundations to allow the creation of guidelines, policies and safeguards that ensure that care is delivered within accepted medical guidelines. The authors hope that this document will serve as a template for policy creation in health care settings across Canada where CPST may be practiced.

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX 1





