Palliative Sedation for Existential Distress?

A Survey of Canadian Palliative Care Physicians' Views

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Aim

Palliative sedation (PS) can be used to treat refractory physical symptoms during end-of-life care. However, use of PS for managing existential distress remains controversial, as it is difficult to determine when the distress is refractory.

There are no apparent recent data on the views and practices of Canadian palliative care physicians on the use of PS for existential distress.

The aim of this study was to determine the expert opinions and practices of Canadian palliative care physicians regarding continuous palliative sedation for the management of refractory existential distress.

Methods

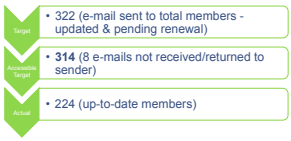
1. Pilot study: feedback from members of the Division of Palliative Medicine, University of Alberta (n=15)
2. Survey questions (number per section):
   - A. Demographics (n = 9)
   - B. Experience with Palliative Sedation (n = 8)
   - C. Experience with Palliative Sedation and Existential Distress (n = 5)
   - D. Views on Palliative Sedation and Existential Distress (n = 5)
   - E. Additional Comments (n = 3)
3. Online national survey

   Available in English and French; Anonymous responses

   Target group: E-mails sent to 322 Canadian Society of Palliative Care Physicians (CSPCP) members (Figure 1)

   Dates: March 24 – April 14, 2014 (allowed two weeks; reminder with additional week)

Figure 1. Sample size



Definitions

Palliative sedation:
- "the use of (a) pharmacological agent(s) to reduce consciousness, reserved for treatment of intolerable and refractory symptoms only considered in a patient who has been diagnosed with an advanced progressive illness."
- assumed patients in their last days of life
- intentional, deep ***continuous palliative sedation (CPS)***, defined as "the use of ongoing sedation continued until the patient's death."[1]

Refractory symptom: "a symptom that can not be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness".[2,3]

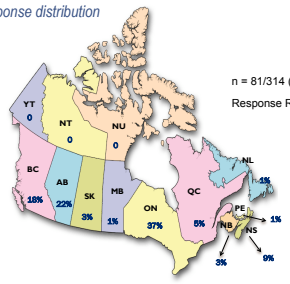
Existential distress: "the experience of patients who may or may not have physical symptoms, but suffer in part from their understanding of their position. It can be related to one or more of: meaninglessness in present life; sense of hopelessness; perceiving oneself as a burden on others; feeling emotionally irrelevant; being dependent; feeling isolated; grieving; loss of dignity and purpose; (fear of) death of self; or fear of the unknown."[1]

Results

- 81 completed surveys returned, (26% response rate) (Figure 2).
- Average number of years practiced in medicine & palliative care = 22 (SD 12) and 15 (SD 8), respectively (Table 1).
- Dyspnea (100%), seizures (95%), & delirium (93%) were the most commonly reported refractory symptoms for which CPS could be indicated (Table 2).
- Most (98%) participants believed that CPS is indicated for refractory physical symptoms with coexisting existential distress; 43% believed that it could be indicated for existential distress alone (Table 2).
- The majority of respondents reported the use of midazolam (100%), but 22% reported using opioids specifically for CPS (Figure 3).
- More (71%) respondents were asked to provide, compared to those who actually provided (31%), CPS for existential distress (Tables 3 & 4).
- Loss of dignity (72%) was reported as the main cause of suffering experienced by patients receiving CPS for existential distress (Table 5).
- Using a 5-point Likert scale, 40% of respondents either strongly disagreed or disagreed, while 43% either strongly agreed or agreed, with the use of CPS for the management of existential distress when no other refractory physical symptoms are present (Figure 4).

Responses

Figure 2. Response distribution



n = 81/314 (accessible target)

Response Rate = **25.7%**

Table 1. Participant characteristics

	n	%
Gender	**80***	**99**
Male	34	42
Female	46	56
Year of added competency training	**81**	**100**
Yes	42	52
No	39	48
Clinical Roles	**81**	**100**
Primary MD	38	47
Consulting MD	73	90
Other	10	13
Medical Specialty	**81**	**100**
Family Medicine	66	81
Internal Medicine	4	5
Other	11	14
Age	**79****	**98**
<30 years	0	0
31-40	17	21
41-50	22	27
51-60	22	27
>61	18	22
Years of Clinical Experience	**Mean**	**SD**
Medical Practice	22.3	12.1
Palliative Medicine	15.0	8.4

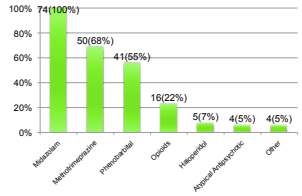
* 1 missing response, **2 missing responses

Experience with Palliative Sedation

Table 2. What do you believe are the refractory symptoms for which CPS could be indicated? (n = 81)

	n	%
Dyspnea	81	100
Refractory physical symptoms with coexisting existential distress	79	98
Seizures	77	95
Delirium	75	93
Pain	70	86
Nausea/Vomiting	60	74
Existential distress alone	35	43
Other	4	5

Figure 3. Medications used specifically for CPS, n = 194 (% reflects 74 respondents)



Experience with Palliative Sedation & Existential Distress

*Table 3. Have you ever **been asked** to provide CPS for the relief of existential distress? (n = 81)*

	n	%
Yes	58	71
No	23	29

*Table 4. Have you ever **provided** CPS for the relief of existential distress? (n=81)*

	n*	%
Yes	25	31
No	52	64

* 4 missing responses

Table 5. Nature of suffering for patients who used CPS for existential distress

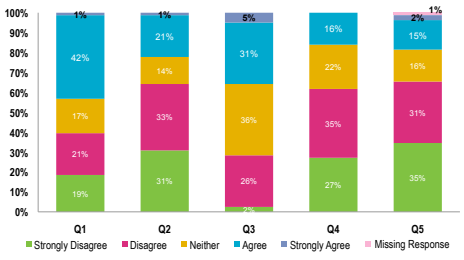
	n	%**
Loss of dignity	18	72
Fear & panic	16	64
Death anxiety	15	60
Dependency/Inability to take care of oneself	14	56
Hopelessness	14	56
Burden on others	11	44
Wish to control the time of death by oneself	11	44

**percentage based on total (n= 25)

Views on Palliative Sedation & Existential Distress

Q1. When no other refractory physical symptoms are present, CPS can be used for the management of existential distress.
Q2. I am comfortable using CPS for the management of existential distress.
Q3. CPS for the management of existential distress shortens life.
Q4. CPS for the management of existential distress is a form of physician assisted suicide (PAS).
Q5. CPS for the management of existential distress is a form of euthanasia.

Figure 4. Views on Palliative Sedation and Existential Distress



Discussion & Conclusion

A wide variety of responses and opinions appear to exist around palliative sedation for the management of existential distress.

Further questions for ongoing consideration include:

1. How is palliative sedation conceptualized in clinical practice compared to the literature?
2. Is there a role for palliative sedation for existential distress alone?
3. To what extent are palliative sedation and euthanasia morally distinct, given variability in practice?

Palliative sedation for the management of existential distress continues to be a complex and potentially controversial issue.

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REFERENCES:

[1] Dean MM, Cellarius V, Henry B, et al., Framework for continuous palliative sedation therapy in Canada. J Palliat Med. 2012 Aug; 15(8):870-9.

[2] 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 Feb;10(1):67-85.

[3] Cherny NI, Portenoy RK., Sedation in the management of refractory symptoms: guidelines for evaluation and treatment., J Palliat Care. 1994 Summer;10(2):31-8.

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