

IMPORTANT NOTICE



- This presentation will be broadcast on OTN.
- We will start promptly at 7pm – please be in your seats by 6:55pm to help us stay on track
- For those connecting on OTN, please ensure you have printed a copy of the protocol (or have an electronic version open to follow along), the one page summary of criteria and process and the evaluation.
- Please note that an incomplete version of the presentation has been posted to OTN and this will be remedied after the fact

Palliative Sedation Therapy



A CASE-BASED PANEL REVIEW OF THE
WATERLOO WELLINGTON PROTOCOL

NOVEMBER 13, 2013

DR. DEBORAH ROBINSON
THE WATERLOO WELLINGTON
INTERDISCIPLINARY PALLIATIVE EDUCATION
COMMITTEE

The Panel



- Michael Chow – Spiritual Care provider
- Megan Hamilton - Pharmacist
- Blair Henry– Ethicist
- Shelley Lillie – Community palliative care nurse
- Dr. Chris Lund – Family Physician

Introduction



- OTN introduction and rules of engagement
 - Welcome and check in with OTN sites
- Timelines
 - OTN broadcast from 7pm – 9pm
 - Question period at end of presentation (goal 8:30)
- Handouts
 - PST protocol
 - Criteria and Process Summary sheet
 - Evaluation form
- Educational Goals
 - Using a case-based review, we will familiarize participants with the contents of the PST protocol

Interesting Reading



- Maltoni, Marco et al.
 - Palliative Sedation in End of Life Care
 - Current Opinion in Oncology July 2013 25(4) 360 -367
 - ✦ PST is a core competency for palliative care clinicians
- Lipuma, SH.
 - Continuous sedation until death as physician assisted suicide/euthanasia: a conceptual analysis
 - Journal of Medical Philosophy 2013 38(2) 190 – 204

Interesting Reading



- Angel Benitez-Rosario, M. et al.
 - Quality of Care in Palliative Sedation: Audit and compliance monitoring of a clinical protocol
 - JPSM 2012 44 (4) 532-541
 - ✦ A quality of care strategy to enhance adherence to guidelines
- Arevalo et al.
 - Palliative Sedation: reliability and validity of sedation scales
 - JPSM 2012 44 (5) 704-714
 - ✦ RASS and KNMG scales are most reliable among those evaluated

Interesting Reading



- Angel Benitez-Rosario, M. et al.
 - Clinical and ethical challenges of palliative sedation therapy. The need for clear guidance and professional competencies
 - International Journal of Clinical Practice 2013 67(11) 1086-8
 - ✦ Review of the challenges faced when making a decision about PST

Acknowledgements



- Blair Henry
- Pallimed Case Conferences: cases.pallimed.org
- Mississauga Haton PST Sample Policy Education PPT
www.palliativecareconsultation.ca/resources

Purpose of the PST Protocol



- To provide clinicians in the Waterloo Wellington region with an approach to PST that has been reviewed by peers with experience in this area.
- To be used as an aide in clinical practice and to clarify the purpose, key definitions, and process of PST
- To ensure effective, safe and appropriate use of PST
- To open dialogue and promote communication

Contents of the PST Protocol



- Purpose and Definitions
- Indications for Use and Criteria for Initiation
- Process and Documentation
- Medications
- Monitoring
- How Can Family and the Clinical Team be supported

Case 1



- Susan is a 54 yo woman with end-stage COPD.
- She has been admitted to hospital with “pain all over”.
- Her Bayshore nurse had noted increased anxiety and hopelessness in past week.
- Susan says she is tired of being sick and exhausted, and wants to be put to sleep.
- She is angry that terminal sedation hasn’t been offered.

Case 1



- Susan lives with her spouse and adult children, all who work full-time.
- Susan experiences dyspnea with activity but is able to transfer independently to commode or wheelchair.
- She is alert with no evidence of confusion. She is not suicidal. She is cachectic and tachypnic.
- Her prognosis is estimated in months.
- She takes medication erratically for symptom control.

QUESTIONS FOR CASE 1



- What is palliative sedation therapy?

Shelley

QUESTIONS FOR CASE 1



- What is palliative sedation therapy?
- Dose Susan meet the indications and criteria for palliative sedation?

Chris

PST Criteria

Is symptom intolerable for patient?

- Consider impact on quality of life, suffering, demoralization, lack of dignity
- Consider patient goals, hopes, wishes, plans in light of symptom

If yes then....

Is patient near end of life (days to weeks)?

If yes then....

Is symptom refractory?*

- Are further treatment options available?
- Can treatment be given without unacceptable side effects?
- Can treatment be given in an acceptable care setting?
- Will treatment be effective within an acceptable time frame?

(*a symptom is considered refractory if the answer is no to any one of the above questions)

(@Non-controversial indications include intractable dyspnea, delirium, seizure, pain, nausea. Controversial indications include existential/spiritual suffering, psychological suffering)

If yes then....

Criteria are met for consideration of PST

QUESTIONS FOR CASE 1



- What is palliative sedation therapy?
- Does Susan meet the criteria for palliative sedation?
- What should we do for Susan?

Chris

Case 1 - Outcome



- A family meeting is held where Susan expresses her frustration that no one can stay at home with her during the day.
- The request for ‘terminal sedation’ is acknowledged and the PST process is explained
- Susan is informed that her symptoms can be treated more effectively
- Around the clock opioids are initiated instead of ‘as needed’ for relief of dyspnea and pain and a comprehensive plan is put in place for her anxiety, depression and sense of isolation

Case 2



- Sarosh is 30 years old with a diagnosis of end-stage osteosarcoma and has exhausted all treatment options
- He has been battling severe pain and dyspnea and has made use of aggressive opioid and adjuvant therapies along with attempts at management with interventional pain techniques
- Sarosh has severe myoclonus refractory to standard therapy and ongoing poorly controlled pain

Case 2



- Sarosh is 'groggy' from medication and while pain improves with increasing narcotics the myoclonus continues to get worse
- Sarosh's PPS is 20% to 30% and his prognosis has been estimated to be days to a couple of weeks
- Sarosh is able to articulate the severity of his pain and physical signs of poorly controlled pain are visible when attempting personal care
- Sarosh is currently at a residential hospice and is well supported by his immediate family and numerous friends

Case 2 - Questions



- Does Sarosh meet the criteria for PST?

Shelley

PST Criteria

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(@Non-controversial indications include intractable dyspnea, delirium, seizure, pain, nausea. Controversial indications include existential/spiritual suffering, psychological suffering)

If yes then....

Criteria are met for consideration of PST

Case 2 - Questions



- Does Sarosh meet the criteria for PST?
- How would you finalize a decision to pursue PST?
- What documentation would be involved prior to initiation of PST?

Blair

Mike

PST Process

Consider palliative expertise consultation to ensure no other options

then....

Evaluate patient's medication list and decide on medications that may be used

then....

Hold a family meeting with interdisciplinary team members to establish

- Patient's goals of care including resuscitation wishes
- Clear understanding of the risks, benefits and process of PST and alternate options
- Informed consent
- Management of nutrition and hydration, oral, eye, skin care
- Timing of initiation and how (subcutaneous continuous infusion, stopping unnecessary meds)
- Expected changes in LOC, respiratory patterns, sounds and ongoing monitoring

then.....

Document PST criteria, decision making process, details of family meeting and medications to be administered and plan for ongoing monitoring

Case 2 - Questions



- Does Sarosh meet the criteria for PST?
- How would you finalize a decision to pursue PST?
- What documentation would be involved prior to initiation of PST?
- What medication would you use?

Megan

Case 2 - Questions



- Does Sarosh meet the criteria for PST?
- How would you finalize a decision to pursue PST?
- What documentation would be involved prior to initiation of PST?
- What medication would you use?
- What orders would you write?



Chris

A white speech bubble with a dark blue outline and a tail pointing towards the bottom left. The name "Chris" is written inside in a bold, dark blue serif font.

Sample PST Orders



- This is palliative sedation therapy
- DNR (if not already documented)
- Continue with (specify narcotic orders)
- Stop (meds to be discontinued)
- Midazolam 5mg subQ stat then, start midazolam 1mg/hr subQ infusion and may increase by 1mg/hr q30 minutes to achieve comfort
- Foley catheter PRN, routine bowel care, routine skin care
- Oral balance gel QID and prn
- Moisture drops to eyes BID and prn
- Hypodermoclysis – normal saline 250 cc daily PRN

Case 2 - Questions



- Does Sarosh meet the criteria for PST?
- How would you finalize a decision to pursue PST?
- What documentation would be involved in the initiation of PST?
- What medication would you use?
- What orders would you write?
- What monitoring would be involved?

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Shelley

Richmond Agitation Sedation Scale (RASS) *

Score	Term	Description	
+4	Combative	Overtly combative, violent, immediate danger to staff	
+3	Very agitated	Pulls or removes tube(s) or catheter(s); aggressive	
+2	Agitated	Frequent non-purposeful movement, fights ventilator	
+1	Restless	Anxious but movements not aggressive vigorous	
0	Alert and calm		
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to voice (≥ 10 seconds)	} Verbal Stimulation
-2	Light sedation	Briefly awakens with eye contact to voice (< 10 seconds)	
-3	Moderate sedation	Movement or eye opening to voice (but no eye contact)	
-4	Deep sedation	No response to voice, but movement or eye opening to physical stimulation	} Physical Stimulation
-5	Unarousable	No response to voice or physical stimulation	

Procedure for RASS Assessment

1. Observe patient
 - a. Patient is alert, restless, or agitated. (score 0 to +4)
2. If not alert, state patient's name and say to open eyes and look at speaker.
 - b. Patient awakens with sustained eye opening and eye contact. (score -1)
 - c. Patient awakens with eye opening and eye contact, but not sustained. (score -2)
 - d. Patient has any movement in response to voice but no eye contact. (score -3)
3. When no response to verbal stimulation, physically stimulate patient by shaking shoulder and/or rubbing sternum.
 - e. Patient has any movement to physical stimulation. (score -4)
 - f. Patient has no response to any stimulation. (score -5)

* Sessler CN, Gonnell M, Grap MJ, Brophy GT, O'Neal PV, Keane KA et al. The Richmond Agitation-Sedation Scale: validity and reliability in adult intensive care patients. *Am J Respir Crit Care Med* 2002; 166:1338-1344.

* Ely EW, Truman B, Shintani A, Thomason JWW, Wheeler AP, Gordon S et al. Monitoring sedation status over time in ICU patients: the reliability and validity of the Richmond Agitation Sedation Scale (RASS). *JAMA* 2003; 289:2983-2991.

Case 2 Outcome



- Sarosh and family appreciate the thorough discussion and proceed with a plan for PST at home
- Sarosh is started on midazolam infusion and the dose is adjusted q15 minutes until a comfortable level of sedation is reached and then is monitored q4h
- Sarosh passes away peacefully 48 hours after initiation of PST.

Case 3



- Carson is a 70 yo man who has been diagnosed with ALS and is experiencing difficulty with muscle control/weakness and has required intermittent respiratory support
- A psychiatrist has determined that he is not clinically depressed and is able to understand and appreciate his current medical condition
- Carson fears that he has reached a point of impending loss of dignity.
- After receiving spiritual counseling and ongoing psychological support, Carson repeatedly asks for the right to die with dignity

Case 3 - Questions



- Does Carson meet the criteria for PST?

Chris

PST Criteria

Is symptom intolerable for patient?

- Consider impact on quality of life, suffering, demoralization, lack of dignity
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If yes then....

Is patient near end of life (days to weeks)?

If yes then....

Is symptom refractory?*

- Are further treatment options available?
- Can the treatment be given without unacceptable side effects?
- Can treatment be given in an acceptable care setting?
- Will treatment be effective within an acceptable time frame?

(*a symptom is considered refractory if the answer is no to any one of the above questions)

(@Non-controversial indications include intractable dyspnea, delirium, seizure, pain, nausea. Controversial indications include existential/spiritual suffering, psychological suffering)

If yes then....

Criteria are met for consideration of PST

Case 3 - Questions



- Does Carson meet the criteria for PST?
- What is existential suffering?



Mike

A white speech bubble with a blue outline and a tail pointing towards the bottom-left. The name "Mike" is written inside in a bold, dark blue serif font.

Existential Suffering



- Existential Suffering:
 - Angst or anguish
 - Meaning, purpose and fulfillment
 - Quality of living
 - Concerns personhood (what makes me “me”)
- Questions/statements that may arise:
 - Why is this happening to me?
 - What happens after I die?
 - It's not death I fear but the dying part
 - Will I be eternally damned for the bad things I have done?

Existential Suffering



- What is happening:
 - Personal integrity is threatened
 - Existential or spiritual suffering
 - Inherently subjective, unique (Cassell)
- Manifestation:
 - 4 core issues: death, isolation, freedom and meaning (Yalom)
 - Could manifest in somatic, psychological and emotional ways
 - “Total Pain” – body, mind and spirit (Dame Saunders)
 - Transcending suffering

Existential Suffering



- Issues:

- Troubling for caregivers
- Suffering needs to be acknowledged and validated
- Empathic listening and staying with the person in their suffering

References:

Balfour Mount and Eric Flanders. Existential suffering and the determinants of healing. *European Journal of Palliative Care*, 2003, 10(2) Supplement.

George P. Smith. 2011. "Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being"

Available at: http://works.bepress.com/george_smith/63

Cassell EJ. *The nature of suffering and the goals of medicine*. N Eng J Med 1982; 306: 639-45.

Yalom ID. *Existential Psychotherapy*. NY: Basic Books, 1980



Case 3 - Questions



- Does Carson meet the criteria for PST?
- What is existential suffering?
- What is the difference between euthanasia, physician assisted death and PST?

Blair

Euthanasia and PAD



- Euthanasia: an intentional termination of life by another at the explicit request of the person who wishes to die...an act done out of concern and compassion for the person who is suffering
- Physician Assisted Death (PAD): a physician supplies information and/or the means of committing suicide to a person, so that the individual can successfully terminate his or her own life

PST vs PAD



	PST	PAD
Intent	Relieve suffering	Accelerate death
Cause of Death	Underlying disease process	Intervention prescribed by physician

Case 3 - Outcome



- Carson's request for physician assisted death is discussed and its underlying meaning in the presence of his family.
- Palliative Sedation Therapy is explained
- A plan is put in place not to pursue aggressive treatment when he develops another respiratory event and a treatment plan using morphine and midazolam is put in place to ensure rapid and adequate management of dyspnea and anxiety can be achieved, including a plan for PST should his dyspnea become refractory

Case 4



- Joan is 89 years old and was diagnosed with Alzheimer's disease five years ago
- She has severe osteoarthritis and multiple compression fractures contributing to her experience of chronic pain
- She resides in a LTC facility and her advance care plan includes a DNR with palliation alone
- Agitation has been progressive to the point she frequently strikes out and threatens staff
- Joan is no longer eating or drinking

Case 4



- Joan is often heard screaming and staff attribute much of her behaviour to poor pain control (assume no other contributing factors)
- Several different options are trialed for pain management over a period of weeks to months
- Family has become quite distressed as her agitation has only become worse with attempts to address her pain issues
- Medication for agitation is gradually increased and Joan becomes progressively more sedated from these measures and passes away 3 days later

Case 4 - Questions



- Did Joan meet the criteria for PST?

Chris

PST Criteria

Is symptom intolerable for patient?

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If yes then....

Is patient near end of life (days to weeks)?

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If yes then....

Criteria are met for consideration of PST

Case 4 - Questions



- Did Joan meet the criteria for PST?
- Did Joan receive PST or simply consequential sedation secondary to medication/ side-effects from medication (double-effect)?

Blair

Case Summaries



- Case 1: Susan with COPD
 - too soon for consideration of PST
- Case 2: Sarosh with osteosarcoma
 - PST was appropriate in this case
- Case 3 : Carson with ALS
 - PST, PAD, Euthanasia and Existential issues
- Case 4: Joan with Dementia
 - Understanding the nuances of when PST is being administered

Where do we go from here?



- Institutional/organizational dissemination and education
 - We hope that those of you here can be ambassadors and take this protocol to your local organizations
- More Education!
- Learn from experience....”phone a friend”
- What will be the location specific (e.g. LTC) educational needs and issues that need to be discussed before successful implementation can be considered?
- Other ideas?

Questions?



Thank You



- Thanks to McMaster Department of Family Medicine, Division of Palliative Care
- Thank you for participating in this CME event
- Thank you to our Panel of Speakers
- Thank you to the education planning committee event team members:
 - Christine Bigelow
 - Cathy Joy
 - Diane Hanlon
 - Marjorie Williams Hambly