Community-Based Primary Palliative Care Community of Practice Series 3

Terminal Delirium

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Facilitator: Dr. Nadine Gebara
Guest Speakers: Elisabeth Antifeau, Dr. Kevin Wade and Susan Stevenson
Date: March 27, 2024

Territorial Honouring

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness and their families.

Stay connected: www.echopalliative.com

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Project ECHO Palliative Care - Canada BY Pallium Canada

LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by the CFPC and Royal College.

Pallium Canada

LEAP CORE

Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Objectives of this Series

After participating in this series, participants will be able to:

- Augment their primary-level palliative care skills with additional knowledge and expertise related to providing a palliative care approach.
- Connect with and learn from colleagues on how they are providing a palliative care approach.

Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	Communication: Part 1	Oct 25, 2023 from 12:30-1:30pm ET
Session 2	Communication: Part 2	Nov 29, 2023 from 12:30-1:30pm ET
Session 3	Managing the last hours of life	Dec.20, 2020 from 12:30-1:30pm ET
Session 4	Palliative care for the structurally vulnerable	Jan 24, 2024 from 12:30-1:30pm ET
Session 5	Procedural management of complex pain: Nerve blocks, vertebral augmentation, radiotherapy	Feb 21, 2024 from 12:30-1:30pm ET
Session 6	Terminal Delirium	Mar 27, 2024 from 12:30-1:30pm ET
Session 7	Creative art therapy in palliative care	Apr 24, 2024 from 12:30-1:30pm ET
Session 8	What in store for Palliative Care in Canada: policy, advocacy and implementation	May 29, 2024 from 12:30-1:30pm ET
Session 9	Grief and Bereavement: Beyond the Basics	June 26, 2024 from 12:30-1:30pm ET

Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting.
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the Q& A function to ask questions and add comments throughout the session via the chat.
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **9 Mainpro+** credits.

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit
- Funded by Health Canada

Disclosure

This program has received financial support from:

- Health Canada in the form of a contribution program.
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees.

Facilitator/ Presenters:

- Dr. Nadine Gebara: Nothing to disclose.
- Elisabeth Antifeau: Nothing to disclose.
- Dr. Kevin Wade: Chief Medical Officer of Gravitii.care, a startup platform to connect home care patients directly with providers.
- Susan Stevenson: Nothing to disclose.

Disclosure

Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content

Introductions

Facilitator:

Dr. Nadine Gebara, MD CCFP- PC
Clinical co-lead of this ECHO series
Palliative Care Physician at Toronto Western Hospital, University Health Network
Family Physician at Gold Standard Health, Annex

Panelists:

Dr. Haley Draper, MD CCFP- PC
Clinical co-lead of this ECHO series
Palliative Care Physician at Toronto Western Hospital, University Health Network
Family Physician at Gold Standard Health, Annex

Dr. Roger Ghoche, MDCM CCFP-PC, MTS
Palliative Care and Rehabilitation Medicine, Mount Sinai Hospital- Montreal

Jill Tom, BSN CHPCN ©
Nurse Clinician for palliative Home Care
Mount Sinai Hospital, Montreal

Introductions

Panelists (continued):

Elisabeth Antifeau, RN, MScN, CHPCN(C), GNC(C)
Regional Clinical Nurse Specialist (CNS-C), Palliative End of Life Care
IH Regional Palliative End of Life Care Program
Pallium Canada Master Facilitator & Coach, Scientific Consultant

Thandi Briggs, RSW MSW
Care Coordinator, Integrated Palliative Care Program
Home and Community Care Support Services Toronto Central

Claudia Brown, RN BSN
Care Coordinator, Integrated Palliative Care Program
Home and Community Care Support Services Toronto Central

Rev. Jennifer Holtslander, SCP-Associate, MRE, BTh
Spiritual Care Provider

Support Team

Diana Vincze
Palliative Care ECHO Project Manager, Pallium Canada

Introductions

Guest Speakers:

Elisabeth Antifeau, RN, MScN, CHPCN(C), GNC(C)
Regional Clinical Nurse Specialist (CNS-C), Palliative End of Life Care
IH Regional Palliative End of Life Care Program
Pallium Canada Master Facilitator & Coach, Scientific Consultant

Kevin Wade, CD, MD, CCFP (PC)
Palliative Care Physician, BC Cancer and Island Health, Victoria, BC
Clinical Assistant Professor, University of British Columbia
Major, 1 Canadian Field Hospital Det Ottawa

Susan Stevenson, DVM
Veterinarian in Mill Bay, BC
Patient/Family Partner

Delirium at the End of Life: A Case based presentation

Session Learning Objectives

Upon completing the session, participants will be able to:

- Appreciate the impact of EOL delirium as experienced by patients and families
- Describe the initial identification and workup of delirium
- Identify pharmacological and non-pharmacological approaches to managing delirium
- Describe how EOL delirium is managed
- Awareness of overlap with EOL Dreams & Visions and implications for clinical practice.

Meet Chris

- 63yo large animal veterinarian, husband, and father of three from Mill Bay, BC.

Chris's Story:
Initial Care at Home

1. Initial Care

Identification of Delirium

- **“Abrupt onset of disturbances in consciousness (arousal), attention, cognition, and perception* that fluctuates over the course of the day”**
- Multiple assessment scales adapted for clinician use:
  - Confusion Assessment Method (CAM) most commonly used
- Three Subtypes:
  - Hyperactive (assoc w/ drug withdrawal, infection, adverse drug effect)
  - Hypoactive (assoc w/ hypoxia, metabolic disturbance, hepatic)
  - Mixed

* Perceptual abnormalities and delusions are commonly associated with delirium (70-80% of hyperactive, 40-50% of hypoactive delirium) but not required for diagnosis

Workup of Delirium (in a patient with a palliative diagnosis)

- May diverge from the typical DIMS workup in important ways
- Alignment with patient goals of care (including **location**)
- Etiology discovered in fewer than 50%
- Estimates of reversibility vary wildly:
  - 68% (Fainsinger and Bruera 1992)
  - 49% (Lawlor et al 2000)
  - 27% (Leonard et al 2008)

Decision Points

- Who is the substitute decision maker? Has the patient previously expressed or documented goals of care?
- What is their preferred location of care?
- If diagnostic workup is within their goals of care, can that diagnostic workup be achieved in their preferred location?
- Can the patient be safely managed in their preferred location?
- Who is involved in caring for them?

"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

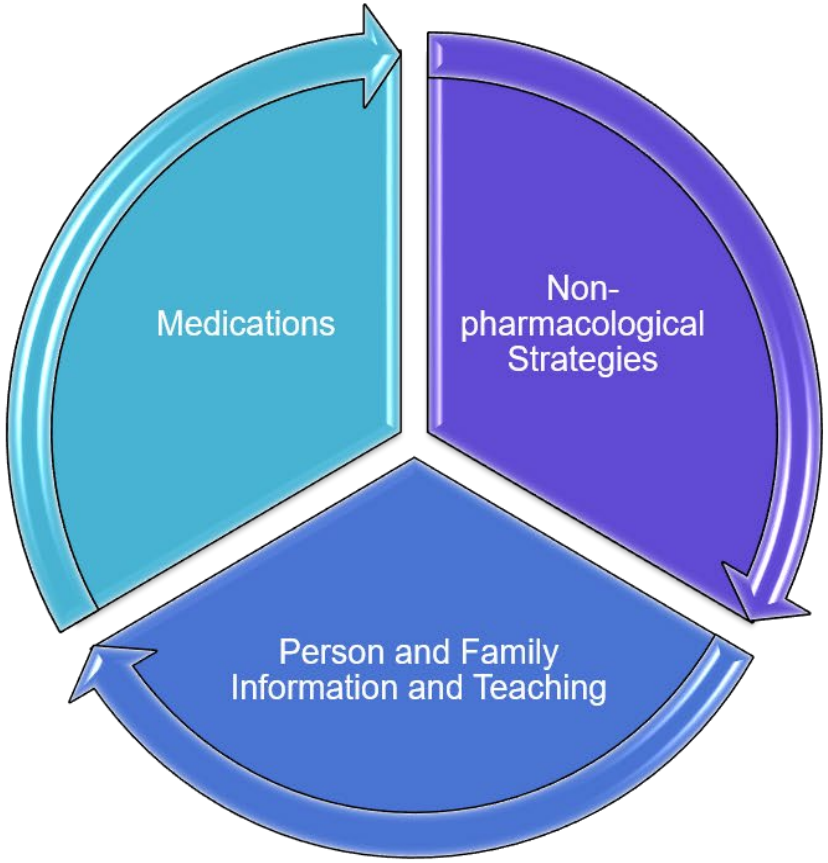
Chris's Story:
Ongoing Management in Hospital

2. Ongoing Management

- Came to ED at Royal Jubilee Hospital in Victoria, BC.
- Admitted to the palliative care unit.


I LIKE TO BE CALLED
DIET
CARE TEAM
Chris
MY GOAL FOR TODAY IS
ESTIMATED DISCHARGE DATE
ACTIVITY
THERAPY SERVICES
NOTES
DISCHARGE TIME

Three Prong Care Planning Approach



Treatment of Delirium – Pharmacological

Antipsychotics	Dose	Notes
Haloperidol	0.5-2 mg Q2-12H PO/SC/IV/IM	Usual first-line therapy, less sedating
Methotrimeprazine	2.5-25 mg Q2-8H PO/SC/IV/IM	Also analgesic, more sedating, anticholinergic at higher doses
Olanzapine	2.5-5 mg Q12-24H PO/SL/SC/IM	Less EPS, available as an oral dissolving tablet
Other Agents		
Benzodiazepines	Lorazepam, midazolam	Sedative only, adjunct to heloperidol, ineffective at treating delirium
Psychostimulants	Methylphenidate, modafinil	Open-label study, case reports. Concern for increasing agitation
Cholinesterase Inhibitors	Donepezil, Rivastigmine	Case reports, well tolerated, minimal evidence

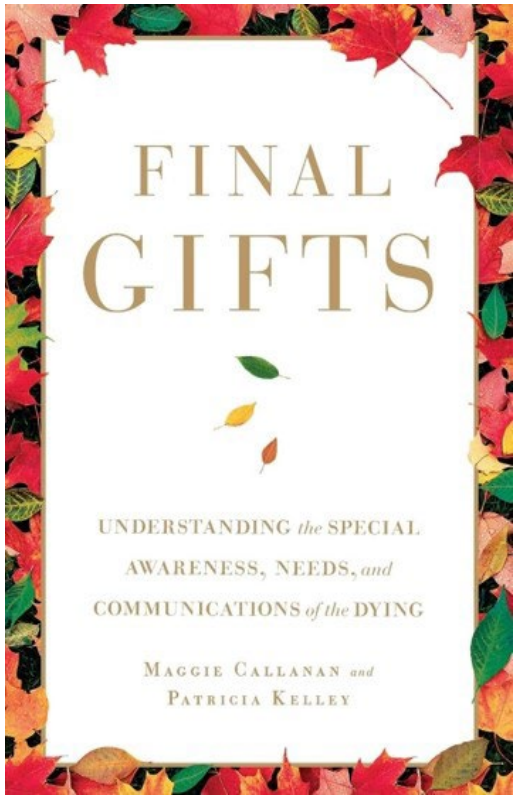
Treatment of Delirium - Nonpharmacological

- Minimize lines and catheters
- Early mobilization, avoid immobility
- Reorient – family, place, time, objects
- Provide visual and hearing aids
- Encourage stimulating activities e.g. word puzzles
- Sleep hygiene – day/night cycles, reduce noise at night, gentle massage, relaxation music at night, warm drinks


AND NOW
FOR SOMETHING
COMPLETELY
DIFFERENT

Two Points of Reference

Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying (2012)



Hospice Patients' End-of-Life Dreams and Visions: A Systematic Review of Qualitative Studies (2024)


Review Article

Hospice Patients' End-of-Life Dreams and Visions: A Systematic Review of Qualitative Studies

American Journal of Hospice & Palliative Medicine®
2024, Vol. 41(1) 99–112

DOI: 10.1177/10499091231163571
journals.sagepub.com/home/hjh
Sage

Elisa Rabitti[1], Silvio Cavuto[2], Matías Eduardo Díaz Crescitelli[3], Maria Chiara Bassi[4], and Luca Ghirotto[5]

- This 2024 Systemic Review aggregated, synthesized and thematically analyzed the findings from 293 qualitative studies (screened to 33 relevant articles) and reported on three themes:
  - i) typologies of EOL-DVs reported,
  - ii) emotional consequences, and
  - iii) inter-subjective meaning-making.

Understanding EOL-DV

- When conscious, about 50-60% of hospice patients report a "visitation" by someone who is not there while they dream or are awake: a phenomenon known as End-of-Life Dreams and Visions (EOL-DVs)

- These visions or hallucinations are about objects, content, events or situations that are perceived as real but no tangible stimuli are apparent. These experiences can be visual, auditory and/or kinesthetic.

- They can occur in the final weeks, days and hours of life

- **Why does it matter?**: EOL-DVs are often misinterpreted as hallucinations or general confusion related to an EOL delirium and treated promptly with sedation.

Understanding EOL-DV (continued)

- EOL-DVs differ from hallucinations due to delirium, which are often anxiety producing, stressful and involve the other symptoms of delirium (e.g., disorganized thinking, loss of attention and awareness, fluctuating consciousness).

- EOL-DVs are generally comforting, and not accompanied by disorganized thinking. They are described with detail and clarity;

- EOL-DVs are thought to be part of the brain's preparation for death, an expression of existential existence (innate human desire for communication and connection) and often results in metaphor as a means for communication.

Understanding EOL-DV (continued)

- EOL-DVs are intensely emotional, intimate and un-socialized (not shared) experiences;

- Of those awake and able to talk about dreams and visions, they describe it as real and vivid experiences, not credited to fantasies or imagination
  - *“It is not a dream, it’s reality (…) When she shows up [in the dreams] they are real, they are (…)*
  - *I am aware of that he is sitting beside me”*

- There are no specific questionnaires or known assessment tools to evaluate EOL-DVs

Typologies & Characteristics of EOL-DV

- ***Not*** the same as Near Death Experiences (NDE) - which occur when severe physical impairment (immediate life-threatening situation, such as cardiac arrest) or the clear perception of an immediate risk of death, and usually recalled by individuals because resuscitated back to life;

- NDEs are attributed to acute physiological changes (hypercapnia, cerebral hypoxia, etc.) – EOL-DVs occur in the absence of any known acute conditions.

Content of EOL-DV:

Various thematic contents are reported:

- ❑ Encounters (e.g., both deceased and living loved ones, pets).
- ❑ Transcendental experiences (e.g., undefined presence, lights, God)
- ❑ Travels (e.g., sense of traveling, rarely specific places, often involve a sense of urgency)
- ❑ Places (e.g., childhood homes, holidays, gardens)
- ❑ Knowing when death will occur (“I’m going to leave today”)
- ❑ Traumatic events (e.g., past abuses, war incidents)

Most EOL-DV involve loved ones (usually younger, healthier) who do not appear intimidating or scary, even if sometimes patients respond to them in a startled way

The dream or vision may be silent or it may involve a conversation with the loved one or another.

Emotional consequences of EOL-DV

- Respondents who could be interviewed report significant emotions (positive and negative) after the experience and that their experience was vivid and memory of it and specific details lingers a long time:
  - *Pleasant emotions* include: feeling comforted, easing of fear, feeling reassured, relaxing
  - *Unpleasant emotions*, often related to traumatic/unsolved issues: frightened, confused, worry, guilt
- Sometimes unpleasant emotions and reactions may require sedation to ease suffering if reassurance and validation do not work.

The Desire for Inter-Subjective Meaning-Making

- Sharing the experience of EOL-DVs with others was difficult for fear of being judged or not being understood or ridiculed and discounted
- Often experience embarrassment, confusion, & uncertainty if they should reveal and discuss with others (health professionals/family)
- Relief was felt when talking about EOL-DV with health professionals
- We can assist the patient by asking questions and active listening to help them decipher and interpret the dreams and visions to make personal sense
- Patients want to elaborate on meanings and be supported in this end of life journey

Implications for Clinical Practice

- Recognize and distinguish between general confusion related to EOL delirium vs EOL-DV and do not assume all confusion requires medication.

- EOL-DVs present the opportunity to engage and listen with family members who can assist in interpreting or better understanding what the dying person may be trying to communicate;

- Patients and families should interpret deathbed phenomena *for themselves* as they know themselves or their loved one best;

- Family can assist nursing in interpretation and meaning-making:
  - "*Knowing the person as you do, does what they are saying or doing make sense to you in any way?"*
  - *Given who they are, is this like them*?"

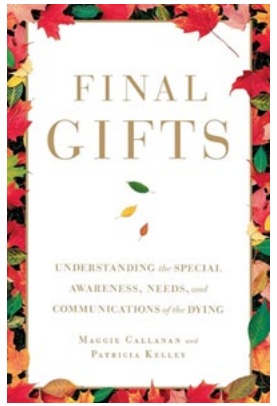
Implications for clinical practice (continued)

- Provides an active role for family members to directly support and interact with their loved one in the dying process by listening, reassuring and strengthening their relationship

- The dying person potentially benefits from familiar voices, reassurance and emotional support in their final days and hours of life, without needing additional medication

- Provides comfort and support to family members during their bereavement that they assisted their loved ones and were able to identify and provide meaning-making input into the experiences within context of who the person was.

Reflection: For Discussion



- *"By keeping open minds and by listening carefully to dying people, we can begin to understand messages they convey through symbol or suggestion. Often we can decipher essential information and in the deciphering relieve a dying person's anxiety and distress. By trying to understand, and therefore participate more fully in the events of dying, families and friends can gain comfort as well as important knowledge about what the experience of dying is like and what is needed to achieve a peaceful death."*

•*Final Gifts*

•*Maggie Callanan and Patricia Kelley*

Chris's Story:
End of Life Care

Other Considerations

- Care Team Education, Experience, Cohesion
- Ethical Concerns
  - Sedation associated with longer, not shorter, prognosis
  - “Law of double effect” may not actually be relevant in most cases
- Continue symptom management (e.g. pain, dyspnea, constipation)
- Further care
  - Hospice transfer
  - Discharge home
  - Palliative Sedation
  - Medical Assistance in Dying

Q&A - Discussion

References - Kevin

- Breitbart, William, and Alici, Yesna. “Agitation and Delirium at the End of Life: ‘We Couldn’t Manage Him.’” *JAMA : The Journal of the American Medical Association* 300, no. 24 (2008): 2898–2910. https://doi.org/10.1001/jama.2008.885.
- Breitbart, William, and Alici, Yesne. “Evidence-Based Treatment of Delirium in Patients With Cancer.” *Journal of Clinical Oncology* 30, no. 11 (April 10, 2012): 1206–14. https://doi.org/10.1200/JCO.2011.39.8784.
- Sutherland, Megan, Aakriti Pyakurel, Amy E. Nolen, and Kalliopi (Kalli) Stilos. “Improving the Management of Terminal Delirium at the End of Life.” *Asia-Pacific Journal of Oncology Nursing* 7, no. 4 (September 14, 2020): 389–95. https://doi.org/10.4103/apjon.apjon_29_20.
- Sykes, Nigel, and Andrew Thorns. “Sedative Use in the Last Week of Life and the Implications for End-of-Life Decision Making.” *Archives of Internal Medicine* 163, no. 3 (February 10, 2003): 341–44. https://doi.org/10.1001/archinte.163.3.341.
- Thomas, Columba, Yesne Alici, William Breitbart, Eduardo Bruera, Liz Blackler, and Daniel P. Sulmasy. “Drugs, Delirium, and Ethics at the End of Life.” *Journal of the American Geriatrics Society* n/a, no. n/a. Accessed March 10, 2024. https://doi.org/10.1111/jgs.18766.
- Yang, Eun Jung, Bong-Jin Hahm, and Eun-Jung Shim. “Screening and Assessment Tools for Measuring Delirium in Patients with Cancer in Hospice and Palliative Care: A Systematic Review.” *Journal of Hospice and Palliative Care* 24, no. 4 (December 1, 2021): 214–25. https://doi.org/10.14475/jhpc.2021.24.4.214.

References - Elisabeth

- Callahan, M and Kelley, P. (2012). Final Gifts: Understanding the Special Awareness, Needs and Communication of the Dying. Bantam Books. 2012.
- Rabitti E, Cavuto S, Díaz Crescitelli ME, Bassi MC, Ghirotto L. Hospice Patients' End-of-Life Dreams and Visions: A Systematic Review of Qualitative Studies. *American Journal of Hospice and Palliative Medicine*®. 2024;41(1):99-112.
- Baumhover NC. The process of death imminence awareness by family members of patients in adult critical care. Dimens Crit Care Nurs. 2015 May-Jun;34(3):149-60.
- Kerr CW, Donnelly JP, Wright ST, Kuszczak SM, Banas A, Grant PC, Luczkiewicz DL. End-of-life dreams and visions: a longitudinal study of hospice patients' experiences. J Palliat Med. 2014 Mar;17(3):296-30
- Hession A, Luckett T, Chang S, Currow D, Barbato M. End-of-life dreams and visions: A systematic integrative review. Palliat Support Care. 2022 Aug 1:1-10. doi: 10.1017/S1478951522000876. Epub ahead of print. PMID: 35912689.
- Grant PC, Levy K, Lattimer TA, Depner RM, Kerr CW. Attitudes and Perceptions of End-of-Life Dreams and Visions and Their Implication to the Bereaved Family Caregiver Experience. Am J Hosp Palliat Care. 2021 Jul;38(7):778-784.

Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- We hope to see you again at our next session taking place **April 24th, 2024 from 12:30-1:30pm ET** on the topic of **Creative art therapy in palliative care.**
- Thank you for your participation!

Thank You

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Stay Connected
www.echopalliative.com