

# Palliative Care Journal Watch

A partnership between Pallium Canada and the Divisions of Palliative Care at Queen's University in Kingston, Canada, and McMaster University in Hamilton, Canada



Queen's University  
SCHOOL OF MEDICINE | DEPARTMENT OF  
Medicine



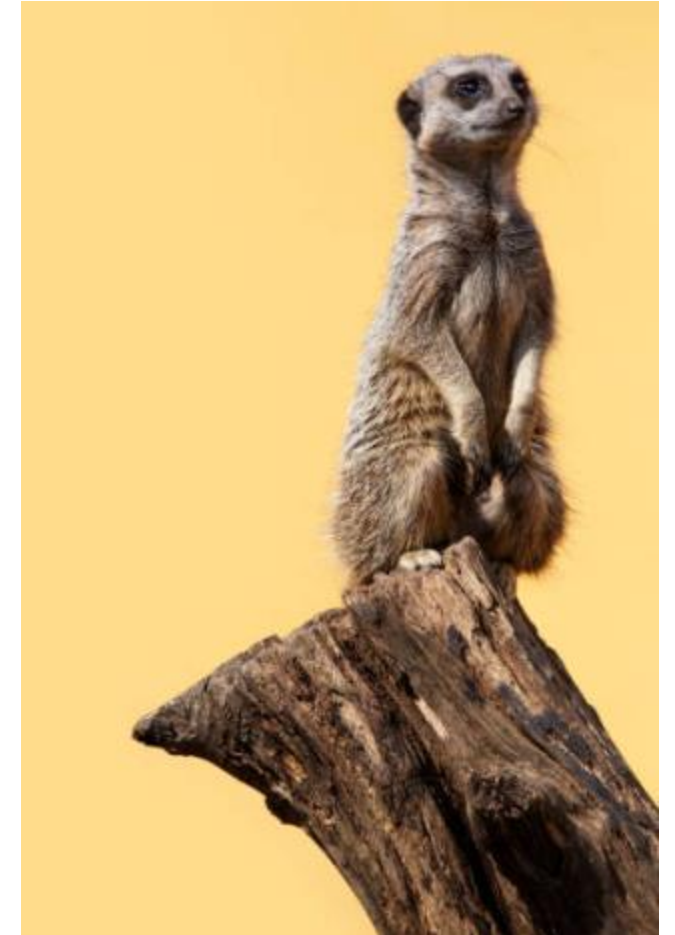
**Host:** Dr. José Pereira & Dr. Adrienne Selbie

**Guest Panelists:** Dr. Aynharan Sinnarajah

**Date:** January 23<sup>rd</sup>, 2023

# Welcome to the Palliative Care Journal Watch!

- Keeps you up to date on the latest peer-reviewed palliative care literature.
- Led by palliative care experts from the divisions of palliative care at 2 Canadian Universities:
  - McMaster University (Hamilton, Ontario)
  - Queen's University (Kingston Ontario)
- We regularly monitor over 20 journals and highlight papers that challenge us to think differently about a topic or confirm our current practices.



# 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.

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

**Stay connected: [www.echopalliative.com](http://www.echopalliative.com)**

# What to Expect from Today's Session

- We will present and discuss the top 4 article selections and provide a list of honourable mentions.
- Please submit questions through the Q&A function.
- This session is being recorded and will be shared with registrants within the next week.
- Recordings, slides and links to articles from all our sessions are available at [www.echopalliative.com/palliative-care-journal-watch/](http://www.echopalliative.com/palliative-care-journal-watch/).
- Check out the Palliative Care Journal Watch Podcast.
- This 1 credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **8 Mainpro+ credits** (each 1-hour session is worth 1 Mainpro credit).

# Introductions

## Host

**Dr. José Pereira, MBChB, CCFP(PC), MSc, FCFP, PhD**

Professor and Director, Division of Palliative Care, Department of Family Medicine, McMaster University, Hamilton, ON, Canada

Scientific Officer and Co-Founder, Pallium Canada

Professor, Faculty of Medicine, University of Navarra, Spain

**Dr. Adrienne Selbie, MD CCFP(PC)**

Palliative Care Specialist and Assistant Professor at Queen's University, Kingston, ON, Canada.

## Guest Panelist

**Dr. Aynharan Sinnarajah, MD CCFP(PC) MPH**

Chair, Dr. Gillian Gilchrist Palliative Care Research, Division of Palliative Care, Queen's University / Lakeridge Health, ON, Canada

# Disclosures

## Pallium Canada

- Not-for-profit.
- Funded by:
  - Health Canada (through contribution agreements 2001-2007, 2013-2018), Patrick Gillin Family Trust (2013-2016), Li Ka Shing Foundation (2019 to current), CMA (2019 to 2022), Boehringer Ingelheim (dissemination of LEAP Lung courses 2019 to current).
  - Partnerships with some provincial bodies.
  - Revenues from LEAP course registration fees and licenses, sales of Pallium Palliative Pocketbook.

## This program has received financial support from:

- Health Canada in the form of a contribution program.

## Disclosures of Co-host/ Guest Panelist:

- Dr. Jose Pereira: Scientific advisor Pallium.
- Dr. Adrienne Selbie: No conflicts of interest to declare.
- Dr. Aynharan Sinnarajah: No conflicts of interest to declare.

## Mitigating Potential Biases:

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

# Featured articles

1. Saji A, Oishi A, Harding R. **Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review.** J Pain Symptom Manage. 2022 Nov 9:S0885-3924(22)00955-1. <https://pubmed.ncbi.nlm.nih.gov/36368570/>
2. Kissane, D.W., Appleton, J., Lennon, J., Michael, N., Chye, R., King, T., William, L., Poon, P., Kanathigoda, S., Needham, K. & Bobevski, I. 2022. **Psycho-Existential Symptom Assessment Scale (PeSAS) Screening in Palliative Care.** Journal of Pain and Symptom Management. Vol 64 (5) 429-437. <https://pubmed.ncbi.nlm.nih.gov/35961431/>
3. Kodba-Ceh, H., Lunder, U., Bulli, F., Caswell, G., van Delden, J.J.M., Kars, M.C., Korfage, I.J., Miccinesi, G., Rietjens, J.A.C., Seymour, J., TOccafondi, A., Zwakman, M., Pollock, K., & ACTION Consortium. (2022) **How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the International ACTION trial.** European Journal of Cancer Care, 31 (6), e13719. <https://pubmed.ncbi.nlm.nih.gov/36168108/>
4. Latuga, N. M.; Grant, P. C.; Levy, K.; Luczkiewicz, D. L. **Treatment of Positive Urine Cultures at End-of-Life and the Effect on Terminal Delirium Management.** American journal of hospice & palliative medicine 2022, 39 (9), 1014–1022. <https://pubmed.ncbi.nlm.nih.gov/34889644/>

# Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review.

## Article Reference:

Saji A, Oishi A, Harding R. Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review. *J Pain Symptom Manage.* 2022 Nov 9;S0885-3924(22)00955-1.

## Selected by:

Leonie Herx

## Presented by:

José Pereira

## Background

- The concern of ‘being a burden to others’ is common among people with life-threatening illnesses. Unclear what underpins this.
- It has been largely explored from the caregiver rather than patient perspective.
- A Self-Perceived Burden (SPB) construct has been described (Cousineau et al).
  - Defined it as ‘a multidimensional construct arising from the care recipient’s feelings of dependence and the resulting frustration and worry, which then may lead to negative feelings of guilt at being responsible for the caregiver’s hardship’.
  - SBP definition refined by McPherson et al: highlighted dependency is not inevitable and SPB reduces sense of self.
  - Cousineau et al’s SPB Scale has identified prevalence of 28% to 73% in patients with advanced cancer, and neurological diseases.

## Study Goal

- Review question is ‘What makes people with life-threatening illness develop SPB regarding their informal caregivers and how do they experience the perception?’

## Study Design

- Systematic review and a thematic synthesis of qualitative primary data.
- Searched in September 2021.
- 9 studies included (219 patients; mostly with advanced diseases and requiring assistance).



# Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review.

## Article Reference:

Saji A, Oishi A, Harding R. Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review. J Pain Symptom Manage. 2022 Nov 9:S0885-3924(22)00955-1.

## Selected by:

Leonie Herx

## Presented by:

José Pereira

## Main Findings

6 themes emerged:

- 1) Sense of burden on informal caregivers and patients,
  - patients felt physical, psychological, and social burdens towards their informal caregivers.
  - Caused significant distress for patients.
  - The patients consequently described feelings of responsibility, guilt, anger, or fear.
  - They described themselves as useless, a failure, or having loss of control.
  - The feelings sometimes made patients feel isolated or hopeless.
  - Patients also described how hard it was to witness informal caregivers' struggling with burdens,
  - This gave a corresponding sense of burden to patients.
- 2) SPB is experienced within lifelong relationships between patients and informal caregivers,
- 3) SPB as a result of comparing hardships and lost opportunities,
- 4) SPB is based on uncertainty,
- 5) Fluctuating SPB
- 6) Reactions to SPB are part of the process.

# Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review.

## Article Reference:

Saji A, Oishi A, Harding R. Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review. *J Pain Symptom Manage.* 2022 Nov 9;S0885-3924(22)00955-1.

## Selected by:

Leonie Herx

## Presented by:

José Pereira

## Main Message

- Self-perceived burden is a highly subjective perception based on uncertainty towards caregivers and the future.
- The perception is not either static or temporary but a fluctuating 'process' in complex balances among numerous factors, therefore it should be continuously explored.
- SPB is a highly subjective perception contrasting self &/or informal caregivers in the past, present, & future. Patients develop SPB feeling uncertain about caregivers' perceptions & increasing future burden. SPB interacts with other factors of surrounding complex balances such as care needs, reality, and identity, which would change over time, and patients' reactions to SPB at the sacrifice of their wishes may conversely increase the total suffering.
- Further research is needed to understand the concept of SPB in non-Western countries and drawing from populations with more diverse diagnoses of life-threatening illness.
- Beyond conceptualization and measurement, interventions to identify and reduce SPB are needed.

# Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review.

## Article Reference:

Saji A, Oishi A, Harding R. Self-perceived Burden for People With Life-threatening Illness: A Qualitative Systematic Review. J Pain Symptom Manage. 2022 Nov 9:S0885-3924(22)00955-1.

## Selected by:

Leonie Herx

## Presented by:

José Pereira

## Strengths

- Systematic review.

## Limitations

- Possible bias possible as review was primarily conducted by one author with consultation with other authors during the review process (all authors agreed on the results).
- Reliance on the pre-existing definition of SPB may have restricted findings but this review would trigger conceptual understandings of SPB.
- Only included papers published in English.

# Discussion

# Psycho-Existential Symptom Assessment Scale (PeSAS) Screening in Palliative Care. Journal of Pain and Symptom Management.

## Article Reference:

Kissane, D.W., Appleton, J., Lennon, J., Michael, N., Chye, R., King, T., William, L., Poon, P., Kanathigoda, S., Needham, K. & Bobeveski, I. 2022. Psycho-Existential Symptom Assessment Scale (PeSAS) Screening in Palliative Care. Journal of Pain and Symptom Management. Vol 64 (5) 429-437.

## Selected by:

Adrienne Selbie

## Presented by:

Adrienne Selbie

## Background

The article identifies that Existential Distress is often not routinely screened for or asked about in Palliative Care Programs. Part of the reason for this gap is clinician discomfort with this topic. They go on to “describe[s] an implementation program for palliative care, where studies of a systematic approach to quality care improvement for psycho-existential distress have been few.” (436).

## Main Message

Training in a screening tool is effective, both to better identify patient distress, as well as to successfully train clinicians, which improves clinician comfort and confidence with these topics. They conclude that identifying psych-existential distress in palliative care patients is important.

## Why is this article important?

As Implementation Research, this article shows clearly that a training program and a standardized screening process can be effective in identifying and addressing psycho-existential concerns. This is noteworthy as this topic is sometimes viewed as too difficult to accurately define and identify and too difficult to address to make it worthwhile. This article challenges that viewpoint and provides a broad and rigorous example of a program and its efficacy.

# Psycho-Existential Symptom Assessment Scale (PeSAS) Screening in Palliative Care. Journal of Pain and Symptom Management.

## Article Reference:

Kissane, D.W., Appleton, J., Lennon, J., Michael, N., Chye, R., King, T., William, L., Poon, P., Kanathigoda, S., Needham, K. & Bobeveski, I. 2022. Psycho-Existential Symptom Assessment Scale (PeSAS) Screening in Palliative Care. Journal of Pain and Symptom Management. Vol 64 (5) 429-437.

## Selected by:

Adrienne Selbie

## Presented by:

Adrienne Selbie

## Strengths

- Large area and lots of patients.
- Clearly identified the prevalence for psycho-existential distress in palliative patients.
- Describes a rigorous and effective implementation plan.

## Limitations

- Focuses on service provision rather than patient outcomes.
- True system change is complex—this study does not capture longitudinal change.
- Difficulties with electronic data.
- May not be fully generalizable across all service delivery models.

## Additional Comments:

Inspiring article!

# Discussion

How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the International ACTION trial. European Journal of Cancer Care

**Article Reference:**

Kodba-Ceh, H., Lunder, U., Bulli, F., Caswell, G., van Delden, J.J.M., Kars, M.C., Korfage, I.J., Miccinesi, G., Rietjens, J.A.C., Seymour, J., TOccafondi, A., Zwakman, M., Pollock, K., & ACTION Consortium. How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the International ACTION trial. European Journal of Cancer Care. 2022, 31 (6), e13719.

**Selected by:**

Adrienne Selbie

**Presented by:**

Adrienne Selbie

## Background

This is a nested Study on Hope as part of International Action Trial which studies effect of ACP Program on QOL in patients with Lung and Colorectal cancer. The group analyzed transcripts of interviews from the Action Trial with attention to themes around hope.

## Main Message

"Grounded in authenticity and an awareness of a difficult reality, promoting empowerment and connection, ACP conversations can provide grounds for hope" (p.6).

## Why is this article important?

As the article points out, one of the reasons that Clinicians sometimes do not introduce or engage in Advanced Care Planning conversations with patients is out of concern that in doing so they will "take away" the patient's hope and thereby actually cause suffering and worsen his or her quality of life. This article challenges that notion by showing how Advanced Care Planning conversations can support hope, in particular hope as understood or defined in an end-of-life context around patient empowerment, relationship building, comfort and quality of life. Viewing Advanced Care Planning with this lens, particularly as supported by transcripts of patients reflecting on their ACP conversations, may encourage more physicians to introduce this topic more often and perhaps earlier.



How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the International ACTION trial. *European Journal of Cancer Care*

**Article Reference:**

Kodba-Ceh, H., Lunder, U., Bulli, F., Caswell, G., van Delden, J.J.M., Kars, M.C., Korfage, I.J., Miccinesi, G., Rietjens, J.A.C., Seymour, J., TOccafondi, A., Zwakman, M., Pollock, K., & ACTION Consortium. How can advance care planning support hope in patients with advanced cancer and their families: A qualitative study as part of the International ACTION trial. *European Journal of Cancer Care*. 2022, 31 (6), e13719.

**Selected by:**

Adrienne Selbie

**Presented by:**

Adrienne Selbie

## Strengths and Limitations

- Variety of ACP planning Style:
  - The interviews are from the ACTION Trial, in which ACP conversations are had with practitioners who have been trained to build expertise and hold conversations that "take into account emotional and psychosocial aspects" of planning, not just "biomedical model" EOL care planning. Different results, therefore, may be found with different approaches to ACP planning.
- Different Definitions or constructs of "hope" would yield different findings.
- Translations could skew some understanding of interviews.
- Did not look at the "counter" themes of "hopelessness" possibly also expressed in interviews.

## Additional Comments:

- This is a remarkable fresh perspective on why Advanced Care Planning is important. It is especially strong as it is drawn from and grounded in actual experience of patients with advanced care planning, across international settings.

# Discussion

# Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine

## Article Reference:

Latuga, N. M.; Grant, P. C.; Levy, K.; Luczkiewicz, D. L. Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine 2022, 39 (9): 1014–1022

## Selected by:

Emma Polle

## Presented by:

José Pereira

## Background

- The decision to initiate antibiotics in hospice patients that are very near end-of-life is a complex ethical and stewardship decision.
- Antibiotics may be ordered to improve urinary tract infection–related symptoms, such as delirium. Infection symptoms may be managed using antipsychotics, antipyretics, antispasmodics, and analgesics instead.
- Currently, there are no studies that compare symptom management between those who receive antibiotics and those who do not.

## Study objective

- To compare antipsychotic and benzodiazepine consumption for delirium management.
- Secondary objectives are to characterize antibiotic usage and compare opioid, antipyretic, and anticholinergic consumption that would manage non-delirium UTI symptoms, such as fever, pain, and bladder spasms

# Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine

## Article Reference:

Latuga, N. M.; Grant, P. C.; Levy, K.; Luczkiewicz, D. L. Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine 2022, 39 (9): 1014–1022

## Selected by:

Emma Polle

## Presented by:

José Pereira

## Methods

- Retrospective chart review of patients admitted to a 22-bed hospice unit (USA).
- March 1, 2016 to Dec 31, 2018.
- Charts were included if the pt was admitted for delirium and had a PPS score  $\leq 40\%$ , the urine culture was positive for organism growth, and the patient died while in the Hospice unit.
- Clinical and demographic data was collected. Medication use was tallied for the 5 days prior to the date of death.

## Main results

- 467 urine samples were ordered in the HIU; 208 were +ve for organism growth.
- 61 charts were included for analysis.
- 35 pts received antibiotics (ABX+) and 26 did not (ABX-).
- Cancer most frequent diagnosis.
- The ABX group died on average 6 days following the UA/C&S vs 8.2 days for the ABX+ group ( $P = 0.046$ ).
- There was no difference in any medication consumption between groups during the 5 days prior to death.
- The ABX+ group had more documented urinary tract-specific infection symptoms (66% vs 38%,  $P = 0.042$ ).
- More than half of antibiotic courses were discontinued prematurely.

# Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine

## Article Reference:

Latuga, N. M.; Grant, P. C.; Levy, K.; Luczkiewicz, D. L. Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine 2022, 39 (9): 1014–1022

## Selected by:

Emma Polle

## Presented by:

José Pereira

## Main Message

- Study did not find a significant difference in antipsychotic or benzodiazepine use in the last days of life,
- This suggests that antibiotics for a suspected UTI during this time may not improve terminal delirium symptom severity.
- Antibiotic initiation at EOL is a complicated discussion and use should be with thoughtful purpose as to the intended outcomes and potential consequences to both the patient and greater healthcare system.

## Limitations

- Design: retrospective chart review.
- No mention of symptom profiles and if and how these were assessed.
- Use of medication consumption as a surrogate marker of delirium severity.
- Exclusion of patients with PPS > 40%.

# Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American journal of hospice & palliative medicine

## Article Reference:

Latuga, N. M.; Grant, P. C.; Levy, K.; Luczkiewicz, D. L. Treatment of Positive Urine Cultures at End-of Life and the Effect on Terminal Delirium Management. American Journal of Hospice & Palliative Medicine 2022, 39 (9): 1014–1022

## Selected by:

Emma Polle

## Presented by:

José Pereira

## Limitations

- Design: retrospective chart review.
- No mention of symptom profiles and if and how these were assessed.
- Use of medication consumption as a surrogate marker of delirium severity.
- Exclusion of patients with PPS > 40%.

# Discussion

# Honourable Mentions

1. van Esch HJ, Stoppelenburg A, van Zuylen L, van der Rijt CC, van der Heide A. **When a dying patient is asked to participate in a double-blind, placebo-controlled clinical trial on symptom control: The decision-making process and experiences of relatives.** *Palliative Medicine*. 2022;36(10):1552-1558. <https://pubmed.ncbi.nlm.nih.gov/36503315/>
2. Paolucci A, Nielsse I, Tang KL, Sinnarajah A, Simon JE, Santana MJ. **The impacts of partnering with cancer patients in palliative care research: a systematic review and meta-synthesis.** *Palliat Care Soc Pract*. 2022;16:26323524221131581. Published 2022 Oct 18. <https://pubmed.ncbi.nlm.nih.gov/36274787/>
3. Kalonji P, Revol A, Broers B, Ljuslin M, Pautex S. **Patient-Related Barriers to the Prescription of Cannabinoid-Based Medicines in Palliative Care: A Qualitative Approach.** *Palliat Med Rep*. 2022;3(1):200-205. Published 2022 Sep 16. <https://pubmed.ncbi.nlm.nih.gov/36203714/>
4. Sanchez-Cardenas, M.A., Correa Morales J.E., & Sanchez-Florez, J.C. (2022). **Inclusion of Essential Components of the World Health Organization Palliative Care Development Model in National Palliative Care Plans: A Documentary Analysis in 31 Countries.** *Health Policy*, 126; <https://pubmed.ncbi.nlm.nih.gov/36127163/>



# Wrap-up

- Please fill out our feedback survey- a link will come up in your browser after this webinar ends.
- A recording of this webinar and a copy of the slides will be e-mailed to registrants within the next week.
- Recordings, slides and links to articles from all our sessions are available at [www.echopalliative.com/palliative-care-journal-watch/](http://www.echopalliative.com/palliative-care-journal-watch/).
- To listen to this session and previous sessions, check out the **Palliative Care Journal Watch** podcast.
- We hope to see you at our next session on **February 27<sup>th</sup>, 2023 from 12-1pm ET.**



# Thank You to our Journal Watch Contributors!

## McMaster University

Dr. Jose Pereira

Dr. Day Dai

Dr. Aveksha Ellaurie

Dr. Humaira Saeed

Dr. Karim Manji

Dr. Martin Chasen

Dr. Alan Taniguchi

Dr. Jesse Soloman

Dr. Jordan LaFranier

Dr. Andre Moolman

Christopher Klinger PhD

## Queen's University

Dr. Leonie Herx

Dr. Anna Voeuk

Dr. Julianne Bagg

Dr. Jean Mathews

Dr. Adrienne Selbie

Dr. Aynharan Sinnarajah

Dr. Emma Polle

## Pallium Support Team:

Diana Vincze - Palliative Care ECHO Project Manager

Aliya Mamdeen - Program Delivery Officer

James O'Hearn - Podcast production

# Thank You



Queen's University  
SCHOOL OF MEDICINE | DEPARTMENT OF  
Medicine



**Stay Connected**  
[www.echopalliative.com](http://www.echopalliative.com)