Severe and Persistent Mental Illness and Palliative Care Community of Practice

What can Palliative Care offer to people with SPMI?

Project ECHO® Palliative Care - Canada BY Pallium Canada

Facilitator: **Daniel Buchman**
Presenters: Alexandra Farag, Kelli Stajduhar, Daniel Shalev
Date: February 21, 2023

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.

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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

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

Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	What is Severe and Persistent Mental Illness	January 17, 2023 from 1-2pm ET
Session 2	What can Palliative Care offer to people with SPMI?	February 21, 2023 from 1-2pm ET
Session 3	What is Palliative Psychiatry	March 21, 2023 from 1-2pm ET
Session 4	How do we move forward? Education and Future Directions	April 18, 2023 from 1-2pm ET

Welcome & Reminders

- You are welcome to use the chat function to ask questions and add comments throughout the session
- 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 **4 Mainpro+** credits.

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit.
- Funded by Health Canada.

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/ Presenter:

- Daniel Buchman & Sarah Levitt: Funding from the Canadian Institutes of Health Research (CIHR) related to palliative psychiatry.
- Kelli Stajduhar: Funding from the Canada Research Chairs Program (CIHR).
- Kathleen Willison: Stipend, LEAP Coordinator, Division of Palliative Care, McMaster University.
- Alexandra Farag: Nothing to disclose.
- Anne Woods: Nothing to disclose.

Mitigating Potential Biases:

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

Introductions

Facilitator:

Daniel Buchman, PhD RSW
CAMH
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Presenters/Panelists:

Dr. Alexandra Farag, MD CCFP (PC)

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Palliative Care Physician, St Joseph's Healthcare Hamilton, Hamilton Health Sciences.

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Assistant Professor, Department of Psychiatry, University of Toronto UHN
Co-Medical Director, IMPACT Program, University Health Network
Staff Psychiatrist, Inpatient Program, University Health Network

Introductions

Presenters/Panelists:

Kelli Stajduhar RN PhD FCAHS FCAN
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Support Team

Aliya Mamdeen
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Palliative Care ECHO Project Manager, Pallium Canada

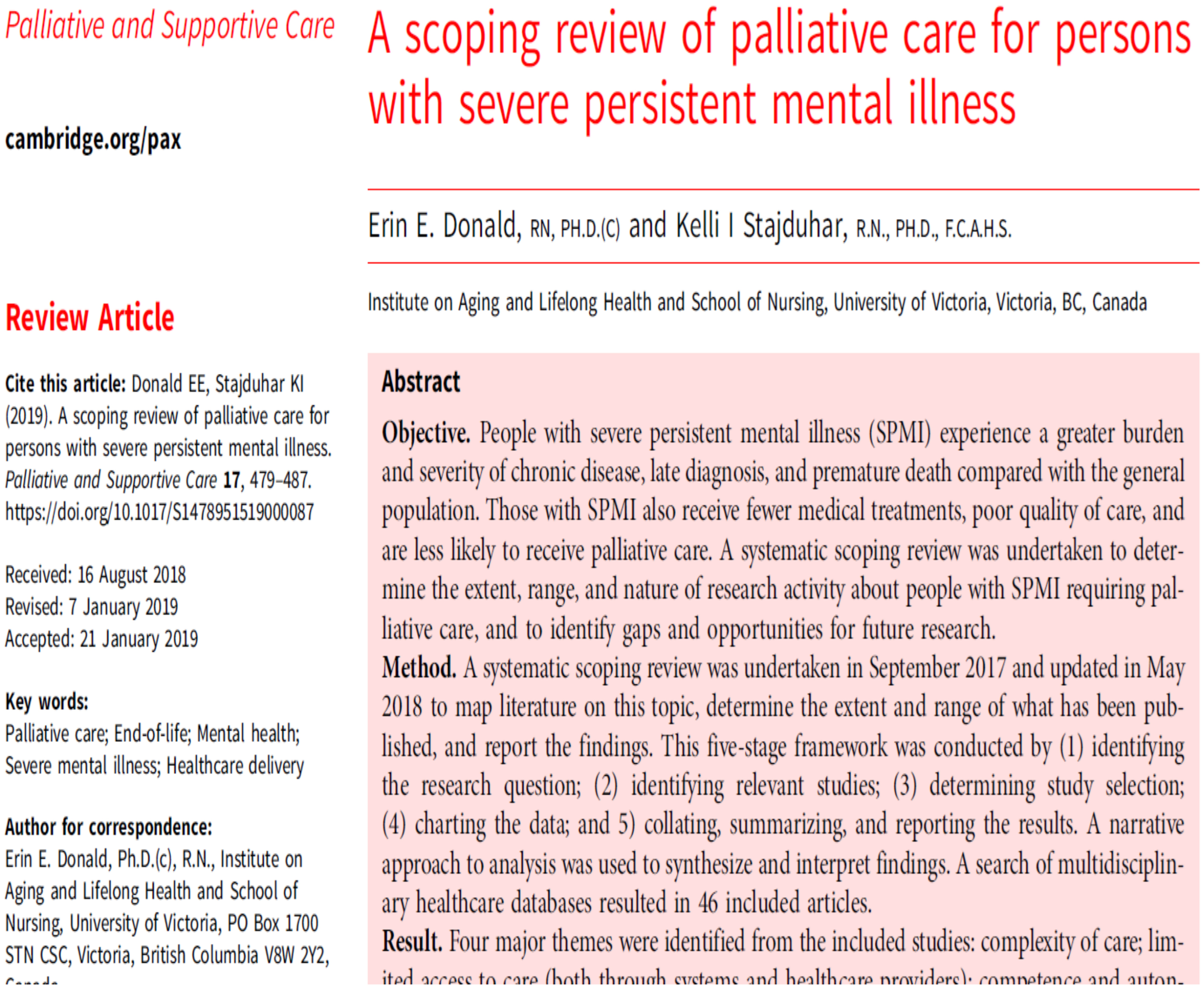
Session Learning Objectives

Upon completing the session, participants will be able to:

- Describe the challenges and barriers to care for people with SPMI who have a concurrent life limiting illness
- Define Palliative Care
  - Understand its evolving definition/understanding
  - Distinguish between palliative care as a specialty and a palliative approach

- Articulate how Palliative Care might contribute to the care of people with SPMI especially near the end of life
- Identify what a palliative approach to care might look like in this population
  - Describe some of the different existing models and the elements that make them successful
  - Identify common elements that could apply to any model

Research perspective



Palliative and Supportive Care

cambridge.org/pax

A scoping review of palliative care for persons with severe persistent mental illness

Erin E. Donald, RN, PH.D.(C) and Kelli I Stajduhar, R.N., PH.D., F.C.A.H.S.

Institute on Aging and Lifelong Health and School of Nursing, University of Victoria, Victoria, BC, Canada

Review Article

Cite this article: Donald EE, Stajduhar KI (2019). A scoping review of palliative care for persons with severe persistent mental illness. *Palliative and Supportive Care* **17**, 479–487. https://doi.org/10.1017/S1478951519000087

Received: 16 August 2018
Revised: 7 January 2019
Accepted: 21 January 2019

Key words:
Palliative care; End-of-life; Mental health; Severe mental illness; Healthcare delivery

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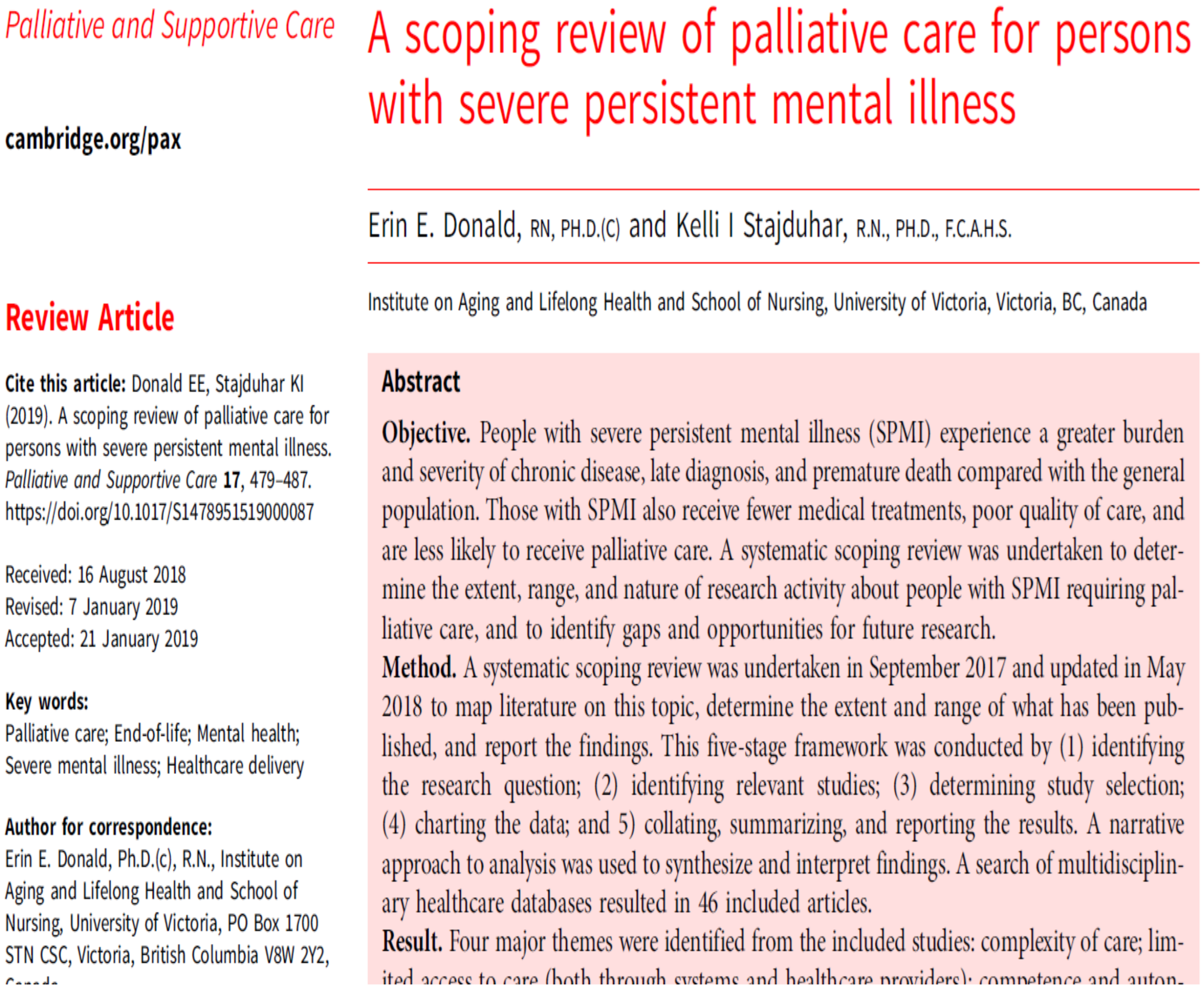
Abstract

Objective. People with severe persistent mental illness (SPMI) experience a greater burden and severity of chronic disease, late diagnosis, and premature death compared with the general population. Those with SPMI also receive fewer medical treatments, poor quality of care, and are less likely to receive palliative care. A systematic scoping review was undertaken to determine the extent, range, and nature of research activity about people with SPMI requiring palliative care, and to identify gaps and opportunities for future research.
Method. A systematic scoping review was undertaken in September 2017 and updated in May 2018 to map literature on this topic, determine the extent and range of what has been published, and report the findings. This five-stage framework was conducted by (1) identifying the research question; (2) identifying relevant studies; (3) determining study selection; (4) charting the data; and 5) collating, summarizing, and reporting the results. A narrative approach to analysis was used to synthesize and interpret findings. A search of multidisciplinary healthcare databases resulted in 46 included articles.
Result. Four major themes were identified from the included studies: complexity of care; limited access to care (both through systems and healthcare providers); competence and auton-

- People with severe persistent mental illness (SPMI) experience unequal access to care, particularly at EOL
- Late presentation results in high needs and a short timeline for care - upstream approach
- Coexistence of physical and psychological symptoms can obscure symptoms such as pain, especially for people who use drugs - stigma
- Challenges experienced by care staff differ: mental health and palliative care clinicians have different skill sets and comfort

Donald, E.E., & Stajduhar, K.I. (2019). A scoping review of palliative care for persons with severe persistent mental illness. *Palliative and Supportive Care,* 17, 479-487.



Palliative and Supportive Care

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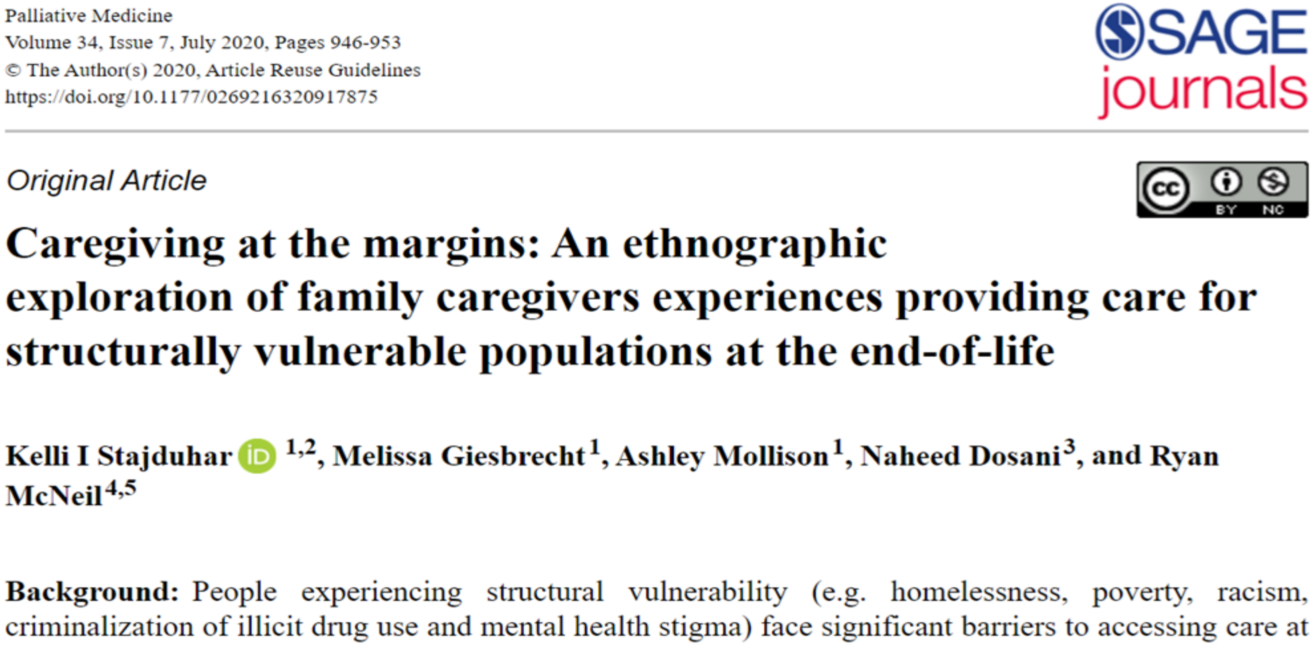
Result. Four major themes were identified from the included studies: complexity of care; limited access to care (both through systems and healthcare providers); competence and auton-

- Many people with SPMI experience stigma, discrimination, isolation and poverty
- Silo-ing of services create barriers to care at EOL - people fall thru cracks
- Death can be sudden and unexpected
- Identification of people who could benefit from a palliative approach is complex

Donald, E.E., & Stajduhar, K.I. (2019). A scoping review of palliative care for persons with severe persistent mental illness. *Palliative and Supportive Care,* 17, 479-487.



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Original Article

Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life

Kelli I Stajduhar[1,2], Melissa Giesbrecht[1], Ashley Mollison[1], Naheed Dosani[3], and Ryan McNeil[4,5]

Background: People experiencing structural vulnerability (e.g. homelessness, poverty, racism, criminalization of illicit drug use and mental health stigma) face significant barriers to accessing care at

- Alienation from friends and family places people with SPMI at a disadvantage
- Mental health workers, housing workers, outreach workers often act as 'de facto' family caregivers; deeply bereaved and limited knowledge of palliative approaches to care

Stajduhar, K.I., Giesbrecht, M., Mollison, A., Dosani, N., & McNeil, R. (2020). Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life. *Palliative Medicine,* 34(7), 946-953.

- Health care services, including palliative care and mental health services do not feel safe or welcoming for people and their chosen supporters
- "They" are not hard to reach. We are hard to reach

Health and Place 53 (2018) 43–51

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Health & Place

journal homepage: www.elsevier.com/locate/healthplace

Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life

Melissa Giesbrecht[a,*], Kelli I. Stajduhar[a,b], Ashley Mollison[a], Bernie Pauly[b,c], Sheryl Reimer-Kirkham[d], Ryan McNeil[e,f], Bruce Wallace[g], Naheed Dosani[h], Caelin Rose[a]

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Intersectionality
Therapeutic landscapes
Canada

ABSTRACT

The process of dying pronounces inequities, particularly for structurally vulnerable populations. Extending recent health geography research, we critically explore how the 'places' of formal healthcare settings shape experiences of, and access to, palliative care for the structurally vulnerable (e.g., homeless, substance users). Drawing on 30 months of ethnographic data, thematic findings reveal how symbolic, aesthetic, and physical elements of formal healthcare 'places' intersect with social relations of power to produce, reinforce, and amplify structural vulnerability and thus, inequities in access to care. Such knowledge may inform decision-makers on ways to enhance equitable access to palliative care for some of societies' most vulnerable population groups.

Giesbrecht, M., Stajduhar, K.I., Mollison, A. et al (2018). Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health & Place,* 53, 43-51.

Clinical palliative care perspective

Providing palliative care to people with SPMI

- Determining capacity and maintaining autonomy
  - Capacity is fluid and specific to a particular decision or task not diagnosis

- People with SPMI may have differences in pain perception/ symptom expression
  - People with schizophrenia can have a decreased response to pain (Evenblij et al., 2016)
  - Behavioural changes may be related to underlying psychiatric illness or uncontrolled symptoms
  - Flat affect, healthcare-related paranoia and stigma can prevent patients from being forthcoming about their symptoms

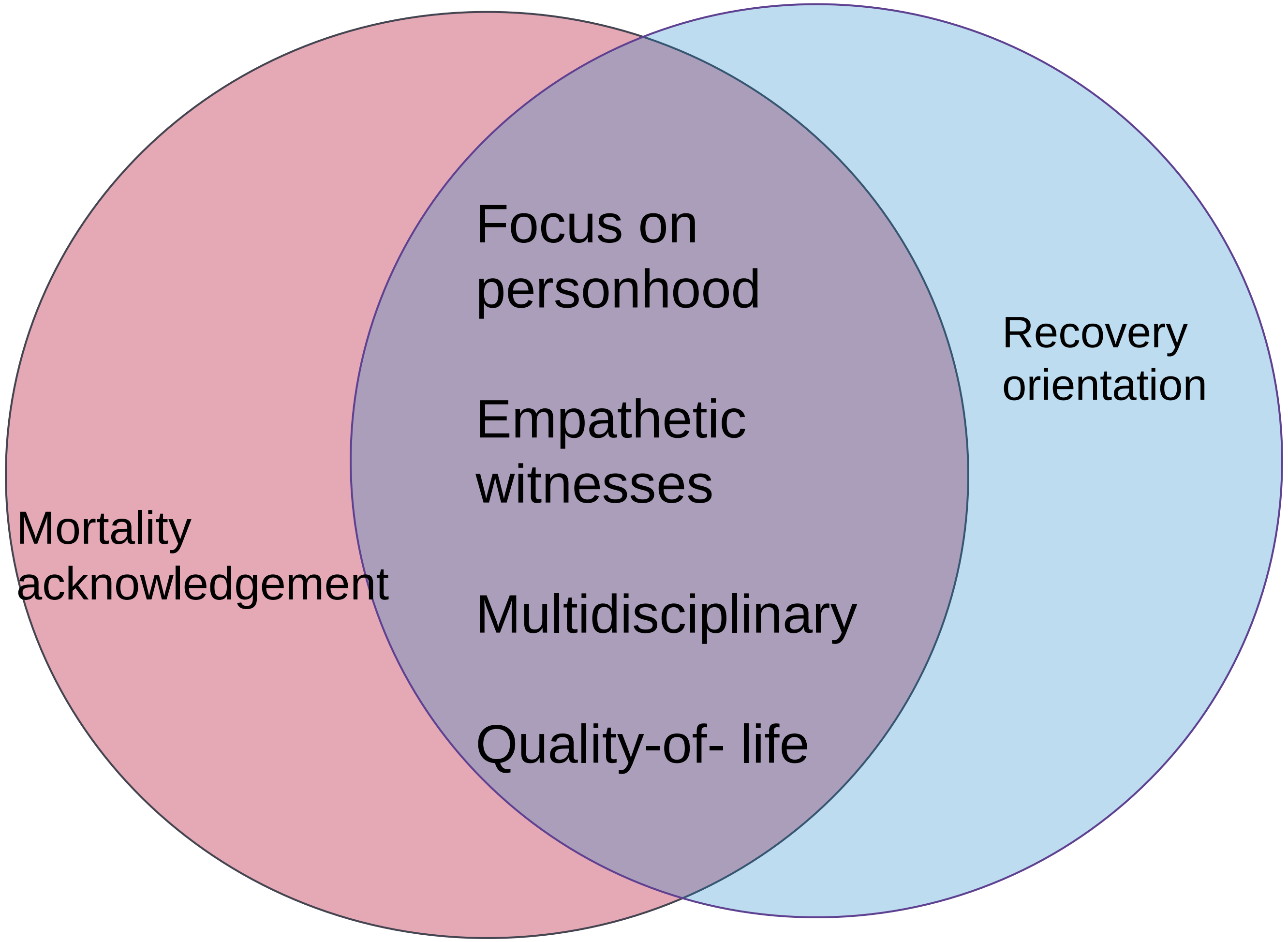
Providing palliative care to people with SPMI

- Medication selection and symptom management can be challenging
    - People with SPMI may be receiving high doses of psychotropic medications to manage their psychiatric illnesses and require considerably higher doses than the average patient for symptom management

- Allowing control helps to rebuild trust in the healthcare team
- Family, chosen family and caregivers (including healthcare team) require support through loss and bereavement

Facilitators of success

- Shared-care model supports established relationships
- Flexibility and willingness to meet people where they are
- Creating opportunities for psychiatry and palliative care to learn together



Mortality acknowledgement

Focus on personhood

Empathetic witnesses

Multidisciplinary

Quality-of- life

Recovery orientation

Palliative Care Approach

Mental Health Approach

Psychiatry palliative care perspective

Do people with serious mental illness access palliative care?

- It’s complicated…

- Well known data from Manitoba (Chochinov et al. 2012) showed decedents with schizophrenia did not have equitable access to palliative care

- But most data actually refutes this
    - Our recent review showed fairly consistent impact of psychiatric comorbidity in palliative care utilization
    - Data show that psychiatric comorbidity predicts palliative care referral

Perspectives of Palliative Care Clinicians

- In data from 700 U.S. palliative care clinicians, most treat patients with psychotic disorders at least occasionally
    - Most report at least rarely being responsible for managing psychotic disorders despite being uncomfortable or very uncomfortable managing such conditions
    - Most palliative care clinicians note that psychiatric comorbidity impacts their comfort delivering palliative care at least some of the time

Barriers to high quality palliative care for people with SMI

- Palliative care clinician training:
  - Fewer than 20% of clinicians are satisfied with opportunities for training in their work environment
  - Minimal training in fellowship programs

- Siloing between psychiatry and palliative care
  - Little cross-training
  - ~10% of palliative care services have embedded psychiatrists or psychologists
  - Fewer than 30% of clinicians satisfied with referral resources

Opportunities for Improvement

Workforce Development:

- Fellowship training
- Recruitment for psychiatrists for PC fellowship
- Professional development

Models of Care:

- Integrated care focused on needs of individuals with SMI

Case based discussion

Case: Teri

Teri is a 52-year-old female with treatment-resistant schizophrenia and chronic psychosis. She developed abdominal pain in late November and presented to the ER several times reporting that “she was pregnant.” She was diagnosed with constipation and sent home with laxatives.

In January, she became nauseous and started vomiting. Her case worker at her lodging home called EMS and she was taken to the ER again and diagnosed with widely metastatic ovarian cancer causing a pleural effusion, incomplete bowel obstruction and bilateral hydronephrosis.

Why may Teri’s diagnosis have been delayed? What could we do better?

Teri continued...

Teri had chronic delusions about bringing her family members back to life and case workers implanting things in her body without her consent. She had been in and out of institutional care throughout her life but had been residing in her current lodging home for 8 years.

Teri had been estranged from her family since her mid 20s and the office of the Public Guardian and Trustee was acting as her substitute decision maker.

She underwent a biopsy for consideration for chemotherapy and radiation. The team attempted to insert a pleural drain and nephrostomy tubes, but Teri became agitated and distressed.

How can we try to understand Teri's wishes? How can we avoid overly aggressive care/ iatrogenic harm?

Teri continued...

Teri declined while in hospital and developed worsening abdominal pain, nausea and vomiting and weakness. Assessing and managing Teri’s symptoms was difficult for the care team.

Efforts were made to notify Teri’s only surviving family member, her brother, of her illness. He declined to be involved in her care. Teri eventually died in hospital. Her social worker from the Schizophrenia Outreach Team was at the bedside.

Did Teri have a good death? How might things have been done differently?

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.
- Please join us for the next session in this series: **What is Palliative Psychiatry?** on March 21, 2023 from 12 -1pm ET.

Thank You

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