

Severe and Persistent Mental Illness & Palliative Care Community of Practice

What is severe and persistent mental illness?



Facilitator: Alexandra Farag

Presenters: Daniel Buchman, Sarah Levitt, Kelli Stajduhar

Date: January 17, 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.



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Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	What is Severe and Persistent Mental Illness?	January 17, 2023 from 12-1 pm ET
Session 2	What can Palliative Care offer to People with SPMI?	February 21, 2023 from 12-1 pm ET
Session 3	What is Palliative Psychiatry?	March 21, 2023 from 12-1 pm ET
Session 4	How do we move forward? Education and Future Directions	April 18, 2023 from 12-1pm ET

Welcome & Reminders

- Please 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.

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- Health Canada in the form of a contribution program.
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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

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Presenters/Panelists:

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Introductions

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Session Learning Objectives

Upon completing the session, participants will be able to:

- Define Serious Persistent Mental Illness.
 - Identify the different illnesses that are included in the group of illnesses called SPMI
 - Increase our understanding of the experience of SPMI
 - Express the concept of SPMI as life limiting illness
- Discuss the concepts of :
 - Structural vulnerability and double vulnerability
 - Ability/disability/ableism
- Define Palliative Care
 - Understand the evolution of palliative care over time
- Describe the concept of palliative psychiatry
 - Discuss the tension between cure, function, and comfort

Overarching objective: To begin to develop a Community of Practice.

What is Severe and Persistent Mental Illness?



Severe and Persistent Mental Illness (SPMI)

Duration

Diagnosis

Disability



Defining Severe and Persistent Mental Illness—A Pragmatic Utility Concept Analysis

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¹URPP “Dynamics of Healthy Aging”, University of Zurich, Zurich, Switzerland, ²Department of Anthropology, McGill University, Montreal, QC, Canada, ³Department of Geriatric Psychiatry, Psychiatric University Hospital Zurich, Zurich, Switzerland

The concept of severe and persistent mental illness (SPMI) lacks a consensual definition. Variations in definitions stem above all from different meanings about the constituent features of the concept and how to operationalize them. Our objective was to clarify the concept of SPMI and to explore the level of concept maturity through pragmatic utility (PU) concept analysis. Our findings suggest that SPMI is a partially mature concept that needs further clarification. We argue that the lack of a uniform definition is inherent to the problem: SPMI refers to a patient population rather than a disease entity, and the term has to be useful for different stakeholder purposes. Therefore, while an agreement on the principle three dimensions included in a definition may be possible (diagnosis, disability, and duration), their operationalization will have to be context-dependent and specific for the task at hand.

Keywords: severe and persistent mental illness, SPMI, palliative psychiatry, pragmatic utility concept analysis, systematic review

INTRODUCTION

Severe and persistent mental illness (SPMI) is associated with suffering in the affected persons and burden to their caregivers. To provide optimal healthcare for these patients is a challenge. To advance service provision for this population, research is needed to guide treatments and resource allocation. However, several authors have highlighted that SPMI lacks a consensual definition (1–5). Variations in definitions stem above all from different meanings about the constituent features of the concept and how to operationalize them. Consequently, researchers, policymakers, and healthcare providers may have various understandings of SPMI, measure different phenomena, and deal with different patient groups. Therefore, an analysis of the definitional basis of SPMI is needed to advance the field.

The term SPMI was introduced by a workgroup convened by the NIMH in 1987 (6) and defined SPMI as a function of the three “Ds”, namely, diagnosis, disability, and duration. The workgroup aimed to improve service and policy planning in the United States (3, pp. 13–14, 6). In the following years, several authors developed definitions of SPMI to be used on the local level (1–4).

Recently, a debate has emerged that connects SPMI with palliative care (7–15). A paradigm shift to “palliative psychiatry” for SPMI has been proposed as this population is at risk of therapeutic neglect and/or overly aggressive care within the existing care paradigms (13). However, this ongoing

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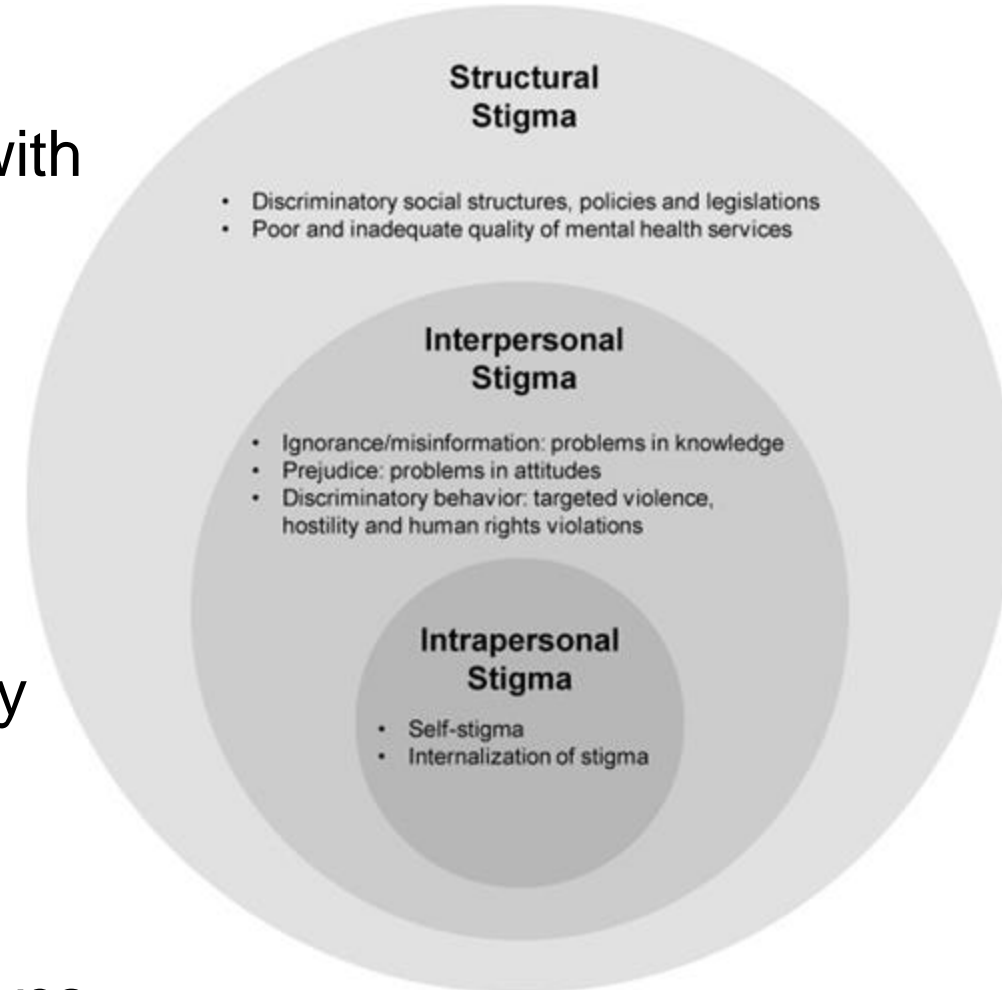
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How do we think about planning care for heterogeneous populations?

What experiences are common to people who live with SPMI?

What experiences are common to people who live with SPMI?

- A culture of ableism can shape experiences with psychiatric disability.
- People living with SPMI experience immense stigma, both within and external to healthcare
- Stigma tracks social disadvantage (Hatzenbueler, et al., 2013).
- Structural vulnerability and double vulnerability
- Limited life expectancy
 - because of risk of comorbid medical conditions
 - because of psychiatric symptoms themselves



Javed, et al., 2021

Structural disadvantage

Structural vulnerabilities

Structural vulnerabilities:
homelessness, poverty, criminalization,
racism, and stigma

Chronic life-limiting illness

Chronic illness: lung, liver, or
kidney disease, cancers, neurologic
disease

Severe **disadvantage** when
health declines



Systemic and Social Inequities

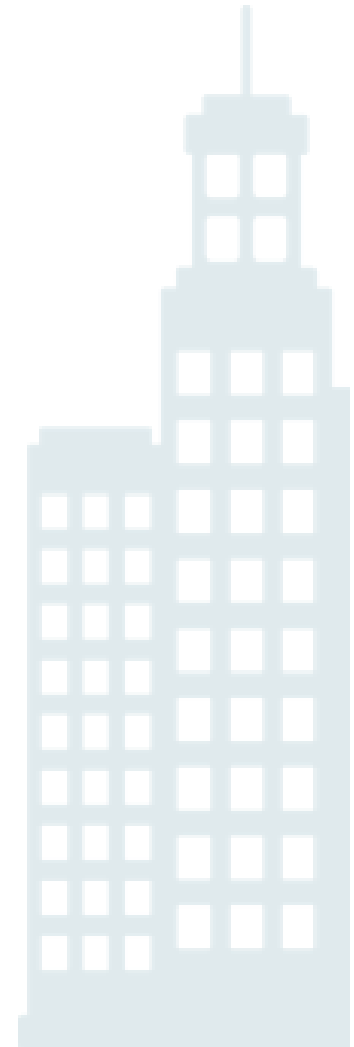


Research shows that people experiencing structural inequity :

- have many unmet needs
- they do not trust the health care system or its providers
- May feel judged as a result of provider bias about mental health or substance use issues and/or because they may be poor and/or homeless, racialized or have disabilities.

Stajduhar, K., Mollison, A., Giesbrecht, M., et al. Just too busy living in the moment and surviving: Barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, 18(11). <https://doi.org/10.1186/s12904-019-0096-7>.

Stajduhar, K.J., Giesbrecht, M., Mollison, A., & d'Archangelo, M. (2020). Everybody in this community is at risk of dying: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner city settings. *Palliative & Supportive Care*, 18(6), 670-675.

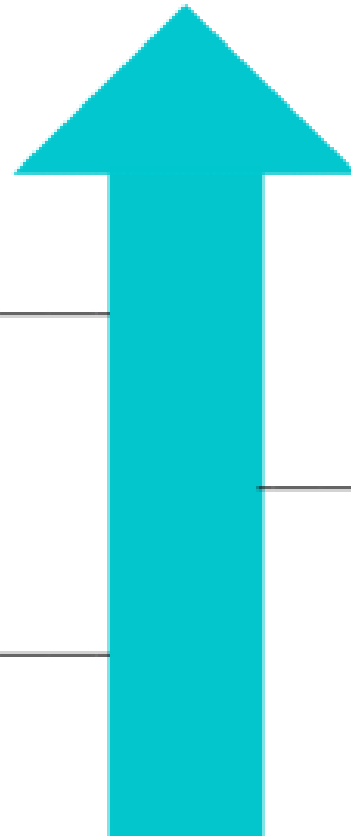




Palliative approaches to care for people experiencing structural vulnerabilities

People impacted by structural inequities such as inadequate housing, racialization, classism, stigmatization of substance use and mental illness continue to experience persistent health and health care inequities.

People who experience structural vulnerability who are also at EOL experience significant barriers accessing care.



People who experience structural vulnerability suffer from more aging-related conditions than those who are decades older, experience “accelerated aging” relative to the general population, and have disproportionately high rates of cancer and other chronic illnesses.

Death Is a Social Justice Issue Perspectives on Equity-Informed Palliative Care

*Sheryl Reimer-Kirkham, PhD, RN; Kelly Stajduhar, PhD, RN;
Bernie Pauly, PhD, RN; Melissa Giesbrecht, PhD; Ashley Mullison, BA;
Ryan McNeil, PhD; Bruce Wallace, PhD*

All too often, palliative care services are not responsive to the needs of those who are doubly vulnerable, being that they are both in need of palliative care services and experiencing deficits in the social determinants of health that make it complex, intersecting health and social concerns. In this article, we argue for a reorientation of palliative care to explicitly integrate the promise of health equity. We articulate the philosophical, theoretical, and empirical scaffolding required for equity-informed palliative care and draw on a current study to illustrate such an approach to the care of people who experience structural vulnerabilities. Key words: discrimination, health equity, professionals, marginalization, palliative care, poverty, public health, social justice, stigma, structural vulnerability

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This article originates with the Equitable Access to Care for People With Life Limiting Conditions Study led by Dr Kelly Stajduhar (principal investigator) and is supported by a grant from the Canadian Institutes of Health Research (CIHR) (21373). The authors are also members of various research initiatives that inform their contributions to this paper, including the Equity Issue in Public Health Project, that is funded by Canadian Institutes of Health Research. We are grateful to the participants of the Equitable Access to Care for People With Life Limiting Conditions Study and the researchers (Kelly Stajduhar, University of Victoria (UVIC); Ryan McNeil, BC Centre for Excellence in Health Services, Victoria, British Columbia; Ashley Mullison, Trinity Western University; Natalie O'Keefe, Penn City Health Associates and McMaster University; Caitlin Shaw, Victoria Hospital, British Columbia; and Community Health Leader and Palliative Care Lead, Resource Unit (PREF), Kitimat Health, 100 Vancouver Island and PREF, Cedar Mountain, Coal Hill

MOST PEOPLE share a common desire to approach the end of life in a peaceful and dignified manner, in the presence of loved ones, and filled with feelings of safety.

Community Health Centre and PREF, Grey Mountain, Coal Hill Community Health Centre and PREF; Ashley Mullison, UVIC; Taylor Dool, UVIC; Carolyn Moulder, UVIC; and Kelly Astorik, UVIC). We thank our Advisory Group comprised of member organizations of the Palliative Research Institute (PRI) in Victoria, British Columbia, Canada. We thank the presursors, providers, facilitators, and generous contributors who made the PREF in the State workshop possible, including the Knowledge Centre of St. John's Hospital, Knight Hospice, Victoria Community, Victoria Hospice, PREF, BC Centre for Excellence in Health Services, Palliative Education and Care for the Interior (PECAI), 1020 Vancouver Island, Terrace Coal Hill Society, the Institute for a Palliative Approach to Nursing, Evidence and Leadership (EVAL), Anne Queenan, and the UVIC Institute on Aging and Lifelong Health.

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“Most definitions of palliative care ... do not make explicit the additional attention needed to address social and structural inequities that profoundly shape health, illness, and dying experiences for people who are made particularly vulnerable by a constellation of sociopolitical, economic, cultural, and historical forces.”

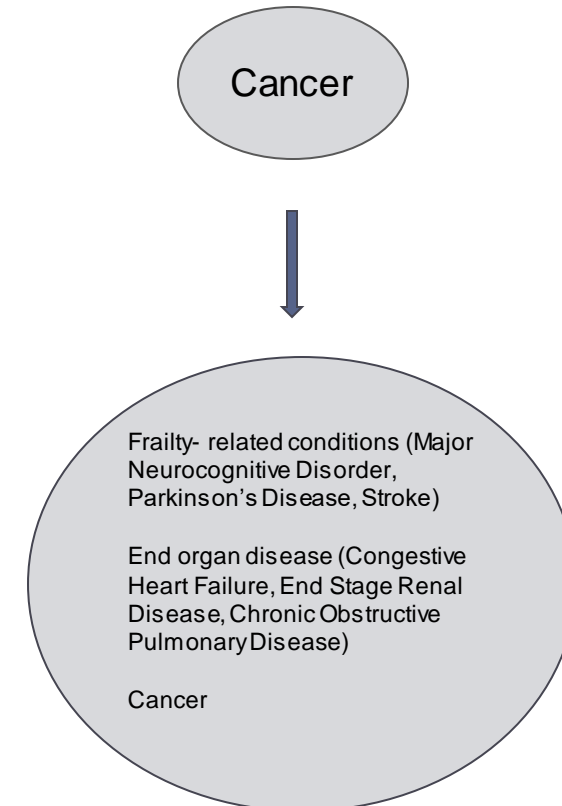
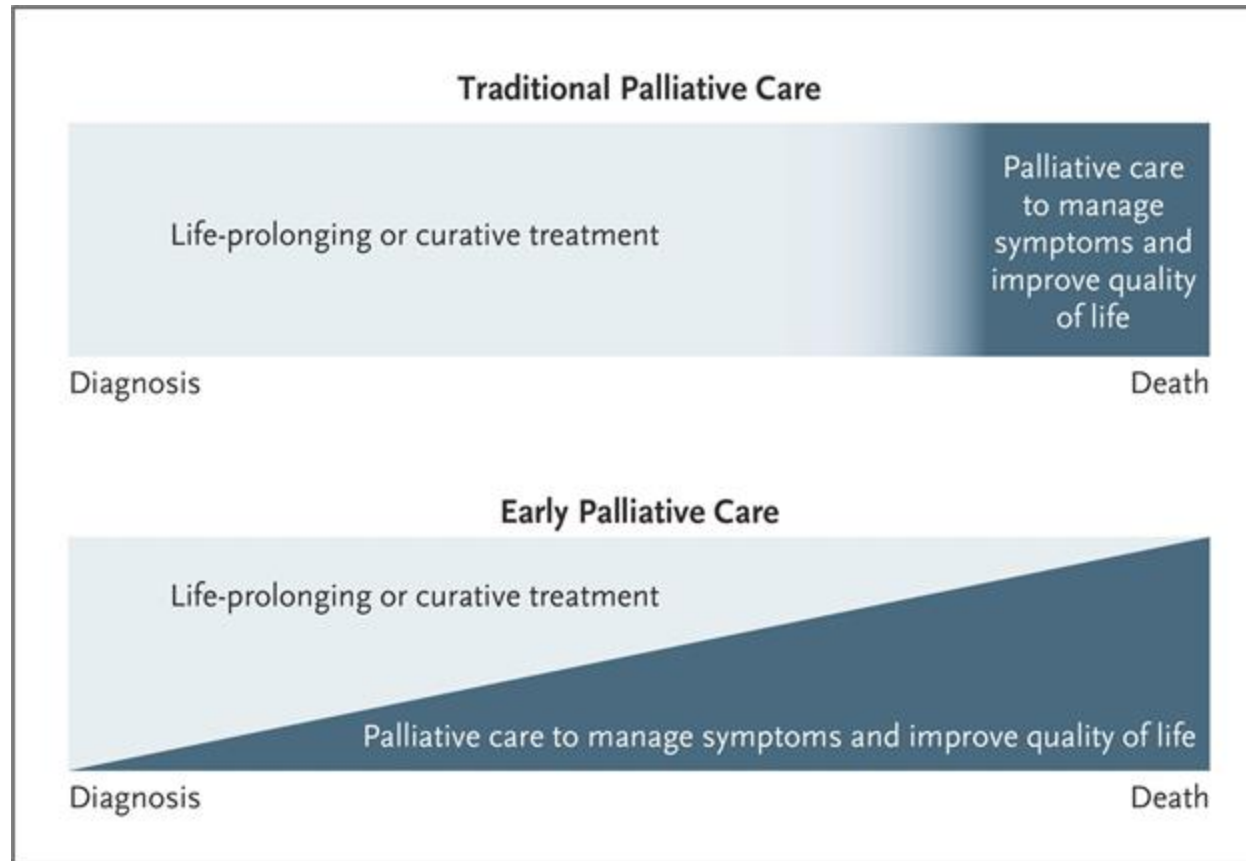
Reimer-Kirkham, Stajduhar, Pauly, et al. 2016

Questions & Reflection



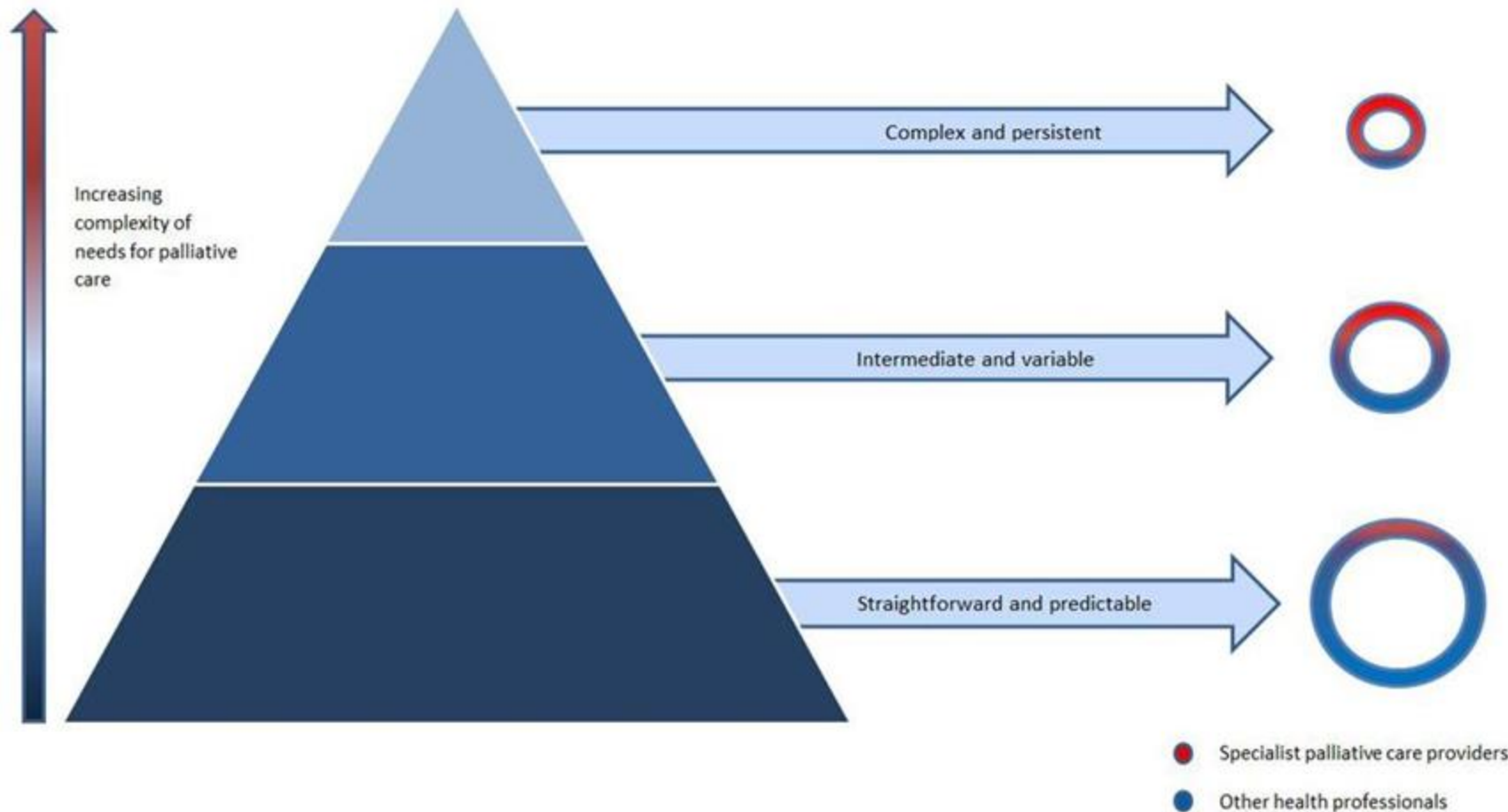
What is Palliative Care as a focus of specialty care vs a palliative approach to care?

Traditional palliative care and the adoption of early palliative care



Parikh R, Kirch R, Smith T, Temel J. Early specialty palliative care. Translation data in oncology to practice. NEJM

Palliative Care is Everyone's Business



- Specialist palliative care involvement is only required for a small group of patients with complex palliative needs
- The majority of palliative care can be provided by other healthcare professionals adopting a palliative approach

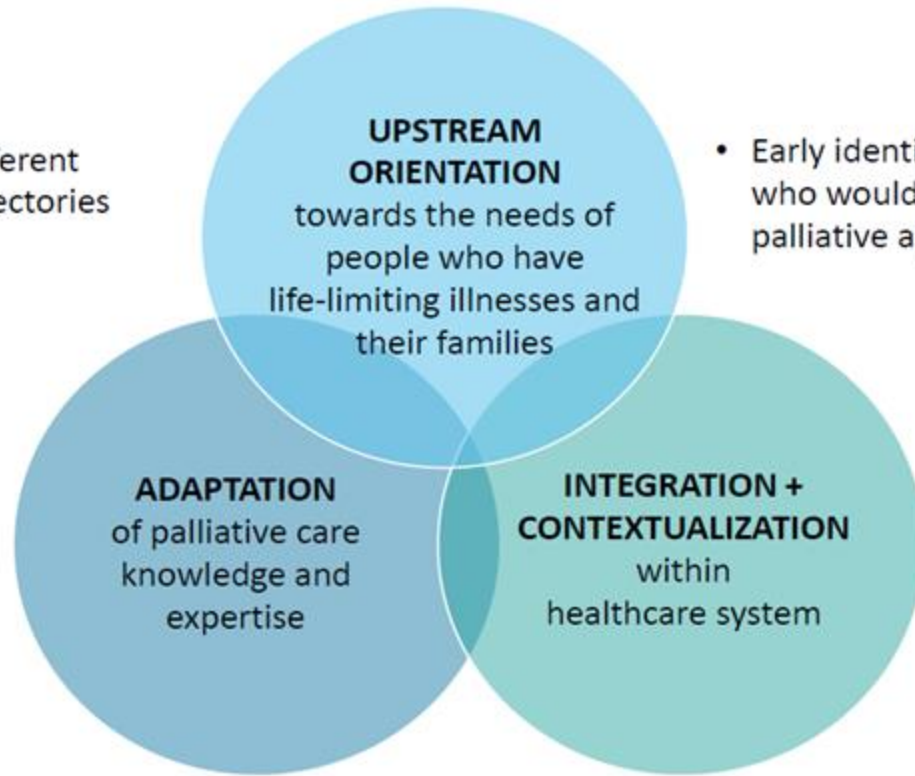
From Framework on Palliative Care in Canada by Health Canada Dec 2018.

Conceptual foundations of a palliative approach

- Understanding different chronic illness trajectories

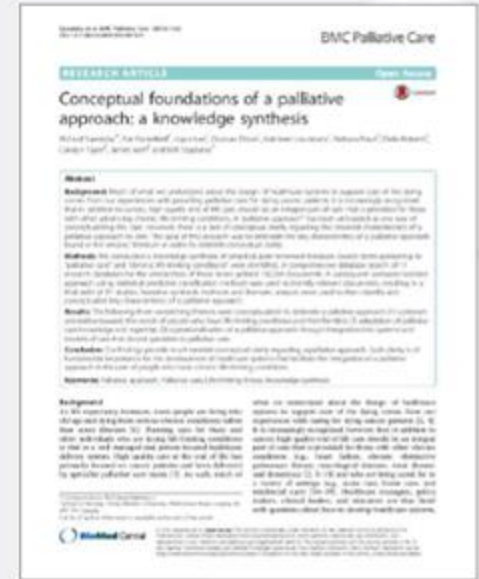
IMPORTANT CONSIDERATIONS

- Different approaches to symptom management
- Tailored communication to illness trajectories
- Uncertain disease trajectories and advance care planning
- Building partnerships in care



- Early identification of people who would benefit from a palliative approach

- “Early” palliative care
- Integration into generalist practice
- Integration with chronic disease management



Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, 15(5). doi: [10.1186/s1290401600769](https://doi.org/10.1186/s1290401600769)

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Questions & Reflection



What is Palliative Psychiatry?

A Palliative Care Model for Psychiatry

SPMI are at risk of:

- Therapeutic neglect
- Overly aggressive care

Palliative care model helps with "personal recovery".

Evidence that improved palliative care might result in fewer requests for MAID.

Traschel et al. Palliative psychiatry for severe and persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry* (2016);16;260.

Table 1 Working definition, features and examples of palliative psychiatry

Definition

Palliative psychiatry (PP) is an approach that improves the quality of life of patients and their families in facing the problems associated with life-threatening severe persistent mental illness (SPMI) through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs. PP focuses on harm reduction and on avoidance of burden some psychiatric interventions with questionable impact.

Features of palliative psychiatry

- Provides support in coping with and accepting of distressing mental symptoms
 - Affirms life but acknowledges that SPMI can be incurable
 - Intends neither to hasten nor to postpone death
 - Integrates the physical, psychological, social, and spiritual aspects of patient care
 - Offers a support system to help patients to live as actively as possible until death
 - Offers a support system to help family members to cope during patients' SPMI
 - Uses a team approach to address the needs of patients and their families
 - Will enhance quality of life and may also positively influence the course of the SPMI
 - Is applicable in conjunction with other therapies oriented towards prevention, curation, rehabilitation, or recovery
-

Do we need a specific palliative care model for psychiatry?

Features narrowed down to only include mental illness	Features broader than in the WHO definition	Features identical in the two definitions
<ul style="list-style-type: none">• Provides support in coping with and accepting of distressing mental symptoms• Affirms life but acknowledges that SPMI can be incurable• Offers a support system to help family members to cope during patients' SPMI• Uses a team approach to address the needs of patients and their families• Will enhance quality of life and may also positively influence the course of the SPMI	<ul style="list-style-type: none">• Integrates the physical, psychological, social, and spiritual aspects of patient care• Is applicable in conjunction with other therapies oriented towards prevention, curation, rehabilitation, or recovery	<ul style="list-style-type: none">• Intends neither to hasten nor to postpone death• Offers a support system to help patients to live as actively as possible until death

“Rather than developing new definitions, professionals in different disciplines should focus on how their patients’ palliative needs should best be met.”

Lindblad, A., Helgesson, G., & Sjostrand, M. Towards a palliative care approach in psychiatry: do we need a new definition? *J Med Ethics* 2019;45, pp. 26-30.

Do we need a specific palliative care model for psychiatry?

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 can Palliative Care offer to people with SPMI?** on February 21, 2023 from 12 -1pm ET.

Thank You



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