Home-based Palliative End-of-Life Care in Newfoundland & Labrador
Barbara Pesut, Karen Stone, Stephen Bornstein, Colin Walsh, Wendy Lasisi
Welcome
Home-based Palliative End-of-Life Care

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Patients and Caregivers
Research Exchange Group on Palliative and End-of-Life Care
Today’s Session

• About CHRSP – Stephen Bornstein
• Background and Methods – Colin Walsh
• Synthesis Findings – Barbara Pesut
• Considerations for Decision Makers – Colin Walsh
• Facilitated Discussion – Stephen Bornstein
What is CHRSP?

• **Contextualized**
• **Health**
• **Research**
• **Synthesis**
• **Program**

CHRSP synthesizes the best available research evidence to find out what works.

CHRSP then looks at local conditions to figure out what might work here.

Designed to support evidence-informed health policy in Newfoundland & Labrador.
Colin Walsh: Background and Methods
Decision makers in Newfoundland and Labrador want to help people receive care in their own homes, including care at the end of life. With this in mind, health system decision makers from across the province asked CHRSP to find out more about home-based palliative end-of-life care (HPC).
Research Question

“What does the scientific evidence tell us about the effectiveness of home-based palliative end-of-life care in maximizing the likelihood of death at home and in minimizing symptom burden? What does the evidence tell us about the resources required for the effective delivery of such care?”
Evidence in Context Method

• Assemble a team
• Synthesize the evidence
• Contextualize the evidence
• Considerations for Decision Makers
• Report in various formats

Newfoundland and Labrador Centre for Applied Health Research
www.nlcahr.mun.ca/chrsp
What did we look for?

- Systematic reviews, meta-analyses
- High-quality primary studies
- Population: adults receiving palliative care at home and/or their caregivers
- Comparator: palliative care in an institution
- Outcomes: the likelihood of death at home, symptom burden, quality of life
Evidence Rating System

Measures the strength of the body of evidence
- Quality of systematic reviews
- Number of systematic reviews
- Consistency of research findings
- Number of underlying primary research studies

<table>
<thead>
<tr>
<th>Body of Evidence</th>
<th>Synthesis Finding</th>
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<td>Weak or Very Weak</td>
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## What did we find?

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<tr>
<th>6 Systematic Reviews:</th>
<th>Methodological Quality (AMSTAR)</th>
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<tr>
<td>Cochrane Review by Gomes 2013</td>
<td>High Quality</td>
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<td>Cochrane Review by Shepperd 2016</td>
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<td>Costa 2016</td>
<td>Moderate Quality</td>
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<td>Luckett 2013</td>
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<td>Miranda 2019</td>
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<td>Sarmento 2016</td>
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### What did we find?

<table>
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<tr>
<th>6 Recent Primary Studies:</th>
<th>Methodological Quality (Downs &amp; Black)</th>
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<tr>
<td>Abe 2019</td>
<td>Good Quality</td>
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<td>Tanuseputro 2018</td>
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<td>Wang 2019</td>
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<td>Kjellstadli 2018</td>
<td>Good Quality</td>
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<td>Nagaviroj 2017</td>
<td>Fair Quality</td>
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<tr>
<td>Tan 2019</td>
<td>Fair Quality</td>
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Limitations of the Evidence

- Definitions of the comparator – “Usual Care” – are highly variable
- Multiple challenges locating evidence about the resources required for effective HPC
Barbara Pesut: Synthesis Findings
Key Message #1

The available research evidence indicates that patients receiving home-based palliative end-of-life care have a greater likelihood of dying at home when compared to patients receiving usual care.
Key Message #2

The available research evidence suggests that receiving home-based palliative end-of-life care tends to reduce overall symptom burden for patients.
Key Message #3

Competent home-based palliative end-of-life care teams tend to provide patients with a sense of security. Patients view home-based palliative end-of-life care teams as being competent when such teams manage symptoms effectively and communicate skillfully.
Key Message #4

Quality of life and caregiver outcomes are notoriously hard to measure. The evidence is inconclusive about the impact of home-based palliative end-of-life care on these outcomes. We found no evidence to indicate that patients and their caregivers are worse off when they receive home-based palliative end-of-life care.
Key Message #5

Limitations of the evidence about the resources required for effective HPC care make it difficult to draw firm conclusions.

Health human resources most often mentioned:
- nurses
- medical professionals
- social workers
- allied health professionals
- mental health professionals

Service components most often mentioned:
- educating patients and caregivers
- psychosocial services
- symptom and disease treatment
- telehealth
Colin Walsh: Considerations for Decision Makers
Training

Healthcare professionals need adequate training in palliative care—
for both home-based and institutional care
More adequately-trained and compensated homecare workers are needed, particularly in rural and suburban areas.
Subsidized Support Hours

Quality patient care at the end of life requires sufficient government-subsidized homecare of all types, including palliative care.
Patients and their families need clear and consistent access to information about what homecare is available to them and how they can access it.
Access to Physicians

Palliative care patients need improved access to physicians on evenings, weekends and holidays.
Communication & Knowledge Sharing

Communication and knowledge-sharing is critical for effective palliative care.

- Across RHAs
- Sharing patient information
- Connecting across disciplines and care contexts
Transportation Issues

Access to public transportation, or to publicly-subsidized transportation for homecare workers and their patients, especially outside the province’s principal cities, is a key consideration.
Understanding Palliative Care

Healthcare professionals need to better understand the benefits of palliative care and to be willing to discuss palliation with their patients, not only at the end of life but proactively, at earlier stages of disease development.
Patients with a variety of health conditions

Physicians and other care providers need improved awareness of the effectiveness of palliative care for patients with conditions other than cancer.
Self-referral

Allowing patients and their families to self-refer may improve patient access to care in cases where physicians are reluctant to discuss palliation with their patients.
The Hospice Option

Given the benefits of hospice care for end-of-life patients, decision makers may wish to consider how to provide more access to hospice care across the province.
Questions/ Discussion
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