

Evidence *in* Context

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Health research – synthesized and contextualized for use in Newfoundland & Labrador

Home-based Palliative End-of-Life Care in Newfoundland & Labrador

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Research indicates that fewer people die at home than patients and their families would prefer. Access to home-based end-of-life palliative care (HPC) might improve the likelihood of a home death for patients who would prefer this choice. HPC also aligns with the work being undertaken by the Government of Newfoundland & Labrador, in partnership with the Government of Canada, towards a *Home First* initiative that will help more people get access to healthcare in their own homes.

To examine this issue, provincial decision makers asked the Contextualized Health Research Synthesis Program (CHRSP) to find out what the health evidence says about the potential for HPC to improve the likelihood of a home death rather than a death in institutional care. In addition, the CHRSP research team looked at whether HPC could improve patient and caregiver experiences in other ways, including: minimizing symptom burden for patients, improving key quality of life indicators, and relieving caregiver burden. Provincial stakeholders also asked us what resources would be required for effective home-based palliative care.



To answer these questions, CHRSP assembled a project team that included subject expert Barbara Pesut, PhD, RN, Research Chair in Palliative and End-of-Life Care at the University of British Columbia; health system leader Karen Stone, Deputy Minister of Health and Community Services in NL; and representatives from the province's four Regional Health Authorities (RHAs): Eastern Health, Central

Health, Western Health, and Labrador-Grenfell Health. The team also included Memorial University researchers and representatives from appropriate government departments. Patient and caregiver advisers and other community stakeholders assisted with contextualization,

considering the synthesis findings in terms of local factors that might have affected their effectiveness, feasibility and acceptability in this province.

This report summarizes key findings from the evidence and the results of our contextualization process. On the final page are some considerations for decision makers who may be planning to implement home-based palliative end-of-life care programs in Newfoundland & Labrador.

The 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?"

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Disclaimer: This document is an executive summary of a larger report that contains fully-referenced material. We have omitted references from this summary for the sake of brevity, but readers who wish to review the fully-referenced report are encouraged to do so at <http://www.nlcahr.mun.ca/CHRSP/> together with an online companion document describing the methodology, data extraction and detailed synthesis results.

Read the full report here: <http://www.nlcahr.mun.ca/CHRSP/>

What did the Evidence Say?

A Summary of Key Findings

- ✓ The 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.
- ✓ The research evidence suggests that patients receiving home-based palliative end-of-life care tend to experience reduced overall symptom burden.
- ✓ 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 effectively manage symptoms and communicate skillfully.
- ✓ Both quality of life and caregiver outcomes are notoriously hard to measure, and the evidence is inconclusive about the impact of home-based palliative end-of-life care on these outcomes. However, there is no evidence to indicate that patients and their caregivers are worse off when they receive home-based palliative end-of-life care as compared to receiving usual care.
- ✓ Limitations of the evidence about the resources required to provide effective home-based palliative end-of-life care make it difficult to draw firm conclusions; however, the following health human resources are mentioned in the highest-quality research literature: nurses, medical professionals, social workers, allied health professionals, and mental health professionals. The following service components were reported as being included in HPC: educating patients and caregivers, providing psychosocial services, symptom and disease treatment, telehealth, and conducting patient assessments.

What evidence did we look for?

To be eligible for inclusion in this study, research evidence had to be published in English and: be a systematic review or a meta-analysis covering at least two studies; be published within the past 10 years; be a high-quality primary study published too recently to have been captured in the systematic review or meta-analysis literature; involve adult patients receiving palliative care at home and/or their caregivers; include a comparator group receiving palliative care in an institution; and measure outcomes related to the likelihood of death at home, symptom burden, or quality of life.

What did we find?

This report synthesizes the results of six systematic reviews. It also includes six primary studies that were published too recently to be included in the systematic reviews. While we did locate other palliative care research studies (both systematic reviews and primary literature), these were excluded from this synthesis because they did not focus on *home-based* palliative end-of-life care. Of the systematic reviews included in this study, two (both Cochrane Reviews) were rated as being of “High Quality” and four were of “Moderate Quality” using the AMSTAR quality assessment tool. Of the six primary studies, four were of good quality and two of fair quality using the Downs & Black Assessment Tool.

Key findings from the research evidence

Limitations of the evidence

Definitions of “usual care” varied widely in the literature, making it difficult to compare HPC to other care modalities. Multiple challenges also arose when attempting to locate evidence about the resources required for effective HPC: a lack of reporting in the literature, vagueness in reporting, non-standardized terminology, and changes over time in approaches to utilizing HPC resources. To provide decision makers with some information about this important topic, we reported on the instances where specific resources were mentioned in the highest-quality research literature. Although this approach cannot tell us definitively what resources are recommended, it will at least provide some indication of the professional personnel and services reported in the best available systematic reviews on home-based palliative care.

The Newfoundland & Labrador Context *for* Home-based Palliative End-of-Life Care



CHRSR researchers consulted with a number of provincial health system stakeholders, palliative care clinicians, patients, and caregivers to identify the contextual factors in Newfoundland & Labrador that may have an impact on the effectiveness, feasibility, or acceptability of home-based palliative

care. The results of these consultations are included in the full report. Key contextual factors are summarized below:

Home Support Access: Newfoundland & Labrador's widely-dispersed population and the comparatively large number of people who live in rural locations can create significant challenges for people hoping to access home-based palliative care. Our consultants suggested that the availability of adequately-trained and compensated homecare workers was also an issue. Compounding this issue are limitations to gaining access to subsidized hours of home support at the end of life. Our consultants also pointed to the need for accessible and clear information about the rules and procedures for accessing subsidized end-of-life home support.

Access to Physicians: According to our consultants, palliative care patients can find it difficult to get access to physicians in the evenings and on weekends. As a result, HPC patients with urgent health problems often end up in the emergency departments of local (or not so local) hospitals. Resorting to emergency departments creates a number of disadvantages for end-of-life patients and their families, including costly and uncomfortable travel, lengthy wait times, and reliance on health professionals who may lack training in palliative care. Our consultants pointed out that a more proactive approach to palliative care (such as earlier referral and advanced care planning) can help to prevent and alleviate many after-hours emergencies.

Alternative Approaches in NL: Our informants highlighted some alternative approaches in the province that have been designed to alleviate the issues related to accessing palliative care from home. These include: interdisciplinary palliative care consultant teams; paramedics trained to provide palliative care in the home; the development of programs for volunteers in the community who provide support to patients when professional services are not readily available; and the potential development of "medication kits" or "symptom relief kits" to provide medications in rural areas and during off-hours.

Health System Organization: Effective palliative care relies on services from multiple disciplines, including community-based care partners. Palliative care programs must, therefore, make connections in the community to support the provision of appropriate care in the home. Our consultants note that organizing multi-disciplinary services can be especially difficult in rural areas that have fewer community-based resources. Communication barriers among the many disciplines involved in providing palliative care can also make collaboration, connection, and care coordination difficult. As an example, our informants highlighted the multiple systems and formats used for patient reporting and record-keeping, even within individual Regional Health Authorities.

Factors Related to Palliative Care Services in Newfoundland & Labrador in General

Training: All too often, patients and families in NL have to rely on care providers who lack experience or training in palliative care.

Attitudes: inattention to/ discomfort with palliative care among care providers can be a barrier to palliative care access.

Capacity: The province will not likely have a sufficient number of palliative care specialists to treat patients as the demand for palliative care services continues to rise. It was suggested that palliative care specialists might provide consultation services as an option for generalists when the need arises.

Barriers: A number of barriers to proactive palliative care were identified, including: the referrals process; the preconception that palliative care is only for cancer patients; and discomfort among physicians and caregivers with palliative care conversations earlier in the disease trajectory.

Communication: Our consultants expressed a strong desire to see increased communication and knowledge-sharing on palliative care approaches across all four Regional Health Authorities.

Hospice Care: While a hospice is being built in Grand-Falls Windsor, other jurisdictions are having a harder time establishing hospice care in the province.

Awareness: The NL healthcare system should consider ways to improve awareness in the health system and in public as to what palliative care is and what it offers to patients and their families.

Contextualized Synthesis: Palliative End-of-Life Care

Considerations for Decision Makers

While the research that we synthesized in this report has shown the potential benefits of home-based palliative care (HPC), both the evidence and our discussions with CHRSP contextualization consultants indicate that, to be effective, HPC needs to be of high quality. Our findings suggest that, in order to create the conditions in Newfoundland & Labrador for high-quality, home-based palliative care, decision makers may wish to consider the following factors:

- ✓ Adequate training of healthcare professionals in palliative care is required for both home-based and institutional care.
- ✓ More adequately-trained and compensated homecare workers are needed, particularly in rural and suburban areas.
- ✓ 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.
- ✓ Palliative care patients need improved access to physicians on evenings, weekends and holidays.
- ✓ Communication and knowledge-sharing is critical for effective palliative care. An improved understanding is needed within all Regional Health Authorities about the approaches being taken province-wide. The ability for care providers to effectively share patient information and to connect with one another across disciplines and care contexts is crucial for quality of care.
- ✓ 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 in terms of access to care.
- ✓ Healthcare professionals across the province 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.
- ✓ Physicians and other care providers need improved awareness of the effectiveness of palliative care for patients with conditions other than cancer.
- ✓ Referrals to palliative care in Eastern Health, currently limited to physician referrals only, may need to be reconsidered. Allowing patients and their families to self-refer, as is the case in other regional health authorities, may improve patient access to care in cases where physicians are reluctant to discuss palliation with their patients.
- ✓ Given the important 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.



For the complete CHRSP report, including details on the evidence reviewed by the project team, and for more information about the CHRSP process, please visit the NLCAHR website: <http://www.nlcahr.mun.ca/CHRSP/>

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