

# Evidence *in* Context

Issue: Home-based Palliative End-of-Life Care  
Released: February, 2021

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

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

Barbara Pesut, Karen Stone, Stephen Bornstein, Colin Walsh, Wendy Lasisi

Newfoundland & Labrador Centre for

**APPLIED  
HEALTH  
RESEARCH**

[www.nlcahr.mun.ca](http://www.nlcahr.mun.ca)

## Find CHRSP Reports Online

All reports of the Contextualized Health Research Synthesis program are available online:

[www.nlcahr.mun.ca/chrsp/](http://www.nlcahr.mun.ca/chrsp/)

This contextualized health research synthesis report was prepared by the Newfoundland and Labrador Centre for Applied Health Research (NLCAHR), Memorial University. It was developed through the analysis, interpretation and synthesis of scientific research and/or health technology assessments conducted by other parties. It also incorporates selected information provided by experts in the subject areas and synthesis methodologies. This document may not fully reflect all the scientific evidence available at the time this report was prepared. Other relevant scientific findings may have been reported since completion of this synthesis report.

Memorial University, NLCAHR, and the CHRSP project team make no warranty, express or implied, nor assume any legal liability or responsibility for the accuracy, completeness, or usefulness of any information, data, product, or process disclosed in this report. Conclusions drawn from, or actions undertaken on the basis of, information included in this report are the sole responsibility of the user.

This report is the property of the Newfoundland and Labrador Centre for Applied Health Research (NLCAHR). Reproduction of this document for non-commercial purposes is permitted provided proper credit is given to NLCAHR.

For further information please contact: [nlcahr@mun.ca](mailto:nlcahr@mun.ca)

Cite as: Pesut, B., Stone, K., Bornstein, S., Walsh, C., Lasisi, W. (2021). Home-based Palliative End-of-Life Care in Newfoundland & Labrador. St. John's, NL: Newfoundland & Labrador Centre for Applied Health Research, Memorial University

ISBN: 0-88901-501-5: 978-0-88901-501-2

# Table of Contents

|  |    |
|--|----|
| About This Report .....  | 4  |
| About NLCAHR.....  | 4  |
| About the Contextualized Health Research Synthesis Program .....             | 4  |
| Who Should Read This Report?.....  | 4  |
| The Research Team .....  | 5  |
| Acronyms .....   | 6  |
| Glossary .....   | 7  |
| The CHRSP Approach to Health Evidence.....                                   | 8  |
| The Research Question.....   | 9  |
| Key Messages from this Report .....  | 9  |
| How to Navigate this Report .....  | 9  |
| Background.....  | 10 |
| Methodology .....  | 11 |
| What evidence did we look for? .....   | 11 |
| The CHRSP Evidence Rating System .....                                       | 12 |
| Evidence included in this report.....  | 13 |
| Synthesis Findings.....  | 14 |
| Home-based palliative care and the likelihood of a death at home .....       | 14 |
| Home-based palliative care and the place of death.....                       | 15 |
| Home-based palliative care and symptom burden .....                          | 16 |
| Home-based palliative care and admission to an institution.....              | 18 |
| Home-based palliative care, quality of life, and related outcomes .....      | 19 |
| Home-based palliative care and caregiver outcomes .....                      | 20 |
| Resources required for effective home-based palliative care .....            | 21 |
| The Newfoundland & Labrador Context.....                                     | 25 |
| Our Approach to Contextualization .....                                      | 25 |
| Home-based Palliative Care in the Newfoundland & Labrador Context.....       | 25 |
| General Palliative Care Services in the Newfoundland & Labrador Context..... | 28 |
| Considerations for Decision Makers .....                                     | 31 |
| References .....   | 32 |
| Appendix A.....  | 37 |
| Appendix B.....  | 39 |

# About This Report

## About NLCAHR

The Newfoundland and Labrador Centre for Applied Health Research, established in 1999, contributes to the effectiveness of the health and community services system of the province and the physical, social, and psychological well-being of the population. NLCAHR accomplishes this mandate by building capacity in applied health research, supporting high quality research, and fostering more effective use of research evidence by decision makers and policy makers in the province's health system.

## About the Contextualized Health Research Synthesis Program

In 2007, NLCAHR launched the Contextualized Health Research Synthesis Program (CHRSP) to provide research evidence that would help guide decision makers in the provincial health system on issues of pressing interest to Newfoundland and Labrador. Instead of conducting original research, CHRSP analyzes findings from high level research already conducted in the subject area, such as systematic reviews, meta-analyses and health technology assessments. Findings are then synthesized and subjected to a systematic process of contextualization: they are analyzed in terms of their applicability to the conditions and capacities of the unique context of Newfoundland and Labrador. Our contextual analysis includes assessing the specific forms an issue may take in this province as well as the applicability of any proposed solutions and

methods to locally available resources, infrastructure, human resources, cultural conditions and financial capacities. CHRSP uses a combination of external experts and local networks to carry out and contextualize the research synthesis and to facilitate the uptake of the results by research users. CHRSP focuses on three types of projects: health services/ health policy projects, health technology assessment projects, and projects that combine the two to examine processes for the organization or delivery of care involving a health technology.

## Who Should Read This Report?

This report provides a synthesis of the relevant research-based evidence on the role of home-based palliative end-of-life care on the likelihood of dying at home, on reducing symptom burden, and on improving quality of life. It also comments on the resources used for effective palliative programs. This report is intended to support decision makers in Newfoundland and Labrador's four Regional Health Authorities and its Departments of Health and Community Services and of Children, Seniors and Social Development. The findings of our synthesis are based on an international search of the literature and may also be applicable to other jurisdictions in Canada and elsewhere but are specifically interpreted for the context of Newfoundland and Labrador. The report includes explanations of research terms and technical language so that there is no need to have a specialized medical or health background in order to understand its content.

# The Research Team

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

### Report Authors:

**Barbara Pesut, PhD, RN**

Professor, School of Nursing,  
University of British Columbia,  
Principal Chair in Palliative and End-of-Life Care  
(Subject Expert)

**Karen Stone**

Deputy Minister,  
Department of Health and Community Services  
Government of Newfoundland and Labrador  
(Health System Leader)

**Stephen Bornstein, PhD,**

Director, NL Centre for Applied Health Research  
(CHRSP Program Director)

**Pablo Navarro**

Senior CHRSP Research Officer,  
NL Centre for Applied Health Research  
(CHRSP Project Coordinator)

**Colin Walsh**

CHRSP Research Officer,  
NL Centre for Applied Health Research

**Wendy Lasisi**

CHRSP Research Assistant,  
NL Centre for Applied Health Research

### Project Team:

**Vanessa Bartlett**

Regional Palliative Care Coordinator,  
Labrador-Grenfell Health

**Sharon Buehler, PhD,**

Honorary Research Professor,  
Division of Community Health and Humanities,  
Faculty of Medicine, Memorial University

**Sandra Farrell**

Regional Manager, Palliative and End-of-Life Care  
Services, Eastern Health

**Shannon Furey**

Grief and Bereavement Consultant,  
Regional Palliative and End-of-Life Care Team,  
Central Health

**Natasha Jarvis**

Regional Director of Community Supports,  
Western Health

**Rosemary Lester**

Chair of the Board of Directors,  
Seniors Resource Centre of Newfoundland  
(Retired)

**Susan MacDonald, MD, CCFP PC FCFP**

Founder, Palliative Medicine, Eastern Health  
Associate Professor of Medicine &  
Family Medicine, Memorial University

**Jennifer Penny**

Project Lead on Palliative Care Review,  
Eastern Health

**Jean Smith**

Clinician in Palliative Care (retired)

**Ruth Wells**

Regional Palliative Care Consultant,  
Central Health

**Gail Wideman, PhD,**

Associate Professor, School of Social Work,  
Memorial University

### External Reviewer:

**Hsien Seow, PhD,**

Associate Professor, Oncology,  
McMaster University,  
Canada Research Chair in Palliative Care,  
Cancer, and Health System Innovation

# Acronyms

|               |  |
|---------------|--|
| <b>AMSTAR</b> | Assessment of Multiple Systematic Reviews                    |
| <b>CADTH</b>  | Canadian Agency for Drugs and Technology in Health           |
| <b>CHRSP</b>  | Contextualized Health Research Synthesis Program             |
| <b>CINAHL</b> | Cumulative Index to Nursing and Allied Health Literature     |
| <b>ERS</b>    | Evidence Rating System                                       |
| <b>HD</b>     | Home Death   |
| <b>HPC</b>    | Home-based Palliative Care                                   |
| <b>NL</b>     | Newfoundland and Labrador                                    |
| <b>NLCAHR</b> | Newfoundland and Labrador Centre for Applied Health Research |
| <b>NNTB</b>   | Number Needed to Treat to Benefit                            |
| <b>PR</b>     | Primary Research   |
| <b>QoL</b>    | Quality of Life  |
| <b>RCT</b>    | Randomized Controlled Trial                                  |
| <b>RHA</b>    | Regional Health Authority                                    |
| <b>SR</b>     | Systematic Review  |

# Glossary

|   |  |
|---|--|
| <b>AMSTAR</b>   | The Assessment of Multiple Systematic Reviews is an 11-item instrument used to assess the methodological rigor of systematic reviews.  |
| <b>Breathlessness/Dyspnea</b>                                   | A sensation of shortness of breath or difficulty breathing   |
| <b>Caregiver</b>  | In the context of this report, a caregiver may be a family member, friend, or paid helper who cares for chronically ill and/or palliative care patients.   |
| <b>Caregiver burden</b>   | The all-encompassing challenges felt by caregivers with respect to their physical and emotional well-being, family relations, work and financial status  |
| <b>Coping</b>   | Caregiver adaptation to stress   |
| <b>End-of-life care</b>   | Care to assist patients who are facing imminent or distant death to have the best quality of life possible until the end of life regardless of medical diagnosis, health condition or age. Palliative care includes end-of-life care, but entails much more (please see palliative care definition below)  |
| <b>Grey literature</b>  | Research that is either unpublished or has been published in non-commercial form. Examples of grey literature include: government reports, policy statements, issue papers, and conference proceedings.  |
| <b>Home palliative care or Home-based palliative care</b>       | Palliative and end-of-life care that is provided in a home setting   |
| <b>Meta-ethnography</b>   | A systematic way of synthesizing qualitative data that involves the identification and translation of key concepts between studies, while considering the context of the data. The result of meta-ethnographical analysis is a reciprocal, refutational and/or lines-of-argument synthesis (1,2)   |
| <b>Overall palliative care outcomes</b>                         | Measurement of patients' physical symptoms, psychological, emotional, and spiritual well-being, and whether care meets needs for information/ supports.  |
| <b>Palliative care</b>  | Not limited to the end of life, this interdisciplinary care focuses on relief of pain and other symptoms and includes physical, psychological, social, and spiritual components to support the best possible quality of life for patients and their families; it attempts to alleviate symptoms without the goal of curing the underlying disease.   |
| <b>Physical function</b>  | A measure of ability to perform activities of daily living   |
| <b>Reinforced home palliative care</b>                          | Palliative care that is provided with the component of caregiver support   |
| <b>Satisfaction with care</b>                                   | Extent to which patients/caregivers are happy with healthcare as a measure of care quality   |
| <b>Sleep disturbances</b>                                       | Disorders of initiating or maintaining sleep   |
| <b>Specialized home palliative care</b>                         | Palliative care that is provided in a home setting by a team of professionals, including doctors and nurses  |
| <b>Symptom burden</b>   | Symptom severity and the patient's perception of the impact of the symptoms  |
| <b>Usual Care (as a control for home-based palliative care)</b> | While the control in research studies on home-based palliative care is often referred to as "usual care," what actually constitutes usual care is often vague or variable across studies. Examples of usual care include: hospital care, hospice care, general medical ward care, primary care services, acute care services, community care, and/or combinations of these and other approaches. Appendix A provides more detail about how the systematic reviews and primary studies included in this report describe usual care. |

# The CHRSP Approach to Health Evidence

**What is Health Evidence?** Health evidence comes in a variety of forms that depend on the methodology of the research and other factors. Researchers may use quantitative (collecting, analyzing and interpreting numerical data), qualitative (collecting, analyzing, and interpreting non-numerical data) or mixed-methods approaches (a combination of quantitative and qualitative). The methodological rigour of a given study will have an impact on the reliability and generalizability of the results.

The most reliable form of health evidence to inform decision making is the systematic review. A systematic review uses systematic and reproducible methods to identify, select and critically appraise numerous primary studies on a given topic. The authors collect and analyse data from the studies that are included in the review to answer a focused research question. CHRSP focuses on this high-level category of health evidence, taking the results from multiple systematic reviews into consideration.

**Locating, Assessing, and Synthesizing Evidence:** CHRSP researchers, working with a health sciences librarian, devise an appropriate search strategy and conduct rigorous electronic and hand searches of periodical indices and databases to locate relevant health evidence which will include high-level research (systematic reviews, meta-analyses, and health technology assessments) and high-quality primary studies that were published too recently to have been included in the review literature. Evidence may also include relevant unpublished literature, government documents, etc. known as "grey literature." Once relevant research materials have been collected, the team critically appraises and summarizes the evidence in terms of its quantity (i.e., we assess whether there is ample evidence on which to base a report) and its quality (i.e., we rate its methodological rigour using validated assessment tools). CHRSP also assesses the strength of the findings using an Evidence Rating System that tells us about the reliability of the body of evidence for a given intervention to produce a given outcome. The results are then synthesized into a series of key findings from the evidence, a phase of the CHRSP project that tells decision makers "what works," according to the published evidence.

**Setting the Evidence in Context:** Once we have assessed what the evidence tells us about "what works," we ask a further question: "Would that work here?" recognizing that local contextual variables must also be considered. Contextual factors may increase or decrease the positive health impacts or cost-effectiveness of an intervention that was reported in the research literature. These variations in effectiveness result from differences between the research settings and local conditions in Newfoundland and Labrador. For instance, interventions that work well in large urban centres with a large number of specialists and other health human resources may not translate well into a rural Newfoundland setting. The CHRSP Project Team tailors its synthesis to the local context at every stage of the project. Contextual considerations may include: patient populations, sites of service and/or the service design, health human resources, organization and delivery of services, health economics, and politics.

**Interpreting the Evidence:** Once the literature has been located, assessed, and synthesized, and contextualized, the CHRSP Project Team will then develop a summary of implications for decision makers to consider when applying the evidence for use 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?”*



## Key Messages from this Report

The following key messages summarize the most relevant findings synthesized in this report and reflect the state of the available research evidence:

1. 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.
2. The research evidence suggests that receiving home-based palliative end-of-life care tends to reduce overall symptom burden for patients.
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.
4. 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, we found no evidence to indicate that patients and their caregivers are worse off when they receive home-based palliative end-of-life care.
5. Limitations in the evidence about the resources that are required to provide effective home-based palliative end-of-life care make it difficult to draw firm conclusions.

## How to Navigate this Report

- The section entitled **Synthesis Findings** provides readers with a comprehensive overview of the scientific evidence examined for this study and provides supporting detail about each of the foregoing key messages.
- Local contextual variables that may have an impact on how decision makers apply the evidence in Newfoundland and Labrador are detailed in this report under the section **The Newfoundland and Labrador Context**.
- The synthesis findings are then considered in light of the contextualization findings to come up with the list of **Considerations for Decision Makers**. Please note that CHRSP prefers to use the

term “considerations” rather than “recommendations” because we recognize that evidence is one of several inputs that health system decision makers may need to contemplate. Ultimately, this report outlines the issues that decision makers may want to *consider* rather than asserting which options they should *choose*.

## Background

The focus of this CHRSP project, home-based palliative end-of-life care, is of interest to health system partners from across Newfoundland and Labrador. This subject was ranked highly enough by all provincial health system partners<sup>1</sup> to be included in the 2020 cycle of CHRSP research projects. The provincial government of Newfoundland and Labrador, in partnership with the Government of Canada is working towards a *Home First* initiative to ensure that more people can access care in their own communities and in their own homes – an initiative that will include palliative care delivered in the home (3).

Research indicates that fewer patients die at home than patients and their families would prefer (4). A key outcome of interest in this report was therefore the *place* of death— in particular, whether or not a patient died at home. Home-based palliative care (HPC) is an intervention that provincial stakeholders believe has the potential to increase the likelihood that a patient will experience a death at home rather than a death in an institutional care setting. In addition to looking at the place of death, our research examined whether HPC might also improve patient and caregiver lives in other ways, including: reducing overall symptom burden and relieving specific symptoms common in palliative care patients; improving quality of life indicators, such as psychological well-being, physical function, and survival; outcomes specific to caregivers, who are often family members and friends; admission to an institution; and death in an institution. While other outcomes were also examined for this report, the evidence base for these was so meagre that we include them only as part of our Outcome Tables.

Provincial stakeholders also asked us what resources would be required for effective home-based palliative care programs. Unfortunately, the limited research on this issue and the many ambiguities in how resource allocation was reported presented a problem. This led us to try to infer the research results in tables that emphasize the professional personnel and services noted in the highest-quality research literature. This analysis did not definitively answer the question posed.

The comparator for home-based palliative care in this study was “usual care.” However, the systematic review literature did not describe usual care with any consistency. Some review authors highlighted the vagueness and variability in defining “usual care,” not only among primary studies but also within individual health systems (5). This lack of specificity posed challenges when comparing home-based

---

<sup>1</sup> Health System partners for CHRSP are: the Government of Newfoundland and Labrador’s Departments of Health and Community Services and of Children, Seniors and Social Development, and the four Regional Health Authorities: Eastern Health, Central Health, Western Health and Labrador-Grenfell Health.

palliative end-of-life care to other care approaches, an issue that is further elaborated in Appendix A of this report.

To carry out this study, CHRSP assembled a multi-disciplinary project team that included research staff at NLCAHR; a Subject Matter Expert, Barbara Pesut, PhD, RN, Research Chair in Palliative and End-of-Life Care at the University of British Columbia; a Health System Leader, Karen Stone, Deputy Minister of Health and Community Services in Newfoundland and Labrador; and representatives from all four NL Regional Health Authorities: Eastern Health, Central Health, Western Health, and Labrador-Grenfell Health. In addition, the project team included researchers from Memorial University and representatives from the Government of Newfoundland and Labrador's Departments of Children, Seniors, and Social Development, and of Health and Community Services. Patient and caregiver advisers and other community stakeholders also assisted with the contextualization of the synthesis findings.

In collaboration with this project team, we established the focus and the parameters of the project, including the populations, interventions, and outcomes that would be eligible for inclusion. The project team agreed that the following research question would guide this study:

***“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?”***

This *Evidence in Context* report details the results of this research, briefly describing the CHRSP methodology, providing a summary of search results, a knowledge synthesis, a contextual analysis of the evidence, and a series of considerations for provincial decision makers to think about when assessing the research evidence about home-based palliative care within the Newfoundland and Labrador context.

## Methodology

### What evidence did we look for?

We developed several search strategies for this report, in collaboration with a librarian at Memorial University Libraries and with our Subject Matter Expert, to identify the relevant research literature on this topic. Our search parameters are detailed in the [Online Companion Document](#) to this report. Our search extended to several periodical indices: PubMed, CINAHL, and Embase, to additional referrals (e.g., Google Scholar or periodical index “related articles,”), as well as including a search for grey literature from the Grey Matters list of the Canadian Agency for Drugs and Technology in Health (CADTH). To be eligible for inclusion in this synthesis, evidence had to be published in English and to:

- be a systematic review or a meta-analysis covering at least two studies and 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;

- include 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.

## The CHRSP Evidence Rating System

The CHRSP Evidence Rating System assesses the *strength* of the combined body of evidence that a particular intervention favours, does not favour, or indicates no benefit in terms of achieving a given outcome for a defined population. The strength of the body of evidence increases with:

- the *quality* of the systematic reviews included in the analysis;
- the *number* of unique primary research studies included within the reviews; and
- the *consistency* of the findings.

### Assessing Quality

We use the AMSTAR instrument to appraise the methodological *quality* of systematic reviews and to categorize systematic reviews in terms of their methodological quality:

- an AMSTAR Score of 0 to 3 indicates Low Quality;
- a score of 4 to 7 indicates Moderate Quality; and
- a score of 8 to 11 indicates High Quality (6).

### Assessing Number of Studies and their Consistency

The table below outlines the thresholds for the number of reviews and included primary studies required to determine the strength of the body of evidence. It is notable that largely inconsistent findings, regardless of the number and quality of systematic reviews, are interpreted as a “Very Weak” body of evidence by default.

| Strength of the Body of Evidence | # of Systematic Reviews                         | # of Primary Studies included in the Systematic Review(s) |
|----------------------------------|---|---|
| Strong                           | 2 or more High Quality Systematic Reviews       | 10+   |
| Moderate                         | 1 or more High Quality Systematic Reviews       | 10+   |
| Weak                             | 1 or more High Quality Systematic Reviews       | 5+  |
| Very Weak                        | 1 review with moderate or inconsistent findings | 1-4   |

Table 1: CHRSP Evidence Rating System: Thresholds for determining the strength of a body of evidence

### Considering the Impact of an Intervention on an Outcome

The CHRSP Evidence Rating System also considers whether the body of evidence favors the intervention (i.e., the evidence indicates that the intervention works effectively enough to consider implementing it); indicates no benefit when the intervention is compared to the control (i.e., the intervention is no better than usual care); or is unable to indicate whether the intervention achieves better outcomes than the control (i.e., the report authors cannot draw any conclusions because there is a lack of evidence or there is conflicting evidence).

## Evidence included in this report

This report synthesizes the results of six systematic reviews and six primary studies. 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 assessment tool. We also found five studies that were rated as being of such “Low Quality” as to be excluded from our synthesis. Two reviewers carried out the AMSTAR quality appraisal independently and the inter-rater reliability was 0.95 which is considered to be high. The table below summarizes our appraisal of the systematic review evidence considered for this synthesis.

| Methodological Quality      | Systematic Review                    | AMSTAR Score |
|-----------------------------|--------------------------------------|--------------|
| High Quality (included)     | Cochrane Review by Gomes 2013 (4)    | 90.91        |
|                             | Cochrane Review by Shepperd 2016 (7) | 72.73        |
| Moderate Quality (included) | Costa 2016 (8)                       | 45.45        |
|                             | Luckett 2013 (5)                     | 54.55        |
|                             | Miranda 2019 (9)                     | 63.64        |
|                             | Sarmento 2016 (2)                    | 54.55        |
| Low Quality (excluded)      | Candy 2011 (10)                      | 36.36        |
|                             | Davis 2015 (11)                      | 9.09         |
|                             | Diop 2017 (12)                       | 27.27        |
|                             | Nordly 2016 (13)                     | 18.18        |
|                             | Wahid 2018 (14)                      | 36.36        |

Table 2: Critical appraisal results to determine quality of systematic review evidence

We also located six primary studies that were published too recently to be included in any of the systematic reviews listed above. The findings from these primary studies are included in the appropriate sections of this report and are summarized in the table below. To appraise the quality of included primary studies, we used the quality assessment tool developed by Downs & Black (15) which applies the following scale:

- a score of 26 to 28 is deemed to be *excellent*;
- a score of 20 to 25 is deemed to be *good*;
- a score of 15 to 19 is deemed to be *fair*; and
- a score of less than 14 is deemed to be *poor*.

| Methodological Quality | Primary Study         | Downs & Black Score |
|------------------------|-----------------------|---------------------|
| Good Quality           | Abe 2019 (16)         | 24                  |
|                        | Tanuseputro 2018 (17) | 24                  |
|                        | Wang 2019 (18)        | 21                  |
|                        | Kjellstadli 2018 (19) | 20                  |
| Fair Quality           | Nagaviroj 2017 (20)   | 19                  |
|                        | Tan 2019 (21)         | 19                  |

Table 3: Critical appraisal results to determine quality of evidence from primary studies

# Synthesis Findings

## Home-based palliative care and the likelihood of a death at home

A strong body of evidence indicates that, when compared to patients receiving usual care, patients receiving Home-based Palliative Care (HPC) had an improved likelihood of dying at home. Despite a slight disagreement among the systematic reviews, the body of evidence on the outcome of a home death was considered to be strong. Primary research published too recently to be included in systematic reviews also indicates that HPC increases the probability of dying at home. Some systematic reviews also reported on place of death, indicating whether the patient died in an institution. Although the evidence for this outcome was not as plentiful and there was some disagreement among report authors, there was some indication that HPC decreases the likelihood of dying in an institution such as a hospital or nursing home.

The highest quality review in this synthesis, a Cochrane Review completed by Gomes et al., was a meta-analysis of seven trials with 1,222 patients. This review reported that the likelihood of dying at home more than doubled for HPC patients with illnesses such as cancer, congestive heart failure, or chronic obstructive pulmonary disease (OR 2.21, 95% CI 1.31 to 3.71;  $Z = 2.98$ ,  $P$  value = 0.003;  $\text{Chi}^2 = 20.57$ , degrees of freedom (df) = 6,  $P$  value = 0.002;  $I^2 = 71\%$ ; (4). However, a moderate-quality systematic review by Luckett et al. found the evidence to be inconclusive (5). Both of these systematic reviews noted that including only high-quality primary research resulted in losing statistical significance while still maintaining the direction of effect (4,5). It is noteworthy that systematic reviews by Shepperd et al. and Costa et al. also reported an increased likelihood that HPC patients would die at home (7,8).

Gomes et al., also included data on Number Needed to Treat to Benefit (NNTB) (4). The authors indicated that for every five new patients receiving HPC, one would die at home. For cancer patients specifically, the NNTB was six patients. Gomes and colleagues also note that these NNTB scores are clinically significant, comparing them to other findings in the medical literature such as the benefits of gabapentin for treating neuropathic pain<sup>2</sup> (4). However, Gomes et al. also state that the primary studies included in their review were marred by the degree of variation in the controls and that this heterogeneity increases the difficulty of aggregating data across studies. (Appendix A elaborates on the issue of variation in the definition of “usual care.”)

Another high-quality Cochrane Review by Shepperd et al. combined data from four studies and also found that HPC recipients were more likely to die at home when compared to patients receiving usual care (7). A moderate-quality meta-analysis by Luckett et al. found that the likelihood of a home death increased when patients received HPC in the form of home nursing (5). However, when the analysis is limited to high-quality primary studies only, this data lost statistical significance; accordingly, the synthesized evidence was deemed to be inconclusive (5). A moderate-quality systematic review and meta-analysis conducted by Costa et al. examined the determinants of home death in adult patients (8).

---

<sup>2</sup> For gabapentin users, the NNTB is 6 for achieving at least 30% pain relief; the NNTB is 7 for achieving at least 50% pain relief.

This analysis indicated that patients receiving nurse and physician home visits and/or multidisciplinary HPC had a greater likelihood of a home death when compared to patients receiving only usual care.

### Home-based palliative care and the place of death

We also examined the effect of receiving HPC on the likelihood of dying in an institution. All six primary studies included in the Cochrane Review by Gomes et al. found that patients receiving HPC were less likely to die in hospital than those receiving usual care. However, when considering only the four included randomized controlled trials (RCT), significance was lost (4). Gomes et al. also found that HPC patients had a lower probability of dying in nursing homes; however differences in the pooled data did not reach statistical significance.

| Outcome                 | Strength of body of evidence | Finding         |
|-------------------------|------------------------------|-----------------|
| Death at home           | Strong                       | Positive effect |
| Death in an institution | Weak                         | Positive effect |

Table 4: Effect of HPC on place of death

We also examined primary research articles published too recently to be included in the systematic reviews in this report. For the outcome of place of death, these studies have similar findings as those in the reviews noted above, with HPC being found to increase the likelihood of a death at home.

| Author                                | Location/<br>Population/Year              | Intervention                              | Comparator                                     | Outcome (Place of death)   |
|---------------------------------------|---|---|--|--|
| Abe et al. 2019 (16)                  | Japan<br>Adults ≥ 65 years                | Homecare (Non-medical professional)       | No homecare                                    | Homecare 1, 2, 3 months prior to death increased home death by 9.5%, 10.9%, 11.9%, respectively                      |
| Kjellstadli et al. 2018 (19)          | Norway<br>Age not specified<br>2012 -2013 | Domiciliary care                          | No Domiciliary care                            | Home death > dying in nursing home or hospital   |
| Tan et al. 2019 (21)                  | Singapore<br>Adults ≥ 21 years            | HPC                                       | No HPC   | HPC and home death preference related to more home deaths  |
| Wang et al. 2019 (18)                 | Southern California<br>Adults ≥ 65 years  | HPC (Kaiser Permanente program)           | No HPC, or hospice only                        | HPC and hospice only had similar home death rates  |
| Nagaviroj & Anothaisintawee 2017 (20) | Thailand<br>Ages 19-66<br>2012 - 2014     | Multi-disciplinary HPC                    | No HPC   | Strong association between multidisciplinary HPC and home death  |
| Tanuseputro et al. 2018 (17)          | Ontario<br>Age not specified              | Palliative care and physician home visits | Rate of palliative care /physician home visits | More community support reduced hospital deaths/ More physician home visits increased the likelihood of a home death. |

Table 5: Place of death outcomes from primary studies included in this report



## 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.**



## Home-based palliative care and symptom burden

When patients are ill, the severity of their symptoms and their perception of the impact of these symptoms are known as “symptom burden.” The systematic reviews in this synthesis suggest that HPC tends to reduce symptom burden for palliative care patients. Additionally, competent HPC teams can also provide patients with an increased sense of security. While our Evidence Rating System assessed the body of evidence for the outcome of symptom burden as being weak, the three systematic reviews (one high-quality review and two moderate-quality reviews) that examined this outcome all found the same positive direction of effect. If we single out the symptom of pain specifically, a moderate number of studies indicated that there is no difference between HPC and usual care on alleviating this symptom. Unfortunately, we were not able to locate sufficient evidence that assessed the impact of HPC on other symptoms of illness.

*When patients are ill, the severity of their symptoms and their perception of the impact of these symptoms are known as “symptom burden.” The systematic reviews in this synthesis suggest that HPC tends to reduce symptom burden for palliative care patients.*

The high-quality Cochrane Review by Gomes et al. found strong evidence suggesting that HPC reduced overall symptom burden for patients (4). A systematic review by Miranda et al. looked at dementia patients receiving HPC that included dementia-specific interventions; these authors also found a reduction of symptom burden as compared to usual care (9).

Gomes and colleagues found that it was not possible to conduct a meta-analysis for symptom burden because included studies used different measures of symptom burden and different methods for reporting their results (4). However, these authors provide an explanation of the specific findings from the primary studies under review. Three of the primary studies, including one

deemed to be of high quality, had statistically significant findings that HPC relieved symptoms more effectively than usual care while another high-quality study found the same outcome but with only marginal statistical significance. However, Gomes et al. note that the effect sizes were small (ranging from .08 difference in mean scores on a 0-7 scale to a difference of 2.1 on a 0-20 scale). They also found two randomized control trials that reported a decrease in symptom burden in groups receiving HPC and increase in symptom burden in control groups receiving usual care.

A moderate-quality systematic review by Miranda et al. focused on dementia patients and found that HPC was effective in reducing symptoms when compared to usual care (9). This review looked at four randomized control trials (three of moderate quality and one of weak quality) and reported conflicting findings on the duration of effects: one study showed long-term positive effects (of the Comprehensive, Individualised, Person-Centered Management approach), while others found that symptoms worsened after the sessions stopped (Multi-Sensory Stimulation sessions). This finding suggests that future



research should consider not only the extent of the effects of interventions on symptom burden but also the duration of these effects.

In addition to looking at the outcome of overall symptom burden, we also examined evidence for the impact of HPC on specific symptoms such as pain, breathlessness, sleep disturbances, nausea/vomiting, constipation, and diarrhea. Gomes et al. examined patients receiving HPC and found a moderate body of evidence on this symptom but no significant difference in the experience of pain between HPC recipients and those receiving usual care (4). Other symptom outcomes had weak bodies of evidence and a general finding of no difference between HPC and usual care, as outlined in Table 6 below.

| Outcome                 | Strength of body of evidence | Finding         |
|-------------------------|------------------------------|-----------------|
| Overall symptom burden* | Weak                         | Positive effect |
| Pain                    | Moderate                     | No difference   |
| Breathlessness          | Weak                         | No difference   |
| Sleep disturbances      | Weak                         | No difference   |
| Nausea/vomiting         | Weak                         | No difference   |
| Constipation            | Weak                         | No difference   |
| Diarrhea                | Weak                         | No difference   |

Table 6: Impact of HPC on all symptom outcomes included in this report

**\*Note:** For the effect of HPC on the outcome of overall symptom burden, the reviews were inconsistent—moderate-quality reviews reported stronger evidence for HPC's effectiveness than high-quality reviews

## 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.**



## Home-based palliative care: team competency

Examining HPC patient experiences and the issue of team competency, a meta-ethnography<sup>3</sup> by Sarmento et al. notes the importance of HPC teams being perceived as competent and how this perception can provide patients with a sense of security and trust that can help to alleviate symptom burden (2). Sarmento and colleagues characterized care teams as being competent when patients perceived HPC teams as being able to effectively manage patient symptoms and to communicate with patients skillfully (2). These authors used qualitative evidence to explore key components of care that shape the experiences of patients and found that, when patients and caregivers had access to a home-based palliative care team that the patient and their caregivers considered to be competent, they also reported that the team provided effective physical and psychological symptom control. This led patients to trust that the team would continue to help with this symptom control in the future and gave them an increased sense of security. Some specific competencies emphasized in this study included:

<sup>3</sup> A meta-ethnography is a systematic way of synthesizing qualitative data. It involves the identification and translation of key concepts between studies, while considering the context of the data. The results of a meta-ethnographical analysis is what Sarmento et al. describe as “a reciprocal, refutational and/or lines-of-argument synthesis.” (2)

- effective communication skills;
- competence as practitioners;
- competence in effectively controlling symptoms (mainly pain, insomnia, and loss of appetite);
- accessible and available service provision;
- access to respite; and
- home visits.

While the qualitative nature of this research makes it harder to connect outcomes directly to interventions, the researchers highlight the importance of having competent professionals available for patients and caregivers in the home. They note that the sense of security provided by these teams helped patients and caregivers continue to live their lives while preparing for death.

### 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.**



### Home-based palliative care and admission to an institution

We also looked at how receiving HPC might affect a patient's likelihood of being admitted to an institution, such as a hospital or other healthcare facility. Here, it is important to distinguish that *admission* to an institution is not the same thing as our previously-reported outcome of death in an institution. Death will not necessarily occur while a patient is in institutional care. The evidence for the impact of HPC on institutional admissions was inconsistent. The moderate-quality systematic review by Miranda and colleagues found evidence from two low-quality primary studies suggesting that patients with dementia who were provided with HPC were more likely than the control group to remain at home (i.e., to avoid being admitted to an institution) (9). However, Gomes et al. reviewed 12 primary studies and found no difference in the rate of institutional admissions between the HPC intervention group and the control group. While some of the primary research reported statistically-significant reductions in admissions, Gomes et al. found that these results disappeared with more in-depth statistical analysis (4).

A recent primary study by Wang and colleagues performed a retrospective cohort study in a large integrated health system in Southern California (18). This study included decedents (persons who had died) who had died at 65 years of age or older, had at least one hospitalization in the 12 months before death, and were enrolled in the Kaiser Permanente HPC program. This program required participants to have an estimated life expectancy of 12 months or less, meet Medicare guidelines, and be homebound.

The patients receiving HPC were compared with two cohorts:

1. the first comparison cohort included patients who were enrolled in hospice before death but who did not receive home-based palliative care (the group was labeled "hospice only");
2. the second comparison cohort included decedents who received neither HPC nor hospice before they died (the group was labeled "no HPC/no hospice").

Wang and colleagues then compared longevity within these cohorts, further dividing the groups into subgroups, those who survived at least 30 days and those who survived at least 180 days. For patients who survived at least 30 days and for those who survived at least 180 days, risk of hospitalization was lower for HPC patients than for both the “hospice only” and the “no HPC/no hospice” patients.

Table 7 below summarizes the findings for a variety of outcomes related to institutional admissions.

| Outcome                          | Strength of body of evidence | Finding       |
|----------------------------------|------------------------------|---------------|
| Institutional admission*         | Moderate                     | No difference |
| Emergency department use         | Weak                         | No difference |
| Intensive care unit use          | Weak                         | No difference |
| Outpatient clinic visits         | Weak                         | No difference |
| Overall palliative care outcomes | Weak                         | No difference |
| Satisfaction with care           | Weak                         | No difference |

Table 7: Effect of HPC on institutional outcomes

\* **Note:** there was disagreement between high and moderate quality systematic reviews about the effect of HPC on institutional admission rates

## Home-based palliative care, quality of life, and related outcomes

On the question of whether HPC improves quality of life and its associated measures including psychological well-being, physical function, and survival, moderate-quality evidence indicated that there was no difference between the HPC intervention groups and groups receiving usual care. The weak body of evidence for spiritual well-being, social well-being and general health also showed no difference among groups receiving HPC versus usual care. The evidence for quality of life outcomes presented by Gomes et al. was of moderate strength, but indicated conflicting findings among the primary studies under review. The authors concluded that there was no statistical difference between patients who received the HPC intervention and the control groups. Gomes et al. refer to a paper by Zimmermann that also found little evidence of significant positive effects of HPC on quality of life, noting the limitations common in palliative care research, including a lack of study power and the difficulty in comparing non-specific outcome measures (4,22).

| Outcome                  | Strength of body of evidence | Finding       |
|--------------------------|------------------------------|---------------|
| Quality of life          | Moderate                     | No difference |
| Survival                 | Moderate                     | No difference |
| Psychological well-being | Moderate                     | No difference |
| Physical function        | Moderate                     | No difference |
| Spiritual well-being     | Weak                         | No difference |
| Social well-being        | Weak                         | No difference |
| General health           | Weak                         | No difference |

Table 8: Effect of HPC on quality of life and related outcomes

## Home-based palliative care and caregiver outcomes

Caregiver burden is a term that describes the all-encompassing challenges felt by caregivers with respect to their physical and emotional well-being, family relations, work and financial status. Conflicting findings in the research evidence about caregiver outcomes indicate that the evidence for HPC having a positive impact on caregiver burden is decidedly inconclusive. A moderate-quality meta-ethnography by Sarmento et al. reported evidence for a positive effect while a high-quality Cochrane Review by Gomes et al. reported no difference in caregiver burden when patients received HPC versus usual care (2,4). Although Gomes et al. reviewed fewer primary studies than Sarmento, its superior AMSTAR rating (Gomes-90.91 vs. Sarmento-54.55) and methodological rigour make its analysis more persuasive. Sarmento and colleagues found many reports that HPC services provided to patients helped to reduce the workload of informal caregivers and relieved them of some responsibility (2). They highlight the sense of security felt by caregivers. However, some of the primary studies in their review also noted that the respite provided by HPC workers was not universally appreciated by the caregivers, some of whom did not like leaving their loved ones in another's care.

Gomes et al. found conflicting results on the impact of HPC on caregiver burden. One study in this review noted a difference in burden only up to the 12-week follow-up, while another study found no difference at all, even when examining caregiver burden from one to 10 months after enrollment. The only study that found a significant difference was published in 1986 by Greer et al. who noted that the effect size was small (4,23).

One recently-published primary study noted that a key limitation in researching caregiver burden is that researchers are generally not granted easy access to caregiver participants and often have to rely on less than rigorously-selected samples (17). In contrast, palliative care patients (who were the primary research participants examined in the other sections of this report) were mostly studied using retrospective methods with national and/or hospital databases (4,5,8,9). Costa and colleagues even remark that “one of the limitations inherent to this literature is the reliance on observational and often retrospective studies,” when dealing with caregivers (8). In addition, caregiving in palliative care is very often informal, with caregivers being friends and family members whose data are not likely to be recorded in large national or hospital databases.

| Outcome                  | Strength of body of evidence | Finding       |
|--------------------------|------------------------------|---------------|
| Caregiver burden*        | Weak                         | No difference |
| General health           | Weak                         | No difference |
| Physical function        | Weak                         | No difference |
| Pain                     | Weak                         | No difference |
| Psychological well-being | Weak                         | No difference |
| Social well-being        | Weak                         | No difference |

Table 9: Effect of HPC on caregiver outcomes

\* **Note:** Moderate quality systematic reviews report stronger evidence on caregiver burden than high quality systematic reviews and there is general disagreement between high and moderate quality reviews.

## Key Message #4

**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, we found *no evidence* to indicate that patients and their caregivers are worse off when they receive home-based palliative end-of-life care.**



## Resources required for effective home-based palliative care

When attempting to locate evidence about HPC resource requirements, multiple challenges arose: a lack of reporting on HPC resources in the literature, vagueness in reporting, non-standardized terminology in describing HPC resources, and changes over time in approaches to utilizing HPC resources (e.g., changes in standard palliative care practices, modifications in the care approaches and duties of the health professionals such as nurses or social workers). These limitations in the research evidence made it difficult to draw firm conclusions about the resources (personnel, service models) required to provide effective home-based palliative care. In an effort to provide decision makers with some information about this important topic, we have counted the instances where specific resources are mentioned in the highest-quality research literature. Although this approach cannot tell us definitively what resources are recommended for effective HPC; it will at least provide some indication of the professional personnel and services reported in the literature.

*... limitations in the research evidence made it difficult to draw firm conclusions about the resources (personnel, service models) required to provide effective home-based palliative care. In an effort to provide decision makers with some information about this important topic, we have counted the instances where specific resources are mentioned in the highest-quality research literature.*

### Creating the Data Tables

Ideally, we would have liked to examine how HPC team composition or how particular services might affect patient outcomes. However, doing so would require the careful extraction of the data from all primary studies within each included systematic review to ascertain whether the research referred to resource allocation, whether resource differences were noted, and whether each study reported on the impact of a given resource on a given outcomes, an exercise beyond the scope of this study.

Instead, we produced two tables with the extracted data from fifteen relevant primary studies reviewed in the two highest-quality systematic reviews in this synthesis, namely the two Cochrane Review (Gomes et al. and Shepperd et al.) (4,7). These reviews were not selected solely on the basis of their quality but also because the authors included extensive descriptions of the included interventions and outcomes. To determine the relevance of these included primary studies, we searched for two major outcomes: home death and symptom burden, while also including primary studies that tested for at least four minor outcomes (only Aiken et al. 2006 met this latter criterion) (23). Because the review by Gomes et

al. reviewed all of the primary studies included in Shepperd et al., we assessed the quality of the primary studies by using the quality rating reported by Gomes et al.

Table 10 reports on the professions providing HPC. Table 11 reports on the services included in HPC care approaches. While these tables may *suggest* possible correlations between resources and effective care, they are limited in what they can tell us. Unfortunately, they say nothing about the numbers of personnel involved, the roles they played, or how included interventions compared to their controls.

### How to read the tables

- The tables below indicate the methodological quality of primary studies moving from left to right (from the highest quality to the lowest quality).
- The number of times that an included resource appeared in the literature (a count out of 15) was used to organize the list of resources from top to bottom, from the highest count to the lowest count
- To report on the frequency of resource inclusion, we used two benchmarks:
  - resources mentioned 'very frequently' were found in 11+ studies and are indicated by dark blue shading
  - resources mentioned 'somewhat frequently' were found in 7-10 studies and are indicated by light blue shading

| Professionals Providing HPC | Count/15 | Article Reference                |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
|-----------------------------|----------|----------------------------------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|
|                             |          | Methodological Quality* (0-1.00) |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
|                             |          | 0.67                             | 0.58 | 0.58 | 0.58 | 0.58 | 0.58 | 0.58 | 0.58 | 0.50 | 0.50 | 0.42 | 0.42 | 0.42 | 0.33 | 0.25 |
| Nurse                       | 14       | x                                | x    | x    |      | x    | x    | x    | x    | x    | x    | x    | x    | x    | x    | x    |
| Medical Professional**      | 10       | x                                | x    | x    |      | x    | x    |      | x    | x    |      | x    |      |      | x    | x    |
| Social Worker               | 8        | x                                |      | x    |      | x    | x    | x    |      | x    |      |      |      |      | x    | x    |
| Allied Health Professional  | 6        | x                                |      | x    |      | x    | x    |      |      |      |      |      |      | x    |      | x    |
| Psychological Professional  | 3        | x                                |      | x    |      |      | x    |      |      |      |      |      |      |      |      |      |

Table 10: Professionals Providing HPC

\*Methodological Quality rated from 0 to 1.00 according to Gomes et al. 2013 (4)

\*\*May be a physician, oncologist, pharmacist, or surgeon

### Professionals Providing HPC: An overview of Table 10

With regard to the professions involved in HPC, as noted in Table 10 above, nursing is the only profession mentioned by fourteen of the fifteen of the primary studies. The only article that did not

mention nursing was Greer et al. from 1986 (23); however, readers are cautioned that the authors of that study provided little information on the composition of the HPC team at all, except to note that it was “interdisciplinary” and so we might surmise that nurses may well have been included in that study, too. While the primary studies did not specify the types of nurses involved (e.g., NP, RN, LPN) the authors did indicate that nurses on the HPC teams were either trained or experienced in areas related to palliative care, including:

- specialty training in palliative care (26,28,31),
- experience in providing cancer care (25,32–34),
- training in pain relief and symptom control (33,34), and
- experience/ training in geriatric nursing (36).

In terms of other health human resources, medical professionals (such as physicians, oncologists, pharmacists, and surgeons) and social workers were included somewhat frequently in the literature about HPC teams.

|                                   |          | McKegney 1981 (25)                                   | Bakitas 2009 (26) | Brumley 2007 (27) | Greer 1986 (23) | Jordhøy 2000 (28) | Rabow 2004 (29) | Ward 1987 (30) | Higginson 2009 (31) | Aiken 2006 (24) | Grande 1999 (32) | Axelsson 1998 (33) | McCorkle 1989 (34) | McMillan 2007 (35) | Zimmer 1985 (36) | Ahlner-Elmqvist 2008 (37) |
|-----------------------------------|----------|--|-------------------|-------------------|-----------------|-------------------|-----------------|----------------|---------------------|-----------------|------------------|--------------------|--------------------|--------------------|------------------|---------------------------|
| Services Included in HPC          | Count/15 | Article Reference   Methodological Quality* (0-1.00) |                   |                   |                 |                   |                 |                |                     |                 |                  |                    |                    |                    |                  |                           |
|                                   |          | 0.67   | 0.58              | 0.58              | 0.58            | 0.58              | 0.58            | 0.58           | 0.58                | 0.50            | 0.50             | 0.42               | 0.42               | 0.42               | 0.33             | 0.25                      |
| Educating patients and caregivers | 12       | x  | x                 | x                 | x               | x                 | x               | x              | x                   | x               |                  |                    | x                  | x                  | x                |                           |
| Psychosocial services             | 12       | x  | x                 | x                 | x               |                   | x               | x              | x                   | x               |                  |                    | x                  | x                  | x                | x                         |
| Symptom and disease treatment     | 11       | x  | x                 | x                 | x               |                   | x               | x              | x                   | x               |                  |                    | x                  | x                  |                  | x                         |
| Telehealth                        | 9        |  | x                 |                   |                 | x                 | x               | x              | x                   | x               |                  | x                  |                    | x                  | x                |                           |
| Assessments                       | 9        | x  | x                 | x                 |                 |                   | x               | x              | x                   |                 |                  | x                  | x                  |                    | x                |                           |

Table 11: Service Included in HPC

\*Methodological Quality (0-1.00) was taken from Gomes et al. 2013 (4)

### Services Included in HPC: An overview of Table 11

Table 11 outlines the HPC services included in the primary studies reviewed by Gomes et al. and Sheppard et al. (4,7). Education for patients and caregivers, psychosocial services, and services to support symptom/disease treatment were all very frequently mentioned, while medical/technical support, telehealth, and assessment services were mentioned somewhat less frequently. Twelve of 15 primary studies mentioned that educating patients and caregivers was included in their care—this included a variety of educational services such as self-care advice, financial advice, and education about appropriate relaxation exercises. Psychosocial services were also included in 12 of the 15 primary



studies, including a number of support services such as emotional, psychological, social, spiritual, and bereavement supports, support groups, counselling services and access to audiotaped reflections. The category of symptom management and treatment of illness appeared in 11 of the 15 primary studies. When mentioned in the literature, such services were either described as the “treatment of symptoms” or as “maintaining palliative care interventions without foregoing disease treatment.” This particular resource— the treatment of symptoms— directly relates to the outcome of symptom burden.

Although not specifically described as “telehealth services” some form of tele-communication with patients and caregivers was mentioned in 9 of the 15 primary studies. We considered references to terms such as telephone access for questions, and follow-up calls as being included in the telehealth category. Lastly, patient assessments, most notably, initial needs assessments, were mentioned in 9 of the 15 primary studies.

### **Resources for HPC: Components of successful palliative care**

The tables above highlight the importance of nurses, educating patients and caregivers, psychosocial services, and symptom/disease treatment in providing home-based palliative care at the end of life. While these particular resources are mentioned most frequently in the literature, the other services and professions included within the tables are notable features of the care models included in many of the primary studies. While the lists of professions and services provide a number of examples, they are not exhaustive. Ultimately, these tables demonstrate the importance of interdisciplinary teams in palliative care, a point that is corroborated in other sources, including the World Health Organization (38), and the Canadian Institute for Health Information (39).

Other research that was excluded in our synthesis for failing to meet the specific inclusion criteria for this report, published within the last five years, examines common components of successful palliative care programs. A review of systematic reviews by Bainbridge et al. found the six most common components to be:

- a linkage with acute care services;
- a multidisciplinary care approach;
- end-of-life expertise and training for professionals involved in care;
- a holistic approach to care;
- pain and symptom management; and
- professional psychosocial supports. (40)

Of these components, all but holistic care and a linkage with acute care services are mentioned in the studies analyzed in the tables above.

### **Key Message #5**

**Limitations in the evidence about the resources that are required to provide effective home-based palliative end-of-life care make it difficult to draw firm conclusions.**





# The Newfoundland & Labrador Context



Throughout the course of this project, we have tried to identify contextual factors specific to Newfoundland & Labrador that may influence the relevance and applicability of the research-based evidence for our province and its population. This section of the report addresses these “contextual factors” and is based primarily on consultations with local decision makers, administrators, clinicians, and stakeholder group representatives from across the province.

## Our Approach to Contextualization

When we refer to “contextual factors” in this report, we mean the local conditions, capacities, and qualities that can have an impact on the reported effects of the included research evidence. Contextual factors have the potential to enhance or to reduce the likely effectiveness, feasibility or acceptability of an intervention when applied in Newfoundland & Labrador. Our Research Team helped us to recruit contextual advisors from across the province. CHRSP staff spoke with, and requested information from, project team members, physicians, patients and caregivers, spiritual care providers, psychosocial professionals, and other key informants to identify contextual factors relevant to this project. Interviews were confidential and anonymous. This section of the report outlines the contextual factors that we

considered, and the issues that were raised in our discussions with these contextual advisors. A complete list of the questions we asked can be found in Appendix B.

*Our expert and stakeholder consultants agreed with the evidence— home-based palliative care can be as effective as, or even more effective than, institutional palliative care; however, they insisted that home-based approaches would only succeed here in NL if the quality of such services was sufficiently high.*

Our expert and stakeholder consultants agreed with the evidence— home-based palliative care (HPC) can be as effective as, or even more effective than, institutional palliative care; however, they insisted that home-based approaches would only succeed here in NL if the *quality* of such services was sufficiently high. Our consultants identified several opportunities for improvement in terms of service quality and delivery and they made some suggestions for the further development of home-based palliative end-of-life care in the province. Our consultants highlighted that effective HPC will need to be part of a continuum of care that also includes institutional palliative care, the delivery of which also faces a variety of challenges in this province. We will first review our consultants’ comments about HPC in NL and will

then review what they told us about the province’s palliative and end-of-life care programs more broadly.

## Home-based Palliative Care in the Newfoundland & Labrador Context

The provincial government of Newfoundland and Labrador, in partnership with the federal government, is implementing a *Home First* initiative in an effort to ensure that more people can access care in their own communities and in their own homes (3). This initiative will include palliative care delivered in the

home. In our discussions with provincial consultants about implementing HPC in this province, the following key contextual factors were indicated.

### Human Resource Factors

**Home Support Access:** Newfoundland & Labrador's widely-dispersed population and the comparatively

*Our consultants suggested that the availability of adequately trained and compensated homecare workers was an issue. Compounding this difficulty is the issue of access to subsidized home support hours at the end of life.*

large number of people who live in rural locations can create significant challenges for people hoping to access home-based palliative care (HPC) across the province. Our consultants suggested that the availability of adequately trained and compensated homecare workers was an issue and that, compounding this difficulty is the added issue of access to subsidized home support hours at the end of life. Our consultants noted the need for clear information to the public about the rules and procedures to accessing subsidized end-of-life home support and noted that there are some limitations on the number of subsidized home support hours, in general, and on those that can only be used in the final 30-60 days of life. Specific information about home support hours at the end of life was often unclear and there appears to be some variation across the Regional Health Authorities (41). For example, in Central Health, 300 paid hours of home support are available at the end of life with the possibility of extending these hours based on client and family needs. (42). Labrador-Grenfell Health's website says that it offers,

"the provision of home supports under the end-of- life program for the last 28 days" without specifying the number of available hours (43).

Issues with access to home support services are not limited to rural areas of the province. A lack of public or publicly-subsidized transportation can also limit access to home support for patients in urban locations. For example, consultants from Eastern Health discussed access issues for homecare services in places quite close to St. John's because some of the neighbouring regions may lack bus routes. This situation can result in challenges for homecare workers travelling to and from their clients' homes (44).

**Access to Physicians:** According to our consultants, it can be quite difficult for patients to access physician services in the evenings and on weekends since many family physicians work only 8:00am to 5:00pm, Monday to Friday. As a result, HPC patients with urgent health problems often need to travel to the emergency department of a local (or not-so-local) hospital. Resorting to emergency departments at end-of-life creates a number of disadvantages for patients and their families, including costly and uncomfortable travel, lengthy wait times, reliance on health professionals who may lack training in palliative care, and the confusion or delirium that can result from the noise and stimulation that are frequent features of hospitals and emergency departments. We know that when patients receive care from physicians in their homes, they have fewer stays in hospital, fewer visits to emergency departments, and are more likely to die at home (45).

Home-based palliative care often requires significantly more after-hours service than other homecare service models (46). Our consultants pointed out that a more proactive approach to palliative care (such as earlier referral and advanced care planning) can help prevent and alleviate many after-hours emergencies. Our consultants also pointed to the work of palliative care consultants and community health nurses in parts of the province who proactively plan and implement interventions for symptom management, including obtaining orders, obtaining medications and teaching patients and their caregivers about symptom management. The need for this more proactive approach is not solely related to home-based care and is also examined in the section below on palliative care services in general (i.e., in institutional care settings).

### **Alternative Approaches to Improve Care Access**

Our consultants highlighted some alternative approaches underway in the province that attempt to alleviate the issues related to accessing palliative care from the home. One consultant mentioned interdisciplinary palliative care consultant teams that meet once a week to brainstorm about how to help patients and families in rural settings. We were told that there are currently two such teams operating in the Eastern Health region. In addition, in other RHAs such as Central Health, a team conducts weekly rounds to discuss new referrals, review the status of palliative care clients, and go over their care goals. Our informants also noted that paramedics in some regions of the province have been trained to provide palliative care; these paramedics can be called upon to provide after-hours treatment to patients in their homes in an effort to delay or avoid a trip to the hospital. Palliative care paramedics are also employed in other Canadian provinces, including Nova Scotia, Prince Edward Island, and Alberta (47–49). Our informants also pointed to the development of “Compassionate Communities,” a care approach adopted by Pallium, a national, non-profit palliative care organization that provides training and experience in palliative care. This approach involves volunteers in the community who provide support to patients when professional services are not readily available (50). An example of a compassionate community initiative offered in St. John’s, NL is Nav-CARE, a program that is being developed through research in select communities across Canada. Under the Nav-CARE model, specially-trained volunteers work with one or two older persons in the home with the goal of providing long term navigation support and companionship (51). In addition, a collaborative initiative of Queen’s College, the Order of St. Lazarus, and Eastern Health has resulted in the development of an online training program for pastoral and palliative care volunteers. Our informants also highlighted initiatives that are now being explored to develop “medication kits” or “symptom relief kits” to provide medications in rural areas and during off-hours. However, some consultants noted that pharmaceutical guidelines for medications (specifically narcotics) may prevent some of the medications needed at end-of-life from being included in a general kit for clients.

*Our informants also pointed to the development of “Compassionate Communities,” a care approach adopted by Pallium, a national, non-profit palliative care organization that provides training and experience in palliative care.*

### **Organization of healthcare services**

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 providing palliative care can also make the collaboration, connection and care organization difficult. As an example, our informants highlighted the different systems and formats used for patient reporting and record-keeping, even within individual Regional Health Authorities.

## **General Palliative Care Services in the Newfoundland & Labrador Context**

### **Human resource factors**

**Training factors:** Our informants agreed strongly with the research evidence indicating that specialized training in palliative care was essential for high-quality palliative care (39). Consultants from the Central Health region noted that they recognize the importance of Learning Essential Approaches to Palliative Care (LEAP) training provided by Pallium Canada for all healthcare providers. However, our consultants also noted that, all too often, patients and families in NL receive support from healthcare providers who lack any experience or training in palliative care. One consultant remarked that this may even be true within facilities equipped with palliative care beds. Our consultants noted that healthcare providers who are not trained in palliative care may not communicate appropriately with patients and their families. Some consultants mentioned that training sessions in palliative care that have been organized for physicians in various communities across the province are often poorly-attended, despite being provided for free and with compensation for physicians.

**Attitudes towards palliative care:** Our consultants pointed out that the lack of attention to palliative care is not limited to poor attendance at training sessions, but also involves an inattention to palliative care, or a discomfort with palliative care discussions, more generally. It is notable that physician discomfort with palliative care is not unique to Newfoundland & Labrador. Pallium Canada's website states that 50% of family doctors across Canada are uncomfortable providing palliative care (52). Some consultants indicated that attitudes and beliefs about death and dying may prevent some healthcare professionals from providing effective palliative end-of-life care. As a result of this general inattention, healthcare providers may not be taking sufficiently proactive approaches to palliative care for our province's patients and their families. This factor was considered particularly unfortunate given that we know that a more proactive approach can strengthen advanced care planning and can help to decrease the demand for after-hours services. Our consultants indicated that successful palliative care in this province will require a greater willingness from generalists (such as family doctors) and from other specialist physicians to be involved in basic palliative care responsibilities.

**Capacity factors:** Decision makers may want to consider that 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. Our consultants suggested that palliative care specialists might provide consultation services as an option for generalists when the need arises. While we certainly heard that the physicians who work with palliative care specialists in this province are doing very good work, our consultants

noted that more of them need to be involved if palliative care in the province is to become more proactive and to improve overall.

**Barriers to proactive palliative care:** Our contextualization interviews revealed a number of barriers that affect the ability of our provincial healthcare system to become more proactive in providing palliative care, such as:

- a requirement in Eastern Health for a physician referral to palliative care, rather than permitting self-referrals by patients or family members;
- the tendency of the vast majority of referrals to involve cancer care only—referrals for patients with other serious illnesses are rare, even though palliative care would benefit these patients as well;
- physician discomfort with palliative care and the reluctance to refer patients to it, or to refer them later than would be optimal;
- the need for our province's physicians to better understand the full range of palliative care options—care options that can be provided throughout an illness trajectory and not only at the end of life;
- the need for physicians to develop skills and knowledge in palliative care, to distinguish among the various levels of palliative care, and to build palliative care capacity within the healthcare system;
- the tendency of patients and their families to seek palliative care, including HPC, too close to the time of discharge from hospital.

As noted previously, we wish to highlight that physician discomfort with palliative care is not exclusive to this province, but is a widespread issue in Canadian healthcare (52).

### **Health system organizational factors**

**Communication and knowledge-sharing across health authorities:** It became apparent throughout the contextualization process, and especially in a focus group with healthcare providers and system managers from across the province, that there is limited awareness in the province's RHAs about the rules and procedures for palliative care in other RHAs. To help improve this situation, a provincial Palliative End-of-Life Committee has been formed and has been meeting since February, 2020. This committee includes leadership representation from each RHA and a Department of Health and Community Services, Health Consultant Lead. While external stakeholders do not sit on this committee, they are invited to present relevant information at the committee's meetings. This committee provides an opportunity for information-sharing and practice discussions across the province.

Improved communication across health authorities was seen by many of our informants as a significant facilitator to the further development and enhancement of palliative care services, including HPC, province-wide. Participants in our focus group also highlighted a lack of awareness about the different approaches being taken in referral procedures, in record keeping, in healthcare coverage, and in initiatives under development. Our participants expressed a strong desire to see some further improvements in province-wide communication and knowledge-sharing.

**Lack of Hospice Care:** An additional organizational barrier to palliative care in Newfoundland & Labrador is the lack of hospice care. While in the Central Health region, a hospice is being built in Grand-Falls Windsor (53), other jurisdictions, such as the Eastern Health region, have had a harder time establishing hospices (54). In comparison, hospices are present in Prince Edward Island, Quebec, Ontario, Manitoba, Saskatchewan, Alberta, and British Columbia (39). Our consultants note that the lack of hospices forces patients at the end of life into hospitals for treatment.

### **Population Factors**

Our consultants agreed that a common barrier to palliative care is the limited awareness as to what palliative care is and what it offers to patients and their families. They note that too many people in the province:

- are reluctant to talk about palliation, despite the fact that palliative care can offer them the services that patients want;
- misconstrue palliative care as involving only care at the end of life;
- assume that end-of-life care is only for the last hours or days, despite being available for patients with a life expectancy of up to eight weeks; and
- are unaware of home-based palliative care as an option.

While, according to the World Health Organization, these public attitudes and this lack of awareness are not unique to Newfoundland & Labrador, these population factors do appear to be especially prevalent throughout this province (38).

## 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 (39). Our findings suggest that, in order to create the conditions in Newfoundland and 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.
- ✓ 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 for care of all types, including palliative care.
- ✓ Patients and their families need clear and consistent 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 of care providers to share patient information and to connect with one another across disciplines and care contexts is crucial for quality of care.
- ✓ Access to public or publicly-subsidized transportation for homecare workers and their patients, especially outside the province's principal cities, is a key consideration.
- ✓ 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.



## References

1. Noblit G, Hare R. Meta-Ethnography [Internet]. Thousand Oaks, California; 2020. Available from: <https://methods.sagepub.com/book/meta-ethnography>
2. Sarmiento VP, Gysels M, Higginson IJ, Gomes B. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. *BMJ Support Palliat Care*. 2017 Dec;7(4):0.
3. Government of Canada. Canada-Newfoundland and Labrador Home and Community Care and Mental Health and Addictions Services Funding Agreement [Internet]. Government of Canada. 2016 [cited 2020 Nov 13]. Available from: <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/newfoundland-labrador.html>
4. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*. 2013 Jun 6;(6):CD007760.
5. Luckett T, Davidson PM, Lam L, Phillips J, Currow DC, Agar M. Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting illnesses? A systematic review and meta-analysis of comparative studies. *J Pain Symptom Manage*. 2013 Feb;45(2):279–97.
6. Shea BJ, Reeves BC, Wells G, Thuku M, Hamel C, Moran J, et al. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ*. 2017 Sep 21;j4008.
7. Shepperd S, Gonçalves-Bradley DC, Straus SE, Wee B. Hospital at home: home-based end-of-life care. *Cochrane Database Syst Rev*. 2016 Feb 18;2:CD009231.
8. Costa V, Earle CC, Esplen MJ, Fowler R, Goldman R, Grossman D, et al. The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliative Care*. 2016 Jan 20;15:1–15.
9. Miranda R, Bunn F, Lynch J, Van den Block L, Goodman C. Palliative care for people with dementia living at home: A systematic review of interventions. *Palliat Med*. 2019 Jul;33(7):726–42.
10. Candy B, Holman A, Leurent B, Davis S, Jones L. Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies*. 2011 Jan 1;48(1):121–33.
11. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. *Ann Palliat Med*. 2015 Jul;4(3):99–121.



12. Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM. Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis. *J Palliat Med.* 2017;20(1):84–92.
13. Nordly M, Vadstrup ES, Sjøgren P, Kurita GP. Home-based specialized palliative care in patients with advanced cancer: A systematic review. *Palliat Support Care.* 2016;14(6):713–24.
14. Wahid AS, Sayma M, Jamshaid S, Kerwat D, Oyewole F, Saleh D, et al. Barriers and facilitators influencing death at home: A meta-ethnography. *Palliat Med.* 2018;32(2):314–28.
15. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *J Epidemiol Community Health.* 1998 Jun;52(6):377–84.
16. Abe K, Miyawaki A, Kobayashi Y, Noguchi H, Takahashi H, Tamiya N. Receiving the home care service offered by certified care workers prior to a patients’ death and the probability of a home death: observational research using an instrumental variable method from Japan. *BMJ Open.* 2019 Aug;9(8):e026238.
17. Tanuseputro P, Beach S, Chalifoux M, Wodchis WP, Hsu AT, Seow H, et al. Associations between physician home visits for the dying and place of death: A population-based retrospective cohort study. Ciccozzi M, editor. *PLoS ONE.* 2018 Feb 15;13(2):e0191322.
18. Wang SE, Liu I-LA, Lee JS, Khang P, Rosen R, Reinke LF, et al. End-of-Life Care in Patients Exposed to Home-Based Palliative Care vs Hospice Only: HomePal EOL Care. *J Am Geriatr Soc.* 2019 Jun;67(6):1226–33.
19. Kjellstadli C, Husebø BS, Sandvik H, Flo E, Hunskaar S. Comparing unplanned and potentially planned home deaths: a population-based cross-sectional study. *BMC Palliat Care.* 2018 Dec;17(1):69.
20. Nagaviroj K, Anothaisintawee T. A Study of the Association Between Multidisciplinary Home Care and Home Death Among Thai Palliative Care Patients. *Am J Hosp Palliat Care.* 2017 Jun;34(5):397–403.
21. Tan WS, Bajpai R, Low CK, Ho AHY, Wu HY, Car J. Individual, clinical and system factors associated with the place of death: A linked national database study. Vaingankar JA, editor. *PLoS ONE.* 2019 Apr 18;14(4):e0215566.
22. Zimmerman C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: a systematic review. *JAMA.* 2008;299(14):1698–709.
23. Greer DS, Mor V, Morris JN, Sherwood S, Kidder D, Birnbaum H. An alternative in terminal care: Results of the national hospice study. *Journal of Chronic Diseases.* 1986;39(1):9–26.
24. Aiken LS, Butner J, Lockhart CA, Volk-Craft BE, Hamilton G, Williams FG. Outcome Evaluation of a Randomized Trial of the PhoenixCare Intervention: Program of Case Management and Coordinated Care for the Seriously Chronically Ill. *Journal of Palliative Medicine.* 2006;9(1):111–26.

25. McKegney FP, Bailey LR, Yates JW. Prediction and management of pain in patients with advanced cancer. *General Hospital Psychiatry*. 1981;3(2):95–101.
26. Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, et al. Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer: The Project ENABLE II Randomized Controlled Trial. *JAMA*. 2009 Aug 19;302(7):741.
27. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*. 2007;55(7):993–1000.
28. Jordhøy M, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet*. 2000;356(9233):888–93.
29. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The Comprehensive Care Team: A Controlled Trial of Outpatient Palliative Medicine Consultation. *Archives of Internal Medicine*. 2004 Jan 12;164(1):83–91.
30. Ward AWM. Home care services — an alternative to hospices? *Journal of Public Health*. 1987 Feb;9(1):47–54.
31. Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial. *Journal of Pain and Symptom Management*. 2009 Dec;38(6):816–26.
32. Grande GE, Todd CJ, Barclay SIG, Farquhar MC. Does hospital at home for palliative care facilitate death at home? Randomised controlled trial. *BMJ*. 1999 Dec 4;319(7223):1472–5.
33. Axelsson B, Christensen SB. Evaluation of a Hospital-Based Palliative Support Service With Particular Regard to Financial Outcome Measures. *Palliative Medicine*. 1998;12(1):41–9.
34. Mccorkle R, Georgiadou Fot, Moinpour C, Goodell B. A Randomized Clinical Trial of Home nursing Care for Lung Cancer Patients. 1989;64(6):8.
35. McMillan SC, Small BJ. Using the COPE Intervention for Family Caregivers to Improve Symptoms of Hospice Homecare Patients: A Clinical Trial. *Oncology Nursing Forum*. 2007 Jan 1;34(2):313–21.
36. Zimmer JG, Groth-Juncker A, McCusker J. A randomized controlled study of a home health care team. *Am J Public Health*. 1985 Feb;75(2):134–41.
37. Ahlner-Elmqvist M, Jordhøy MS, Bjordal K, Jannert M, Kaasa S. Characteristics and Quality of Life of Patients Who Choose Home Care at the End of Life. *Journal of Pain and Symptom Management*. 2008 Sep;36(3):217–27.
38. World Health Organization. Palliative Care [Internet]. World Health Organization - Palliative Care. 2020 [cited 2020 Nov 13]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

39. Canadian Institute for Health Information. Access to Palliative Care in Canada [Internet]. Ottawa, ON: Canadian Institute for Health Information; 2018 p. 67. Available from: <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>
40. Bainbridge D, Seow H, Sussman J. Common Components of Efficacious In-Home End-of-Life Care Programs: A Review of Systematic Reviews. *Journal of the American Geriatrics Society*. 2016;64(3):632–9.
41. Government of Newfoundland and Labrador. Provincial Home Support Program: Client Handbook [Internet]. p. 8. Available from: <https://www.gov.nl.ca/hcs/files/personsdisabilities-pdf-home-support-program-client-handbook.pdf>
42. Central Health. Palliative & End of Life Care: Information & Frequently Asked Questions [Internet]. [cited 2020 Nov 13]. Available from: <https://www.centralhealth.nl.ca/palliativecare>
43. Labrador-Grenfell Health. Palliative Care – Home and Public [Internet]. [cited 2020 Nov 13]. Available from: <https://www.lghealth.ca/your-health/programs-and-services/population-health/community-health/palliative-care-home-and-public/>
44. CBC News. “Death-denying society” needs to talk about palliative care, says N.L. doctor. CBC News [Internet]. 2016 Jan 17 [cited 2020 Nov 13]; Available from: <https://www.cbc.ca/news/canada/newfoundland-labrador/palliative-care-doctor-eastern-health-1.3405372>
45. Ontario Long-Term Care Association. This is Long-Term Care 2016 [Internet]. Ontario: Ontario Long-Term Care Association; 2016 p. 16. Available from: <https://www.oltca.com/OLTCA/Documents/Reports/TILTC2016.pdf>
46. Health Quality Ontario. Palliative Care at the End of Life: Report Update 2019 [Internet]. Health Quality Ontario; 2019 p. 17. Available from: <https://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-2019-en.pdf>
47. EMS Initiative [Internet]. Alberta Health Services. [cited 2020 Nov 13]. Available from: <https://www.albertahealthservices.ca/info/page14899.aspx>
48. Nova Scotia Department of Health of Wellness. Emergency Health Services: Paramedics Providing Palliative Care at Home [Internet]. Government of Nova Scotia. [cited 2020 Nov 13]. Available from: <https://novascotia.ca/dhw/ehs/palliative-care.asp>
49. Health PEI. Paramedics Providing Palliative Care at Home Program [Internet]. Government of Prince Edward Island. [cited 2020 Nov 13]. Available from: <https://www.princeedwardisland.ca/en/information/health-pei/paramedics-providing-palliative-care-home-program>
50. Pallium Canada. About Pallium [Internet]. Pallium Canada. [cited 2020 Nov 13]. Available from: <https://www.pallium.ca/about-pallium/>

51. Nav-CARE. Locations [Internet]. Nav-CARE. [cited 2020 Nov 13]. Available from: <https://nav-care.ca/locations/>
52. Pallium Canada. Facts & Research [Internet]. Pallium Canada. [cited 2020 Nov 13]. Available from: <https://www.pallium.ca/facts-research/>
53. Barry G. With architects hired, N.L.'s first hospice is closer than ever. CBC News [Internet]. 2020 Oct 1 [cited 2020 Nov 13]; Available from: <https://www.cbc.ca/news/canada/newfoundland-labrador/lionel-kelland-architect-design-project-rfp-opening-building-1.5743440>
54. CBC News. A better ending: Why this palliative-care doctor is pushing for a hospice in St. John's. CBC News [Internet]. 2020 Oct 13 [cited 2020 Nov 13]; Available from: <https://www.cbc.ca/news/canada/newfoundland-labrador/st-johns-hospice-push-susan-macdonald-1.5759937>

# Appendix A

## Systematic reviewers' comments on controls used in their reviews

|                    |                       |  |
|--------------------|-----------------------|--|
| Systematic Reviews | <b>Costa 2016</b>     | The researchers make note that the difficulty inherent in this literature is that it often relies on observational and retrospective studies. While they mention "usual care" as the comparator for some primary research they include, there is no discussion on what this means.   |
|                    | <b>Gomes 2013</b>     | HPC was compared with "usual care," which varied across studies and reflects health system differences and local service provisions.   |
|                    | <b>Luckett 2013</b>   | The quality of the primary research was limited by the lack of what Luckett et al. call "ideal comparators." In their words, "Given the variation in standard care even within the same health service, comparison groups tended to receive an eclectic mix of ill-defined services, with substantial variation between individual patients. Poor delineation of the level, intensity and quality of home nursing within the context of access to medical care, equipment, social support, and patient/ caregiver education and training limits the degree to which results can be ascribed to any one component." |
|                    | <b>Miranda 2019</b>   | Provided no detailed examination of the controls in the primary research that they used. However, upon further inspection of the primary articles a limited description of the controls has been provided by us below.   |
|                    | <b>Shepperd 2016</b>  | The researchers compared the interventions to inpatient hospital care or hospice care, and routinely available primary health care. However, they make note that the exact care received varied across trials, reflecting the differences in health systems and the way standard care is delivered. Further, the researchers note that for some trials, patients crossed over between intervention and control groups.   |
|                    | <b>Sarmiento 2016</b> | Due to the qualitative methods used for the meta-ethnography, there were no controls mentioned by the researchers.   |

Specific controls from certain primary research articles included in the systematic reviews

- Gomes et al. 2013
  - Various amounts and levels of primary care services, acute care services, hospice care, and home health services.
  - Control indicated as hospital palliative care.
  - Usual care shared among hospital departments and the community (included family physicians, nursing homes, and home nursing with 24 hours a day coverage by nurses and nurse assistants everywhere but small districts). However, routines were not well-defined and there was no specialist palliative care provision.

- An interdisciplinary team, represented by the standard Medicare-reimbursed services available in the community, provided homecare.
  - The patient's physician and outpatient staff provided traditional outpatient care (no general or specialized home nursing care).
- Miranda et al. 2019
  - Activity groups. (Shared many features with the intervention Multi-Sensory Stimulation sessions)
  - Hospital care or general medical ward care
  - Usual community control. It appears that in the case of problems arising, the control group was referred to the Alzheimer's Association and other community resources, along with having their questions answered by Alzheimer's care specialist, social workers, and clinicians.
- Shepperd et al. 2016
  - Home care (without specialized end-of-life care), acute inpatient care, primary care services, and hospice care.
  - Inpatient care at a Veterans' Administration hospital.
  - While having no well-defined routine, care consisted of conventional care shared among the hospital departments and the community.

# Appendix B

## Contextualization Interviews

Various questions were considered in our contextualization process. Questions were asked if they were relevant to the consultant's experience. Some of the questions were added or altered after additional information was garnered from consultants. Coronavirus concerns led us to offer consultants a variety of options to participate, including video calls, telephone calls, replying to a set of questions over email, and responding to a set of questions in a group video chat facilitated by NLCAHR's Research Exchange Group (REG) on Palliative and End-of-Life Care. Impromptu questions and elaborations, especially from the REG discussion, means that these lists are not exhaustive.

### Health System workers

- What is your experience with home-based palliative care in Newfoundland & Labrador?
- Can you describe how home-based palliative care is implemented in your Health Authority?
- Can you describe how hospice might work in the province and what issues there have been implementing it here?
- What resources are essential for successful home-based palliative care in Newfoundland & Labrador?
- Are there any initiatives, active or planned, for palliative care in the province?
- From the point of view of the patients and families, are formal caregivers provided with adequate training necessary for home-based palliative care?
- What barriers have you noticed to the implementation of home-based palliative care in our province?
- What facilitators are there to the implementation of home-based palliative care in our province?
- What are the issues related to ensuring anyone that wants/needs palliative care services has the opportunity to find out about and utilize them?
- Are there any specific patient groups that would benefit more from home-based care than institutional care?
- What kind of financial concerns are involved with home-based palliative care at the government level?
- What kind of financial concerns are involved with home-based palliative care at patient/family level?
- What is the general public perception about home-based palliative care in Newfoundland & Labrador? Are they generally aware of the palliative care program in Newfoundland & Labrador?
- Has the home-based palliative care program improved patient's/caregiver's perception of Newfoundland & Labrador's health system? How/Why?
- Are there unique factors within the Newfoundland & Labrador healthcare system that affect the implementation of palliative care services, especially that of home-based care in the province?
- How do patients/caregivers tend to respond to the option of palliative care in the home?
- What kind of advanced planning is done with patients? Is there anything that should be planned but often isn't?
- How has Coronavirus affected home-based palliative care in the province?



- In what ways do you think home-based palliative care in Newfoundland & Labrador affects the odds of patients dying at home/in their preferred place?
- How do you think home-based palliative care in Newfoundland & Labrador affects patient's symptom burden?
- How do you think home-based palliative care in Newfoundland & Labrador affects patient's quality of life?
- How satisfied are families with home-based palliative care?
- What alternatives are available to home-based palliative care in Newfoundland & Labrador? Can you describe them?
- Are you aware of other ways that home-based palliative care is provided in other jurisdictions, outside the province, that would or would not work well in Newfoundland & Labrador? Can you describe them?
- Do you believe there's a need for home-based palliative care in Newfoundland & Labrador? Why/why not?
- Are there any other additional comments on palliative care in Newfoundland & Labrador that you'd like to share?

### **Patients and Caregivers**

- What is your experience with home-based palliative care in Newfoundland & Labrador?
- If you have any experience with people availing of home-based palliative care in Newfoundland & Labrador, please describe the process?
- How are patients that receive palliative care asked about their preferred place of death as a part of the palliative care process?
- How might the characteristics of palliative care patients specifically in Newfoundland & Labrador affect the operation of home-based palliative care?
- Are there patient/caregiver groups who are more likely to NOT have access to home-based palliative care in Newfoundland & Labrador?
- Are there patient/caregiver groups who are likely to benefit more from Home-based Palliative Care than institutional care?
- In what ways do you think home-based palliative care in Newfoundland & Labrador affects the odds of patients dying at home/in their preferred place?
- How do you think home-based palliative care in Newfoundland & Labrador affects patient's symptom burden?
- How do you think home-based palliative care in Newfoundland & Labrador affects patient's quality of life?
- How satisfied are families with home-based palliative care?
- What alternatives are available to home-based palliative care in Newfoundland & Labrador? Can you describe them?
- Are you aware of other ways that home-based palliative care is provided in other jurisdictions, outside the province, that would or would not work well in Newfoundland & Labrador? Can you describe them?
- Are there any resources (e.g., nursing, educating patients and caregivers, psychosocial services, and symptom and disease treatment) that you have found particularly useful for home-based palliative care from a patient/caregiver perspective?

- In your experience as a patient/caregiver, what strengths and/or challenges have you encountered regarding the organization of home-based palliative care in Newfoundland & Labrador?
- How is the financial burden for patient families/caregivers while utilizing home-based palliative care in Newfoundland & Labrador?
- What are the public or media expectations currently to do with home-based palliative care in Newfoundland & Labrador?
- Do you believe there's a need for home-based palliative care in Newfoundland & Labrador? Why/why not?
- Are there any other additional comments on palliative care in Newfoundland & Labrador that you'd like to share?