



*Rapid* **EVIDENCE** *Reports*

## Chronic Disease and Palliative Care

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*Celebrating the 10<sup>th</sup> Anniversary of the  
Contextualized Health Research Synthesis Program*

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## About This Report

### About NLCAHR

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

### About *Rapid Evidence Reports*

NLCAHR designed *Rapid Evidence Reports* to provide support for evidence-informed decision making in the Newfoundland and Labrador healthcare system on an expedited basis as compared to the lengthier '*Evidence in Context*' reports issued through the Contextualized Health Research Synthesis Program. Through these expedited reports, NLCAHR provides a succinct review of recent research evidence on a high-priority research topic selected by decision makers in the province.

*Rapid Evidence Reports* include:

- A clear statement of the issue and the background to the issue/problem;
- A description of the scope and nature of the pertinent English-language scientific literature from the past five years;
- A summary of the principal features of the available evidence – points of consensus, points of disagreement, areas of uncertainty or silence on some or all of the following issues: effectiveness of interventions, potential benefits and harms, risks, costs, and cost-effectiveness; and
- A brief analysis of the types of issues that might affect the applicability of the evidence to the local context.

It is important to note that, unlike our other decision-support product, the '*Evidence in Context*' report, a *Rapid Evidence Report* is **not** a comprehensive and systematic synthesis of the literature on the topic. This rapid report provides neither critical appraisal of included articles nor a full analysis of the contextual issues involved in applying evidence to the Newfoundland and Labrador healthcare setting. Rather, a *Rapid Evidence Report* provides decision makers with a summary of the scope and nature of the recent scientific literature on the topic in question, an initial assessment of the strengths and gaps in this literature, and a review of the key points of agreement and disagreement among researchers.

## Researchers and Consultants

For this report, the research team from the Newfoundland and Labrador Centre for Applied Health Research included Sarah Mackey, Research Officer, Contextualized Health Research Synthesis Program (CHRSP) and Dr. Stephen Bornstein, Director of NLCAHR. Our team benefited from the advice and expertise of Dr. Barbara Pesut, PhD., RN, a professor in the School of Nursing at the University of British Columbia. Dr. Pesut holds a Canada Research Chair (Tier 2) in Health, Ethics and Diversity. Her program of research explores ways to improve a palliative approach to care, particularly for rural populations. Dr. Pesut's credentials are included in the Appendix (page 24).

## Background

The Public Health Agency of Canada has reported that the leading cause of death globally is chronic disease. In Canada, 65% of deaths are attributable to a major chronic disease each year (1).

Unlike forms of cancer for which the disease trajectory is more foreseeable, many other major chronic diseases do not necessarily follow predictable stages or timelines but could benefit greatly from palliative supports early in the disease and as it progresses to a terminal phase (2–5). As the length of time that people live with chronic diseases has increased, there is growing awareness of a gap in care between chronic disease management and palliative care for those with advancing chronic disease (6,7). One author contends that:

*Identifying and addressing physical, psychological, social, and spiritual needs should not be confined to the terminal phase of disease and neither should advance care planning. Patients whose diseases are potentially controllable or even curable also benefit from a supportive and palliative care approach that aims to assist quality of life. Likewise, recognizing disease progression and engaging in honest goals-of-care discussions accompanied by wise treatment choices in a way that promotes realistic hope and prepares for future possibilities should not be relegated only to end of life (8, p.367).*

Our health system partners in Newfoundland and Labrador are concerned about the significant impact of chronic disease on population health in this province and about the effect of chronic disease on health system sustainability. Newfoundland and Labrador's demographic and geographic characteristics make the province particularly susceptible to the burdens associated with chronic disease, with over half of NL residents aged 12 years and older having at least one chronic disease (9). Following from a topic submitted by Central Health, our six health system stakeholders asked the Contextualized Health Research Synthesis Program (CHRSP) to review the evidence on how to integrate a palliative approach to care before end-of-life for those with serious chronic disease.

Our research question is as follows:

*“What does the scientific literature tell us about ways of integrating a palliative approach to care at an early stage for patients with serious or advanced chronic disease and the effectiveness of doing so?”*

## Scope and Nature of the Scientific Literature

For this *Rapid Evidence Report*, we searched for peer-reviewed articles within the health periodical indices PubMed, CINAHL Embase, and Ageline and conducted secondary searches using Google Scholar. We aimed to locate systematic review evidence published in English since 2013, comprehensive alternative reviews, and any primary research published in English since 2014 but not yet included in the systematic review literature.

### Inclusion and Exclusion Criteria

The populations considered for this study were adults (over the age of 18) that had serious or advanced chronic disease (including cancer). We paid particular attention to four chronic diseases: chronic or congestive heart failure, chronic obstructive pulmonary disease, end stage renal disease, and stroke, whenever evidence for these was available (see Table 1 below). We gave preference to articles that described a palliative *approach* to care rather than articles that focused specifically on *palliative care*. The elements of a palliative approach of most interest for this report included early intervention or elements of palliative care that are introduced or integrated into care at an early stage, or at least palliative elements that are introduced earlier than at end-of-life. We used the following inclusion/exclusion criteria to select and screen articles.

Table 1: Inclusion and Exclusion Criteria for this Report

Parameter	Inclusion Criteria	Exclusion Criteria
<b>Population</b>	<ul style="list-style-type: none"> <li>Adults with chronic disease in general</li> <li>Adults with specific chronic diseases, in particular: chronic or congestive heart failure, chronic obstructive pulmonary disease, end stage renal disease, or stroke</li> <li>Adults with cancer</li> </ul>	<ul style="list-style-type: none"> <li>Those articles that focused only on adults with certain single chronic diseases e.g., HIV, dementia.</li> </ul>
<b>Setting</b>	<ul style="list-style-type: none"> <li>Ambulatory</li> <li>Hospital</li> <li>Community</li> </ul>	
<b>Intervention</b>	<ul style="list-style-type: none"> <li>Approaches or models that integrate palliative care earlier than end-of-life</li> <li>Palliative approach to care</li> </ul>	<ul style="list-style-type: none"> <li>Specialist care only</li> <li>Any article that did not speak to an upstream or integrated approach to palliative care</li> <li>Palliative care whose timing was not specified</li> <li>Primary palliative care</li> </ul>
<b>Outcome</b>	<ul style="list-style-type: none"> <li>All relevant outcomes</li> </ul>	

In total, this report includes 10 systematic studies. The higher quality studies were:

- one Cochrane review (10); and
- two other systematic reviews with narrative analysis rather than meta-analysis (11,12).

Because of the paucity of fully systematic and high-quality research on the effectiveness of an early palliative approach for advanced chronic diseases, we also included seven other reviews that used systematic methods (13–19). In addition, we included 13 primary studies that used various methodologies. Of these primary studies:

- one was a randomized clinical trial (20);
- one was a secondary analysis of a randomized clinical trial (21);
- three were completed secondary analyses of randomized controlled trials (22–24);
- one used a qualitative design (25);
- one was a multi-centre, randomized clinical trial (26);
- two were an observational studies (27,28);
- three were pilot studies (29–31); and
- one was an exploratory analysis (32).

The main difficulty in gathering and assessing information for this report is that ‘early palliative care’ is not well-defined in a uniform way across the research literature. What is deemed as ‘early’ palliative care varies from study to study. This is indicative of a shift that has occurred from conceiving of palliative care as being exclusively for end of life to it being applicable early in the course of life-limiting illness, as a way to improve the quality of life of patients and their families (33). Evidence on this early approach to palliative care can thus still be considered preliminary and will continue to be refined as the concept is further understood and studied.

## Summary of the Research Evidence

Overall, there is limited robust evidence for a palliative approach to care and the effectiveness of integrating palliative care components at an early stage in disease progression. Available evidence has yet to identify an effective approach that applies to all settings and contexts. At a fundamental level, the parameters of the research necessary to guide this topic are still being determined. Below, we describe the limitations of some key parameters of the research.

## Limitations of Key Parameters

### *Inconsistency in the Terminology*

Differences in terminology present a challenge when comparing research evidence that examines palliative care. According to Sawatzky et al., the term ‘palliative care’ can be used to refer to:

- a philosophical approach to care; or
- a healthcare service; or
- both (17).

The conceptualization of palliative care as an approach to care has evolved over the years and is now understood as appropriate for patients and families with a range of life-threatening chronic diseases and conditions at various stages in the progression of their disease. The aim of this approach to care is to improve quality of life throughout the disease trajectory from its early stages until end-of-life (33). However, many research authors noted that, in practice, access to palliative care is often limited to the terminal phase of illness (10,12,15,19).

Despite a growing interest in the available systematic and primary literature on how to effectively integrate palliative care elements at an early stage for chronic disease, “there is no universally accepted definition of ‘early’ palliative care”(15). In the absence of a uniform definition, various terms are employed in the literature, including: ‘early palliative care,’ ‘a palliative approach,’ ‘simultaneous palliative care’ or ‘early integrated palliative care.’ These terms are intended to distinguish palliative care delivered in the earlier stages of disease from end-of-life palliative care. In most cases, the studies included in this report include ‘early’ as part of their inclusion or exclusion criteria. Some examples are:

- time since diagnosis of a life-limiting illness (e.g., less than x months after diagnosis); or
- presence of certain prognostic signs or symptoms (e.g., x time before death, x stage of disease); or
- the site where the palliative consultation takes place (e.g., outpatient versus inpatient)(15).

The more recent primary studies in this report also used a variety of benchmarks to define early palliative care, such as:

- time of confirmed diagnosis (29);
- stage of disease (30);
- symptom burden (32); and
- prognosis (28,31).

The most comprehensive conceptualization of a palliative approach to care was provided by a recent mixed-methods knowledge synthesis that set out to define the characteristics of a palliative approach based on empirical peer-reviewed literature (17). Articles were included in the synthesis if palliative care principles were integrated into healthcare by professionals who were not specialists in palliative care. The authors then analyzed the essential characteristics that those articles used to define a palliative approach for life-limiting chronic populations. Three main themes emerged:



- an upstream orientation to care;
- adaptation of palliative care knowledge and expertise; and
- the operationalization of a palliative approach through integration into systems and models of care that do not specialize in palliative care.

Highlighted in this definition is a move away from an explicit focus on specialized palliative services in favor of an upstream integration of services within a full range of healthcare services...

*...where a palliative approach can be enacted by any healthcare professional by adapting palliative care knowledge and expertise to meet the needs of people with chronic life-limiting conditions (17, p.11).*

### *Lack of Validated Methods to Identify Early-Stage Palliative Trajectories*

Definitional issues aside, high-quality evidence for well-validated methods to identify palliative trajectories is also not available at this time. One systematic review examined the best evidence on methods for early identification of palliative trajectories and preconditions for early integration of palliative care for cancer, chronic heart failure and chronic obstructive pulmonary disease populations. The authors described a number of disease-specific methods and general methods that are studied in the literature but ultimately concluded that further validation of these methods is necessary. These authors also concluded that no method can be recommended for routine clinical practice at this time and that more research is necessary to determine the key components of these methods such as when the palliative trajectory begins, what specific clinical indicators to use and how to prioritize the disease-specific and general indicators of end-stage disease (14).

### *Populations Studied*

The systematic review literature we reviewed examined a variety of disease populations in different combinations. This made comparisons between studies difficult. Overall, the diseases represented in the literature include: cancer (various types), end stage kidney disease (ESKD), heart failure,<sup>1</sup> chronic obstructive pulmonary disease (COPD), HIV/AIDs, dementia, neurological disease, and unspecified chronic disease or life-limiting conditions (10–19). Of the 10 systematic studies included in this report, cancer is the most consistently represented chronic illness followed by heart failure, COPD and ESKD (in no particular order).

Most commonly, review authors sought out all available evidence on various chronic disease populations, including cancer (15–19). For these reviews, the authors either identified the percentage of each disease population present in the included studies or, at a minimum,

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<sup>1</sup> Authors used similar terms to describe chronic heart issues. Three reviews referred to heart failure (15,16,18,19), five reviews referred to congestive heart failure (11,12,14,17,18) and one of these also referred to chronic heart failure (14). We use the terms authors used when describing included research. We assume these terms all capture chronic types of heart failure given the parameters required for research to be included in this report.



provided a list of included disease populations. A minority of reviews pre-specified a select number of chronic diseases, including cancer (11,14) choosing to exclude other chronic diseases. Two other reviews focused on individual disease populations, with one focusing exclusively on cancer (10), and the other focusing on ESKD (13). A final systematic review included patients with advanced cancer/or non-cancerous chronic disease that included advanced congestive heart failure, COPD, and chronic disease generally (12).

Although we found numerous disease populations represented in the systematic literature, many chronic diseases were rarely studied in depth, such as COPD and ESKD (11,13). Reviews cautioned that there may not be a “one size fits all” palliative approach for all chronic illnesses. In other words, what works for a cancer illness trajectory may not be suitable for ESKD (13,17). Chronic disease trajectories can often be difficult to predict (14).

The populations represented in the primary literature echoed those in the systematic evidence. The majority focused on newly diagnosed cancer patients with advanced cancers, specifically:

- lung, non-colorectal GI cancer (21),
- metastatic non-small cell lung cancer (22),
- stage IV gastrointestinal, genitourinary, gynaecological or breast cancer; stage III/IV lung cancer; or locally advanced oesophageal or pancreatic cancer advanced (25),
- inoperable pancreatic cancer (26),
- advanced lung and gastrointestinal cancer (23),
- advanced cancer (24,27),
- incurable lung or non-colorectal GI cancer (20).

As well, three other primary studies focused on populations with specific chronic diseases [heart failure (29), chronic lung disease (30,32)] while two focused on advanced chronic illnesses in general [including cancer (28,31)].

#### *Barriers to Early Integration of Palliative Care for Specific Populations*

One review identified barriers to early integration of palliative care for specific populations. For cancer populations, the authors found the following barriers to the early integration of palliative care:

- physician’s prognostic skills;
- physician attitudes about conveying prognostic information to patients and their families; and
- the misconception by staff that palliative care is appropriate only at the end of life.

Specific barriers for chronic heart failure and COPD populations included:

- unpredictable illness trajectory and prognosis;
- risk of sudden death;
- a public misperception that chronic heart failure and COPD are benign conditions;

- limited patient understanding of prognosis; and
- a lack of effective communication about the disease between physician and patient (14).

## Approaches Studied

Overall, there was limited evidence in the systematic review literature to suggest which model of care should be used when implementing early palliative care. Inherent differences among approaches, models and settings discussed in the available literature made it difficult for research authors to draw clear comparisons (12,15,17,19). One overview concluded that there was little evidence to guide the choice of model for integrating early palliative care into outpatient and home care. These authors also contend that there isn't even good evidence to suggest that the same model of care is equally effective across different diseases (15). Below we will highlight the various approaches and models covered in the literature.

### Palliative Approach

Four reviews of various care delivery models and settings either referred to or analyzed the literature using the term 'palliative approach' (12,13,17,18) as did one primary study (30).

A knowledge synthesis of empirical peer-reviewed literature found three types of care delivery models prominent in the literature for the integration of a palliative approach to care within mixed settings and among mixed disease populations (17).

- The authors termed the first model of care delivery as 'early' palliative care and it has mostly been applied to populations of cancer patients. Palliative care knowledge and expertise is applied upstream with minimal adaptation. It includes the involvement of palliative care specialists early on and throughout the course of the illness.
- The second model integrated a palliative approach into generalist practice on a system-wide basis, mostly applied in primary care and residential care settings. Characteristic of this approach is that it is "applied to particular sectors of healthcare for people who have various life-limiting conditions and comorbidities" rather than being focused on one particular disease (17). Palliative care specialists work with a generalist multidisciplinary team to develop the capacity to integrate a palliative approach.
- The third approach the authors identified adapted disease or condition-specific models that coordinate care across healthcare sectors for the management of different conditions at various stages. This approach uses partnership and collaboration between experts in chronic disease or geriatrics and palliative care specialists in order to ensure that appropriate services are provided for a range of care needs. The authors ultimately concluded that research is still needed to

determine which models of care are most appropriate, useful and cost-effective for the integration of a palliative approach (17).

A systematic review by Tassinari et al. compared what they termed an ‘early simultaneous palliative care approach plus standard care,’ versus standard care alone for those with advanced cancer and/or non-cancerous chronic disease in mixed settings. The authors explained that

*the model of the simultaneous care from the first diagnosis to the end-of-life period is frequently counter-posed to the sequential model, in which clinical oncology, palliative care, and end-of-life care are sequentially given along the natural history of the disease (12 p.69).*

However, they found that patients with advanced disease were enrolled in the trials they assessed, rather than patients that had just been diagnosed. This means that palliative care was given simultaneously with standard care for those with advanced disease earlier than it would be initiated in standard practice, where there is a discrete difference between standard care and the initiation of palliative care. There were a range of models reported in the trials for the early simultaneous approach and the authors concluded that the impact of these models should be further analyzed to determine which elements are the most important (12).

Another knowledge synthesis explored a palliative approach to nursing-care delivery. This synthesis aimed to determine approaches to nursing-care delivery that support the integration of a palliative approach in different care settings. It found that a palliative approach “is understood as being embedded within all levels, including the system, the care delivery of each setting, and the health care team” rather as a discrete nursing care delivery model (17). The authors highlighted effective communication, diverse delivery teams and interdisciplinary teamwork as common components of existing care delivery systems (17).

Crawford et al. used the term ‘palliative approach’ loosely in a scan of the literature on end-stage kidney disease (ESKD). These authors sought out evidence on life-limiting illness, holistic care, and unit-of-care but found little research on the specific ESKD disease population. They also expressed doubt that models of care developed for other diseases could be applied to this disease population, given its unique characteristics (13).

Two primary studies looked at palliative approaches for specific chronic lung conditions. The first study looked at the acceptability and feasibility of integrating a palliative approach to care for people living with advanced stage COPD using an advance practice nurse and found this to be a feasible approach (30). Another primary study from 2017 conducted an exploratory analysis of a multidisciplinary collaborative care model for patients diagnosed with idiopathic pulmonary fibrosis that focused on community-based care. The main elements of this model included advanced care planning, early discussions about patients’

goals, development of self-management action plans for dyspnea, and engagement of primary care and allied health home care to provide support within a patient's home (32).

### Early Palliative Care

One high-quality systematic review, one narrative overview, and eight primary studies that focused on cancer populations described interventions or approaches using terms such as 'early palliative care' or 'early integration of palliative care'. A Cochrane review examined all types of professional palliative care services that provided or coordinated comprehensive care for patients at early advanced stages of cancer in various settings. The term 'early cancer' was used to describe a patient diagnosed with a malignant tumor with a survival time between three months to two years. This review found that studies most often assessed models of coordinated care or evaluated interventions delivered by specialized palliative care teams. Coordinated care models were described as being observed in common clinical practice. For these models, supportive palliative care is offered and coordinated by the primary oncologist in collaboration with the primary nursing team with primary care providers also referring patients to various specialists for different palliative care domains. In the integrated care model "oncologists routinely refer patients to specialist palliative care teams early in the disease trajectory, rather than excluding involvement of other specialists"(10). When they compared three studies of coordinated care with four studies of integrated care, the authors found that the type of model used to provide early palliative care did not affect patient outcomes (10).

Eight recent primary articles focusing on cancer populations also examined early integrated palliative care interventions. Five out of eight of these studies defined 'early' as including participants who were within eight weeks of being diagnosed with advanced cancer. In most cases, interventions included scheduled visits with professionals that specialized in palliative care (physician-led and nurse-led) at least once every two, three, or four weeks until death. Health professionals often carried out an assessment of patient needs and helped manage those needs either in person or over the phone. The majority of these primary studies were conducted in an outpatient setting, with a minority conducted in hospital, hospice or intensive-care environments (20–27). We discuss the outcomes of these studies in a later section of this report.

### Integrated Palliative Care

A systematic review by Siouta et al. sought to identify empirically evaluated models of integrated palliative care<sup>2</sup> for mixed chronic disease populations in Europe. In this study, integrated palliative care included instances when palliative care is provided alongside regular treatment as well as instances when care was provided only at the end of life. The

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<sup>2</sup> Siouta et al. quoted the following definition of integrated palliative care '...involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers (paid and unpaid)' (19, p.2).

authors used this definition for the purposes of their study but also acknowledged that there is no unanimously agreed-upon definition for ‘integrated palliative care.’ This review identified seven evaluated models for chronic disease. Four of these were for integrated care in oncology and three were focused on cancer and chronic disease at end-of-life. The authors noted that differences in care settings and team compositions made comparison difficult; instead, they grouped model components according to five characteristics:

1. **Focus of the intervention:** the authors found that all models of integrated palliative care focused on symptom treatment (mostly physical and emotional symptoms). Areas of focus for some studies was on consulting about end-of-life care decisions, advanced care planning, support for coping with disease. For a number of others, the focus was on nurse and physician training or education for patients and professionals on disease and palliative care services.
2. **Type of setting:** various settings were reported in the literature. There was often more than one setting used, with inpatient and home-care settings most often represented.
3. **Timing of Palliative Care initiation:** the timing of palliative care initiation was found to be provided at the end-of-life or provided concurrently with regular treatment, or both, in the studies analyzed.
4. **Composition of team:** three different team compositions were identified. Teams included medical and nursing staff or multidisciplinary teams (medical and other health professionals) or multidisciplinary teams plus palliative care experts.
5. **Collaboration strategy:** three different collaboration strategies were identified: teams composed only of those implementing a model; teams that also included experts involved with patient treatment, or teams that simply followed predefined protocols.

Direct comparison of the models was not possible because of differences in the outcomes and measures used by the included studies. But the authors did find “strong agreement on the benefits of the involvement of a palliative care multidisciplinary team including better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions, cost effectiveness and patients dying in their preferred place” (19).

### Multi-component Palliative Care

One systematic review investigated multi-component palliative care interventions that included two or more of the following elements for patients with cancer, congestive heart failure, COPD or ESRD:

- symptom management;
- psychological support/counseling;
- spiritual/existential support;
- advanced care planning;
- education about illness or disease;

- care coordination; or
- bereavement services (11).

Overall, Phongtankuel et al. reported that the care components most commonly received through multi-component palliative care in mixed settings included symptom management, psychological support/counseling and disease education. Nurses delivered the majority of these interventions, followed by physicians, social workers, and chaplains.

### Rural-Specific Models and Interventions

We included three primary studies that examined approaches of early palliative care for rural populations. The results from these studies are preliminary and not necessarily generalizable to settings beyond those where the original research was conducted; however, they do serve as examples of innovative approaches that hold potential for rural settings.

The first pilot study examined the feasibility of an early palliative care intervention for heart failure patients and their families living in rural areas. The intervention included an in-person outpatient palliative care consultation as well as weekly telephonic nurse coaching sessions and monthly follow-up calls. The study allowed the researchers to identify areas that need to be strengthened to test this intervention in a full clinical trial. Initial results suggested that moderate to small improvements can be made in certain patient and caregiver outcomes (29).

Another pilot study examined a nurse-led navigation service for rural older adults living at home and their families. Over the course of two years, a nurse navigator made biweekly home visits to provide services such as symptom management, education, advance care planning, advocacy, mobilization of resources, and psychosocial support. The authors concluded that nurse navigators have the potential to meet the needs of this population and recommended further research to confirm these preliminary findings (28).

A similar intervention in another pilot study provided early palliative support in rural communities through a model called N-CARE (Navigation: connecting, accessing, resourcing, and engaging). Navigation support was provided by trained volunteers through in-home visits, and a nurse navigator supported the volunteers. Independent and joint visits were conducted with clients throughout the one-year pilot. Overall, the pilot intervention was found to be a feasible way to foster a compassionate community approach to palliative care for those with advancing chronic illness (31).

## Outcomes for Early Palliative Care

The varied outcomes and outcome measures reported in the systematic literature limit a systematic analysis of the effects of early palliative approaches to care on specific outcomes. Outcomes were compared in all but one of the systematic studies which means that the

effects reported within the available literature are still preliminary at this point. Overall, the literature included in this report investigated these outcomes:

- symptom management (10,12,14,15,20,23,24,30);
- survival (10,12,14);
- quality of life for patients (10,12,14,15,20,23,24);
- quality of life for caregivers (15);
- quality of care (12);
- the need for aggressive care at end-of-life (14,15);
- the use of advanced directives (15);
- length of stay in hospital (15,27);
- cost (12,15,32); and
- patient and family satisfaction (12).

Symptom management and quality of life were the outcomes most often reported.

The authors of systematic review articles that compared like outcomes did report improved outcomes for symptom management and quality of life in some instances; however, some of these studies also found no significant difference for some of the same outcomes for early palliative care.

The strongest evidence of the benefits of early palliative care for patient outcomes involves cancer populations. A Cochrane review conservatively reported very low to low certainty that patients with advanced cancer that received early palliative care interventions in comparison to usual or standard care alone experienced small improvements in quality of life and symptom intensity. The review also reported uncertain effects on survival and/or on depressive symptoms for this population. Because these results were based on a small number of trials with small effect sizes, on trials that studied different populations, looked at different interventions and used different methods, the Cochrane review authors urge care in interpreting these results (10).

It is worth noting that evidence from two recent primary studies have since strengthened the case for palliative approaches to improve depression, finding that early integrated palliative care reduces depression symptoms in cancer patients (20,24).

Interestingly, a recent primary study (this study involved secondary analysis from a randomized trial) showed differing effects of early palliative care based on patients' age and sex. These differences were noted in quality of life, depression symptoms, and coping strategies among patients with advanced lung cancer. The authors found increased use of active coping and decreased use of avoidant coping in younger patients who received early palliative care whereas there were no significant benefits shown in older adults for this outcome. Also, improved quality of life and mood were shown for male patients who



received early palliative care but the same significant effects were not experienced by female patients (23).

A narrative review that examined various chronic disease populations in mixed settings found that most trials demonstrated improvements in quality of life, symptom control, overall survival, quality of care, and patient or caregiver satisfaction while others trials found no improvement for some of the same outcomes. These authors note that the available data are not yet conclusive but they take a less conservative stance than other authors, encouraging the use of simultaneous palliative care as the standard of care for patients with advanced chronic disease (12).

The overview by Davis et al. of evidence on advanced disease in various settings cited mixed findings across the study literature with some trials reporting benefits while others did not find any improvement (15). These authors examined why there might be differences in the findings among various reviews. The authors cited a range of methodological limitations (structure of interventions, care team compliance, definition of usual care, flawed study design and flawed procedures), differing definitions of early palliative care and palliative patient, and the models of care involved that can affect possible conclusions. Similar limitations are acknowledged and examined by many of the reviews we analyzed. Differences in study design, clinical conditions and settings, outcomes, and outcome measurements were commonly mentioned.

Only one systematic review discussed the *appropriateness* of the outcomes studied by the primary research studies contained within the review. This review suggested that health-related quality of life and symptom intensity are appropriate outcomes for advanced cancer populations and found that survival is a contentious outcome to measure, given that survival is not the main focus of palliative interventions (10).

Also worth noting is a White Paper on recommendations of the European Association for Palliative Care (EAPC) Task Force on outcome measurement for palliative care (34). Although this report speaks to palliative care in general, it likely has implications on early palliative care approaches as well. The EAPC found “that measures should be well-validated for the populations in which they are to be used” and that they should be appropriate for clinical care as well as research (16). These authors suggest that the key to comparing care across different settings and populations is to use validated outcome measures, stating that validated outcome measurement is necessary in order to understand different models and commonalities of care across different settings and populations. The EAPC Task Force report includes twelve recommendations to help introduce outcome measurement into practice in a way that makes outcomes comparable, both nationally and internationally.

Another recent systematic review that focused on end-of-life care highlighted a lack of evidence on the quality of patient-reported outcome measures for non-cancer chronic disease patients. These authors suggest that more research is necessary to develop a core

set of patient-reported outcomes that can be used across multiple end-of-life care settings and disease trajectories for patients with non-malignant chronic disease (16).

## Contextual Issues

Throughout the course of this project, we have tried to identify contextual factors unique to Newfoundland and Labrador that may influence the relevance and applicability of the research-based evidence on early palliative approaches to care within the province. Although it is difficult to identify specific contextual issues based on the limited evidence available at this time, a few potential contextual variables can be suggested.

### Demographic & Population Health Factors

Newfoundland and Labrador has the oldest and the most rapidly aging population in Canada, with seniors currently representing 19.1% of the population. Additionally, in this province, the average number of years a person at age 65 can be expected to live, is below the Canadian average. A lower life expectancy is considered an indicator of lower overall population health (35). Related to the province's below-average health status is the heavy burden of chronic disease, with 63 % of residents over the age of 12 having at least one chronic disease condition, such as heart disease, cancer, and lung disease (36). Definitive research evidence is not yet available on the specifics of how and when to incorporate palliative components upstream in the course of patient care. But as evidence emerges, it will be important for health care system professionals and decision-makers of the province to be attentive to the links that are made between chronic disease management and palliative care. There is potential for a large number of people in the province with advancing chronic disease to benefit from proven, early palliative care approaches.

### Geographic Factors

The distribution of the NL population over a vast geographical area makes access to care an important contextual variable to consider when planning palliative care approaches. Palliative approaches to care that rely heavily on specialized services may be less feasible for residents living in smaller communities with limited access to secondary and tertiary healthcare facilities. More innovative approaches may be required in rural contexts to meet the unique challenges of care delivery in these areas. Palliative approaches that are fully integrated into primary care and other basic services are likely to be particularly important for rural areas of the province. This approach could help patients, especially in rural areas, avoid unnecessary care setting transitions that can be costly and stressful in the last year of life caused by a lack of planning prior to the end of life (37). That being said, early palliative approaches to care may have to be planned differently for urban centres in the province.

### Developing a National Palliative Care Strategy

One final consideration is that the effective implementation of early palliative approaches to care in this province will have to be informed by any significant changes made to palliative

care approaches at the national level. Recently, the Government of Canada has called for the development of national strategy to address various barriers to palliative care, such as:

- a lack of public and professional awareness that palliative care does not just encompass end of life care;
- a lack of adequate education or training for non- specialist palliative care professionals;
- a lack of validated methods to identify patients appropriate for palliative care referral;
- a lack of infrastructure, care delivery models and regulatory standards; and
- a lack of adequate evidence base to inform safe and effective practice and the need for more funding for research on palliative care (38–40).

Provincial decision-makers will need to bear this emerging national strategy in mind as they develop approaches to early palliative care.

## Summary of Key Points

- Overall, there is very limited robust evidence for a palliative approach to care and for the effectiveness of integrating care an early stage in disease progression. Available evidence has yet to identify robust findings that apply to all settings and all contexts. At a fundamental level, both the parameters of the research and the definitions necessary to guide it are still being uncovered.
- The literature we reviewed featured a large number of approaches and models that differed widely in the terminology used, the diseases considered, the types of care included, and the outcomes discussed. These differences made it difficult for authors of the research we included in this report to draw clear comparisons and conclusions on how best to implement an early palliative approach to care at this time (12,15,17,19).
- More research is necessary to provide evidence on the effectiveness of an early palliative approach to care including evidence that validates tools for identifying patients early on, patient-reported outcome measures, and models of care.
- The best current evidence on early palliative care relates to studies of cancer patients for whom care is mainly delivered by palliative care specialists. Although this evidence is promising, research authors in the field consider the findings to be very preliminary and suggest that more research is necessary to confirm early findings (10,14,15).
- With regards to non-cancerous chronic disease populations, there is very little research evidence of good quality to rely on thus far. There is also no evidence that palliative

approaches to care and associated care delivery models that work for cancer populations would work for other chronic disease populations as a one size fits all model (15).

- As more evidence becomes available on appropriate approaches to early palliative care and their effectiveness on patient outcomes, there is potential for this upstream approach to care to have benefits for an aging population and for the high numbers of people living with advancing chronic diseases in Newfoundland and Labrador.

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## Appendix: Our Consultant

**Barbara Pesut** PhD, RN is a Professor in the School of Nursing at the University of British Columbia. She holds a Canada Research Chair (Tier 2) in Health, Ethics and Diversity. Her program of research explores the implications of religious, spiritual and geographic diversity for palliative care. Recent projects have examined ethical issues in rural palliative care, palliative family caregiving and educating nurses for a palliative approach. She is currently implementing a model of volunteer navigation in sites across Canada to better support those living with serious chronic illness.

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