Evaluation of an End-of-Life Program in the Community Setting

by © Catherine Noseworthy

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Abstract

Background and Purpose: The palliative end-of-life (PEOL) program is provided by Eastern Health to assist patients and families in accessing palliative care services in the home and community setting. These services include home visits by Registered Nurses to provide supportive services to eligible patients who are dying and want to stay at home or be discharged home from an acute care facility. Through my own observations and self-assessment, I have identified a need for a formal evaluation of the PEOL program in Rural Avalon. The purpose of this practicum project was to evaluate an existing PEOL program offered in a small rural community in NL.

Methods: An integrative literature review was conducted to examine and understand more on the topic of palliative and end-of-life care in rural communities. An environmental scan was completed to identify current and existing palliative care programs that address rural populations within Canada. Data collection included consultations with key stakeholders to identify issues related to end-of-life care planning in the rural district.

Results: Eight major themes were identified from the interviews, and recommendations made on how to improve end-of-life care services in the chosen rural community setting.

Conclusion: The findings from this evaluation support the requirement of the Eastern Health authority to implement changes to facilitate improvement to the current PEOL program in the rural community district. It has been found that rural communities face unique obstacles in accessing palliative and end-of-life care services at home. Recommendations have been made on how to improve the program so that patients feel secure in their decision to stay at home.

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To my parents, to whom I owe my value in education and work ethic. Thank you for always supporting me and encouraging me in all my endeavors. I am forever grateful.

Table of Contents

Introduction

The palliative end-of-life (PEOL) program is provided by Eastern Health to assist patients and families in accessing palliative care services in the home and community setting. These services include home visits by Registered Nurses to provide supportive services to eligible patients who are dying and want to stay at home or be discharged home from an acute care facility. The overall goal of the program is to provide comfort measures, and to support patients and their families. Services included under the PEOL program include: Nursing visits, home care, medical equipment and supplies, financial coverage for pharmaceuticals for pain and symptom management, consultative services (e.g. social work, occupational therapy), and grief and bereavement counselling (Eastern Health, 2017).

Eligibility into the program is based on the following criteria: (1) The patients have a terminal illness or end stage diagnosis, (2) the patient requires palliative end-of-life home care and expresses a wish to palliate at home, and (3) treatment is based on comfort measures only and death is anticipated. Assessment for eligibility into the program also includes the completion of the Palliative Performance Scale version 2 (PPSv2), Palliative Prognostic Index (PPI), and the Edmonton System Assessment Scale (Eastern Health, 2017). Entry into the program is typically initiated when death is anticipated within the last four weeks of life. However, according to Eastern Health Policy, community health nursing support and equipment may be provided prior to the four weeks upon consultation with the PEOL coordinator.

Background of Study

Through my own observations and self-assessment, I have identified a need for a formal evaluation of the end-of-life program in Rural Avalon. I have worked as a Community Health

Nurse (CHN) in various community health sites, and currently I work in a one nurse community health office in a rural district. Through these experiences, I see the unique challenges rural communities face when accessing palliative care services in the home setting. Additionally, to my knowledge there has not been a formal evaluation of the end-of-life program since its implementation.

This project is important as Newfoundland and Labrador is currently experiencing costly healthcare challenges with a growing aging population, a high incidence of chronic disease, and large rural populations (Government of Newfoundland & Labrador, 2018). Providing quality, timely access to end-of-life care services in the community setting can help alleviate undue suffering, prevent unexpected visits to emergency departments, and reduce overall costs to healthcare organizations. An evaluation of the end-of-life program is needed so that recommendations can be made on how to improve the program so that patients feel secure in their decision to stay at home.

Purpose of Study

The overall purpose of this practicum project was twofold. First was to formally evaluate the existing PEOL program offered through Eastern Health with a focus on the rural district. Second, based on this evaluation, I would offer recommendations to the regional health authority on how to improve the program to better serve end-of-life patients and their families who wish to die at home.

Objectives

Objectives for this practicum project included the following:

1) To identify areas within the end-of-life program in Rural Avalon that require improvement by completing consultations with key stakeholders including community health nurses, nurse practitioners, physicians, social workers, occupational therapists, and end-of-life coordinators that work in the rural district.

2) To complete a comprehensive literature review and environmental scan to identify evidence to support this evaluation and the recommendations made to the Eastern Health authority.

3) To evaluate the effectiveness of the end-of-life program in meeting the programs stated goal "To comfort and support clients and their caregivers through a combination of active and compassionate services that enable the client to stay at home or to die at home if that is their wish" (Eastern Health, 2017, para. 1). This will be completed by analyzing the data collected from key informants' interviews and offer recommendations to Eastern Health regarding how to improve the program so that patients and families feel secure in their decision to stay at home.

Overview of Methods

A comprehensive literature review was completed to develop a greater understanding of end-of-life care in the community setting. The search was conducted using two databases PubMed and CINAHL. Search terms included "end of life" and "rural communities". Under "Subject: Major Heading" in the CINAHL database, "palliative care", "terminal care", "hospice care", "terminally ill patients", "rural health services", and "rural areas" were selected. An environmental scan was completed to identify and examine current palliative care programs that service rural populations within Canada, and to apply what has been learned in preparing recommendations to Eastern Health on how to enhance the current end-of-life program in the rural district.

Lastly, consultations were completed with 7 key stakeholders who have been directly involved in end-of-life care delivery in the rural district. Interviews were identified as the most appropriate and beneficial methods for data collection to receive meaningful responses from all participants. Recruitment included directly contacting participants either through email or in-person contact to identify interest. All participants were eager to participate and provided consent prior to commencing the interviews. All participants were asked 5 questions (see Appendix A) and were recorded using a secure password protected personal Apple iPhone device. Consent for recording was verbally obtained by all participants. All recordings were sent to a secure personal computer, and interviews were then deleted from the iPhone.

Participants included a primary care physician, a social worker, two registered nurses, a PEOL coordinator, an occupational therapist, and a nurse practitioner. All data including in-person and over the phone interviews were collected at the community health office site located in the rural district. Permission was obtained by all participants prior to commencing the interviews. Participants were advised on the purpose of the interview (to evaluate the PEOL program). Permission and consent were obtained from participants prior to being recorded on the iPhone device for the purposes of data collection.

Summary of Literature Review

Five major themes were identified from the literature review (see Appendix B). These included: (1) Access to end-of-life care, (2) advanced care planning, (3) financial barriers, (4) education, and (5) volunteering.

Access to End-of-life Care

Access to end-of-life care in rural communities was a major theme identified in the literature. Physician unavailability, lack of home care workers to assist with activities of daily living, recruitment and retainment of healthcare professionals including community health nurses (CHNs), and long driving distances to access services were some of the key barriers that patients and families experienced when attempting to access palliative and end-of-life services in rural settings. Inequitable service delivery in the form of the number of visits made by community health nurses to end-of-life patients were found in the literature. Wilson et al. (2009) identified that rural areas faced unique challenges in developing and maintaining end-of-life services in communities. One of the reasons for this was the recruitment and retainment of health care professionals providing end-of-life services. It was identified that the loss of even one health care professional can have a profound impact in small remote communities.

Advanced Care Planning (ACP)

Several challenges were found that created barriers in timely, and effective end-of-life care planning. Fowler and Hammer (2013) identified that barriers may be related to lack of time for discussions concerning end-of-life care, and the clinician’s skill and interest in having difficult discussions surrounding the topic. The Canadian Institute for Health Information (CIHI) (2018) have reported that few Canadian physicians specialize in palliative care, with just 12% of medical students being required to complete a clinical rotation in a palliative care field. Even more surprising, is that three out of five physicians state that they do not feel well prepared in caring for individuals in need of palliative care. These statistics are concerning, as ACP should begin in the early stages of diagnosis of a life-threatening illness so that a patients’ wishes are clearly understood and disagreements do not arise that may lead to undue suffering and stress on patients and families.

Financial Barriers

Literature examining the costs associated with end-of-life care illustrate that there are financial barriers and inconsistencies between rural and urban communities in Canada. A study by Dumont, Jacobs, Turcotte, Turcotte, and Johnston (2015) found costs related to medical equipment and aids to be 63.3% higher in rural regions. Further, prescription medication costs were higher in rural regions (20.1%), while urban regions had higher home care costs (25.8%).

Education

Specialized education surrounding end-of-life care delivery was a key theme identified in the literature. Wilson et al. (2009) found as a result of their ethnographic study in Alberta that rural health care professionals face unique challenges in gaining and remaining current in palliative and end-of-life knowledge. This was found to be a result of no available replacements for rural health care professionals to attend educational events, and without a replacement their absence would be highly felt by the community. Furthermore, it was identified that mental health professionals, counsellors, and psychologists were rare in rural settings meaning that available health care professionals had to be “generalists” and a “jack of all trades”.

Volunteering

Volunteering was identified in the literature as an important role in the delivery of end-of-life care in the community setting. A study by McKee, Kelley, and Guirguis-Younger (2007) examined the roles of hospice volunteers as “being there” and “just listening”. Their ideal role was described as providing companionship and support to individuals in rural areas who were at risk of dying alone without adequate care. An important piece of their volunteer work also included establishing a therapeutic relationship and completing tasks health care professionals typically do not have time to perform.

Summary of Consultations

Consultations were completed with key stakeholders who provide and support the end-of-life care process in the rural district (see Appendix C). Data collection included in-person interviews and over the phone interviews. In total seven interviews were completed, two in-person and five over the phone. Interviews lasted from four minutes and thirty-six seconds to twenty-nine minutes and three seconds. Questions were left open-ended, and participants were encouraged at the end of the interview to add information they felt would benefit the evaluation. Eight major themes were identified from the consultative process including the following: (1) Physician support, (2) access to equipment, (3) financial and time constraints, (4) mental health, (5) interdisciplinary teams, (6) home support workers, (7) palliative care education, (8) access to medications.

Physician Support

Access to family physician support in the rural district was identified throughout the consultations as a limitation when providing end-of-life care in the community. It was acknowledged that many physicians do not make home visits, providing significant challenges when a patient required the assistance of a physician. It was addressed that many individuals do not have a family physician, therefore making home palliation difficult. One participant identified that patients often have to present to their local emergency department to receive necessary pain medication when they experience a pain crisis if there is no prescriber. One participant identified Nurse Practitioners as a potential solution to this problem, especially in rural areas where physician shortages exist, and prescribers are needed.

Access to Equipment

It was identified that not all the recommended equipment is covered under the PEOL program. While equipment is available to help support patients during the end-of-life, one participant identified that not all equipment is covered under the program such as transfer belts and certain bathing equipment. This may impact a patient's quality of life and their ability to remain at home if the necessary equipment is not available to families to care for their loved one.

Financial and Time Constraints

Lack of staff including Registered Nurses and Nurse Practitioners was identified as a significant barrier to timely access to PEOL services. It was acknowledged that large caseloads make it difficult to see patients as quickly as they would prefer. Travel time was another barrier to providing end-of-life care at home given the geographically dispersed nature of the rural district. Time and financial constraints for physicians was identified in the consultations. Waitlists for clinics were identified as typically 4-5 weeks in the rural district making it difficult for physicians to complete home visits for end-of-life patients. Further, financial constraints for fee for service physicians were identified as barriers for physicians to complete home visits.

Mental Health

Although not a common theme throughout the consultations, one participant identified limited mental health services for end-of-life patients. The lack of grief counselling services in the area was identified as a barrier. Better connection with mental health and spiritual care would strengthen the PEOL program and assist patients and their families through the grieving process.

Interdisciplinary Teams

It was identified that working as a part of the team was the best approach in providing end-of-life care in the community setting. Participants acknowledged that without a team approach care provision would be deemed “impossible”, as often health care professionals must rely on one another to support an end-of-life patient.

Home Support Workers

Lack of formal support to assist patients and families was identified as a significant barrier. Often patients end up in an emergency department given the lack of home support services to help families caring for loved ones. It was also identified that some home support workers do not want to drive long distances to provide end-of-life support to patients making it a challenge to recruit workers in rural geographically dispersed areas.

Palliative Care Education

Throughout the consultations it was identified that there is a need for more specialized education surrounding palliative care and having specialized Registered Nurses in end-of-life care in the community setting. Further, it was found that some health care professionals do not fully understand when a patient is “end-of-life”, which in turn creates challenges to timely access to the end-of-life program.

Access to Medications

Access to medications in rural pharmacies was identified as a limitation, especially when end-of-life patients require pain medication. Often, smaller pharmacies do not have all the necessary palliative care medication in stock and families must drive long distances to receive the medication from a larger pharmacy.

Summary of Research

It has been identified throughout the literature review, environmental scan, and the consultations that rural communities, including the rural district examined here, face unique obstacles when accessing end-of-life care services in the community setting. Recommendations have been made to Eastern Health on how to improve the program so that patients and families feel secure in their decision to stay at home.

Recommendations

Hiring more nurse practitioners under the Community Supports Program (CSP) for Rural NL has been identified as a key solution to the current physician shortage. Nurse Practitioners are a fiscally responsible solution to the lack of prescribers in rural communities. Within their scope of practice, nurse practitioners can provide a wide range of services for palliative patients and help patients stay at home longer if it is their wish. Expanding service delivery to include 24/7 access to a palliative health care provider is needed to improve the current PEOL program. As found throughout the consultations, if an emergency event happens over a weekend or after community health hours patients must seek necessary medical care from their local emergency department. This can be alleviated by expanding community health service delivery hours.

Specialized education for paramedics to provide palliative and end-of-life care to patients at home would help individuals, families, and health care organizations. Throughout the environmental scan it has been identified as a successful approach by certain provinces to help expand service delivery and accessibility in the community setting. Further, it is recommended that Eastern Health offer specialized palliative and end-of-life care education for all health care professionals which would increase knowledge and comfort levels for all involved. This would include making it mandatory for all members of the health care team in the rural district to receive Pallium LEAP training. Ensuring that relief to attend these educational events is also required so that patients and their families do not feel the loss of a health care professionals' absence when attending these events.

Although interdisciplinary teams currently exist in the rural district, it has been identified that better integration may improve end-of-life care for patients and families. Having a clearer understanding of each other's roles in providing end-of-life care is required to improve collaboration among a health care team. This would better streamline services and provide better outcomes for patients and health care professionals. Having regular team meetings through Skype is one fiscally and time efficient option given the geographically dispersed nature of the district.

The hiring of a discharge planner at the health care facility in the rural district would ensure continuity of care from the acute care setting to the community setting. It was identified by key informants that often patients are not being referred to palliative care services in a "timely" manner. The presence of a discharge planner who specializes in palliative care delivery would better streamline processes when patients wish to be discharged in the community for end-of-life care. The development of standing orders for medications and an attached "DNR" (do not resuscitate) form would benefit both patients and Eastern Health. This may prevent the need for patients to receive care from an emergency department where a physician or a nurse practitioner (possibly unfamiliar with the patient) would have to write an order. The last recommendation to Eastern Health includes expanding the current "Doorways" walk-in mental health program to include home visits for end-of-life patients. This would expand access to include counselling services for end-of-life patients and their families in their home where otherwise these services would be inaccessible.

Advanced Nursing Practice Competencies

Through the process of completing the Master of Nursing practicum project each of the following advanced nursing practice competencies have been met as defined by the Canadian Nurses Association (CNA) (2019): Research, leadership, consultation and collaboration, and education.

Research

According to CNA (2019) advanced practice nurses are able to “identify, appraise, and apply research” (p.32). By completing this practicum project, I have collected data by completing a comprehensive literature review, environmental scan, and completing consultations with key stakeholders in the rural district to identify areas within the PEOL program that require improvement. I have developed my competency in using data collection and analysis methods throughout this project. I have also intensively analyzed all data and applied my findings by providing carefully considered recommendations to Eastern Health on how the health authority can improve the existing program.

Leadership

My leadership skills were greatly enhanced in taking on this project. It was an initiative that was needed in the rural area for some time. In addition, throughout the experience, I demonstrated leadership by actively engaging with key stakeholders and completing in-person and over the phone interviews to collect data to advocate for enhanced care delivery for the rural district. According to CNA (2019), advanced practice nurses are able to “advise clients, colleagues, the community, health-care institutions, policy-makers, and other stakeholders on issues related to nursing” (p. 33). This competency was met by analyzing the data collected from the consultations and applying appropriate recommendations to Eastern Health on how to improve the PEOL program. I also completed a presentation to palliative care coordinators and managers of Eastern Health in February 2020 outlining my findings and recommendations.

Consultation and Collaboration

CNA (2019) defines an advanced practice nurse as able to “consult and collaborate with members of the health-care team and stakeholders whose services impact the determinants of health” (p. 34). Throughout this practicum research project, I have consulted and collaborated with many members of the health care team including all key stakeholders in the rural district and key informants with the PEOL program. These stakeholders were individuals from various disciplines; by engaging with them, it has contributed to my intra and inter collaboration experiences. I have also collaborated with my supervisor Dr. Nicole Snow Ph.D., and successfully applied all feedback to my work throughout this project. I have also been collaborating with a Primary Care Manager who is currently completing province wide research on palliative care service utilization within all aspects of care within the trajectory of the health authority.

Education

According to CNA (2019) advanced practice nurses are able to “contribute to nursing and the health-care system by disseminating new knowledge through formal and informal channels, including presentation and publication at the municipal, regional, national and international levels" (p. 31). I have met this competency by delivering a formal presentation of my methods, findings, and recommendations to the Faculty of Nursing at Memorial University of Newfoundland and Labrador (MUN) and to some of my student peers. I plan on delivering another formal presentation to my colleagues with the Community Support Program in early 2020.

Next Steps

My next steps after this practicum research project is to deliver my findings and recommendations to Eastern Health officials to further expand my practicum report findings. I also plan on collaborating further with the Primary Care Manager conducting research in the area and find ways on how my recommendations can be considered by policy makers so implementation can take place.

Conclusion

Rural communities do face disparities compared to urban regions in end-of-life care service delivery. In this report I have illustrated how rural areas face several unique obstacles that influence palliative patients' ability to seek end-of-life care services in the home. Providing quality, timely access to end-of-life care services in the community setting can help alleviate undue suffering, prevent unexpected visits to emergency departments, and reduce overall costs to healthcare organizations. An evaluation of the PEOL program in a district in NL has been completed and recommendations made on how to improve the program so that patients feel secure in their decision to stay at home.

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Appendix A

Interview Questions

Interview Questions

1. Describe your current role as a health care provider in the delivery of end-of-life care in the community setting.

2. Identify limitations to your practice when providing palliative care services under the Palliative End-of-Life (PEOL) program.

3. What value do you place as a health care provider on end-of-life services in the community setting?

4. Explain areas of the PEOL program that work well, and areas you would like to see modified?

5. In your experiences with the PEOL program, what challenges have rural families faced when choosing to stay at home to palliate?

Appendix B

Towards end-of-life in the community setting:

An integrated literature review

Catherine Noseworthy

Memorial University

Towards end-of-life in the community setting: An integrated literature review

The history of palliative care can be documented back to the 4th century when Christians in Europe provided care to the sick and the poor. Step forward to the 20th century and the term "hospice" was first applied to specialized care to dying patients by physician Dame Cicely Saunders. Her work with terminally ill patients began in 1948, and eventually led to the first hospice in London (National Hospice and Palliative Care Organization, 2016). Since that time, hospice palliative care has developed nation-wide and is an important part of healthcare delivery throughout health care systems and organizations. According to the Canadian Hospice Palliative Care Association (2019), in Canada, both terms "palliative" and "hospice" have the same meaning. Another term "end-of-life care", focuses on the imminent near death of an individual. This differs from palliative care which is deemed appropriate upon the initial diagnosis of a serious illness. The term may be even be applied when patients are seeking cure focused medicine (Ontario Medical Association, 2016).

Historically, palliative care has been provided in institutions through hospitals and hospice centres. However, due to current healthcare challenges with a growing elderly population and high incidences of chronic disease, a shift to community-based palliative care has been of interest to many healthcare organizations to help reduce costs and keep individuals at home longer. The Canadian Institute for Health Information (CIHI, 2018a) states that the need for palliative care is expected to rise in Canada with 7 of the top 10 causes of death resulting from chronic conditions. While we understand the importance of palliative care, results from the CIHI indicate troubling findings. Although the report indicates that most Canadians would prefer to die in their own home, fewer than 1 in 6 people (15%) who died in 2016-2017 received publicly funded palliative home care. It is therefore warranted to understand the obstacles individuals face in receiving palliative care in the community setting, especially in rural areas. Throughout this paper, I will discuss the results of a comprehensive literature review with the anticipation it will provide the evidence and insight required to understand the topic further. I will complete this by critically appraising the literature, and I will discuss and draw relevant conclusions through the use of an integrative approach.

Literature Review

A comprehensive literature search was conducted using two databases Pubmed and CINAHL. The initial search included the terms “end of life” and “rural communities”. A librarian from Memorial University (MUN) libraries was consulted to assist with the retrieval of relevant literature. Under “Subject: Major Heading” in the CINAHL database, “palliative care”, “terminal care”, “hospice care”, “terminally ill patients”, “rural health services”, and “rural areas” were selected. The results from the CINAHL database included the retrieval of 21 articles. From the 21 results, 5 articles were included in the literature review. Many of the articles did not correspond with rural community-based palliative care and focused on in-patient care, and medical assistance in dying. In the Pubmed database, 95 articles were recovered in total using the same search terms. Additional filters used included: species “Humans”, text availability “Free Full Text”, and publication dates “10 years”. Four articles were incorporated in the literature review. Many articles were excluded for the same reason using the CINAHL database. Additionally, several articles did not translate with palliative care and focused on chronic conditions. To be specific with the intentions of this literature review, end-of-life care needed to be the forefront of the literature. After an intense review, major themes were identified. Grey literature including reports and articles were also incorporated into this literature review. A discussion of the major themes will follow.

Access to End-of-Life Care

Accessessibility to palliative care in rural communities was a key theme identified throughout the literature. Artnak, McGraw, and Stanley (2011) identified unique challenges rural communities in America face when accessing end-of-life care. Through a review of the literature, they found that physician unavailability, lack of health care workers to assist with activities of daily living in the home, and long driving distances to access health services were the top challenges rural residents faced when attempting to receive end-of-life services. Wilson et al. (2009) found similar findings after completion of an ethnographic study in Alberta, Canada. One of the main themes identified was that rural areas faced unique challenges in developing and maintaining end-of-life services in communities. One of the reasons for this was the recruitment and retainment of health care professionals providing end-of-life services. It was identified that the loss of even one health care professional can have a profound impact in a small remote community, as it may take years to find a replacement. Individuals identified through interviews that if they wanted a second opinion from another physician or did not have faith in a particular physician, they would have to travel long distances to another community to seek the service. These driving distances acted as barriers themselves. Often, taxi services were limited in remote areas, creating obstacles for the elderly to receive access to required health care services. Although not specifically mentioned in the literature, access to public transportation in rural areas may be limited or non-existent in comparison to urban areas. Even if available, obstacles still remain, as many end-of-life patients may be physically incapable of using public transportation as a method of travel.

Challenges related to accessing nursing homecare services in rural communities was also identified throughout the literature. A retrospective cohort study completed in three Canadian provinces examined the utilization patterns between the provinces. Seow et al. (2017) found that the smallest community sizes had the lowest proportion of patients receiving nursing homecare services each week compared to the larger community sizes. As expected, as death approached, the number of nursing visits increased in both the small and larger communities. The gap in services remained as a person’s death approached. This finding may relate back to evidence found in the literature that there is a lack of health care professionals, including community health nurses (CHNs) available to provide services. Further, long driving distances due to the geographical makeup of rural communities may also be a limiting factor nurses face when providing care to end-of-life patients. A similar retrospective study by Lavergne et al. (2015) studied palliative care program (PCP) enrollment data in three districts in Nova Scotia, Canada. The findings indicate that urban residents had higher odds of enrollment in a PCP than their rural counterparts. Likewise, those living a greater distance from a PCP had a higher chance of hospitalization.

As the literature suggests, accessibility to health care services is a barrier rural communities face. Nevertheless, it is also important to understand healthcare professionals’ perspectives on the obstacles they face in providing care to rural communities. Kelley, Habjan, and Aegard (2004) conducted a survey on palliative healthcare providers in Northwestern Ontario who completed at least 30 hours of a palliative educational program delivered by the Northern Educational Centre for Aging and Health (NECAH) in Lakehead University, Ontario. Seventy-four participants stated that insufficient home care and home visits was the biggest obstacle they faced in providing high quality palliative care. More than 50% of respondents stated that lack of 24-hour availability of healthcare professionals, along with a lack of time was significant barriers to providing quality end-of-life care. Palliative healthcare professionals also identified a lack of funding for equipment and supplies, and lack of communication and coordination between health care providers as an obstacle. These findings are not surprising as it has been identified through similar findings in the literature that rural communities face greater challenges in accessing end-of-life health care services in comparison to urban regions. Therefore, an argument can be made that not all Canadians have equitable access to palliative care services. This can have profound negative impacts on an individual's quality of life, especially if their wish is to die at home. Barriers to end-of-life services in the community may lead individuals to seek the necessary care in acute care facilities which are known to be costly for health care organizations. For example, according to the Canadian Institute for Health Information (2018b), 42% of Canadians died in acute care hospitals in 2016-2017. Many were people with cancer who were found to be 3 times more likely to receive palliative care services compared to individuals with other illnesses. Understanding the barriers rural communities face in accessing end-of-life care services can inform healthy public policy in the value of quality end-of-life care services.

End-of-life Planning

End-of-life care planning also known as advanced care planning (ACP) was another identified theme in the literature. A number of challenges were found that created barriers in timely, and effective end-of-life care planning. According to the Canadian Nurses Association (2018), effective end-of-life care planning starts with having the conversation early and revisiting the topic through an individuals life. Nurses are key in starting the conversation to help encourage individuals to reflect on their wishes. Middlewood, Gardner, and Gardner (2001) completed a retrospective research study to examine the medical records of inpatients who died in a hospital in Australia. They found from a sample of 100 patients that 46 of those patients were documented as having a DNR completed within two days or less of the patient's death. Of the 46 patients, 12 had their DNR signed on the same day of death. Artnak et al. (2011) state that often the discussions with patients regarding their wishes are not held. This may lead to unfortunate circumstances where a patient may be too ill to make their own decisions especially regarding resuscitation measures. Cultural values and religion may impact a patients's desire to engage in early end-of-life conversations and adequately prepare for ACP. This may lead to unexpected medical decision making that can lead to undue suffering on patients and their families.

A report by Fowler and Hammer (2013) highlights the barriers clinicians have with their patients concerning end-of-life care plans. The identified barriers may be related to lack of time for discussions concerning end-of-life care, and the clinician's skill and interest in having difficult discussions surrounding the topic. Disagreements concerning a patient's wishes may be another challenge when planning for end-of-life care. Historically, family physicians were often identified as the "decision maker". However, recently a shared decision making approach has evolved and includes the patient, their support network, and the health care team. Unfortunately, disagreements do arise when a patient's wishes are unknown and the patient can no longer provide consent. Therefore this emphasizes the importance of early end-of-life care planning so patients wishes are clearly understood, and disagreements do not arise that may lead to undue suffering and stress on both patients and families.

Often, family physicians are the primary and initial contact for individuals with a terminal illness. It is therefore paramount that physicians have the knowledge and skills surrounding palliative care so patients have early discussions and timely access to palliative care options. The Canadian Institute for Health Information (2018b) released a report that few

Canadian physicians specialize in palliative care, with just 12% of medical students required to complete a clinical rotation in a palliative care field. Even more surprising, is that three out of five physicians state that they do not feel well prepared in caring for individuals in need of palliative care. These statistics are concerning, as ACP should begin in the early stages of diagnosis of a life threatening illness. If health care professionals are not comfortable discussing palliative care options, it may limit a patient's access to quality, timely palliative care.

Financial Barriers

The *Canada Health Act* is Canada's federal legislation for publicly funded health care insurance. The Act's primary objective is to "protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Government of Canada, 2018a, pars. 2-4). Unfortuantely, literature examining the costs associated with end-of-life care illustrate that there are financial barriers and inconsistencies between rural and urban communities in Canada. A Canadian quantitative longitudinal prospective study by Dumont, Jacobs, Turcotte, Turcotte, and Johnston (2015) compared the total costs associated with a 6 month participation in a palliative care program (PCP) between rural and urban areas in the provinces of Nova Scotia, Quebec, and Manitoba. Their goal was to evaluate the costs shared between the public health care system (PHCS), the family, and not-for-profit organizations. Data on both the urban and rural samples were drawn from two previous studies in recent years from the same authors. The urban sample consisted of 125 patients enrolled in a PCP and 127 informal caregivers, and the rural sample consisted of 80 patients enrolled in a PCP and 84 informal caregivers. They found through statistical analysis that the total cost for a 6 month participation in a PCP reached CAD $26,652 (± 1.704) in urban regions, and CAD $31,018 (± 1159) in rural regions (a 16.4% increase comparison). Costs related to medical equipment and aids were found to be 63.3% higher in rural regions. Further, prescription medication costs were higher in rural regions (20.1%), while urban regions had higher home care costs (25.8%). In total, families paid 20.8 % and 21.9% in the rural and urban areas, with the PHCS assuming 76.6% and 77.7% of the mean total costs.

Artnak et al. (2011) reviewed the literature for costs associated with chronic disease and end-of-life care with a focus on rural and urban areas. Understanding the financial barriers associated with chronic disease management and its impact on end-of-life care delivery is important as financial barriers may impact an individual’s ability to seek required treatment and services. Approximately $7,900 is spent yearly on individuals who have a chronic disease in America. This is expected to increase in the next 20 years do to a rise in chronic illness such as diabetes, cancer, and heart disease (Centers for Disease Control and Prevention, as cited in Artnak et al., 2011). Individuals with chronic disease also tend to pay more out of pocket expenses which may limit one’s quality of life. Artnak et al. (2011) discuss the health care financing costs associated with chronic illness and end-of-life. One of the issues they identified are the expensive “last chance” therapies some end-of-life patients endure that are often ineffective and unnecessary. They also mention the demographics of rural areas and how rural areas tend to be “poorer” in comparison to their urban counterparts. The authors state that this is often contributed to an elderly population, where the working class population tend to leave rural areas to find employment. With a growing elderly population and a smaller percentage of working class individuals, communities as an entirety are often financially disadvantaged compared to urban communities with higher working class populations. Further, transportation concerns do to availability and cost also impacts an individual's access to required service delivery. Wilson et al. (2009) also support this finding in their ethnographic study where individual's cited travel as the most prevalent challenge in accessing specialized care.

It is evident that those receiving palliative care in rural communities face greater financial hardships than these in urban communities. This can have negative impacts on individuals, especially the elderly and disadvantaged groups. Access to end-of-life care programs should be accessible for all individuals regardless of socioeconomic status. Strengthening palliative care programs to include financial coverage for all required equipment, medications, and home care costs will help eliminate disparities among both urban and rural areas, and allow all individuals to participate in an end-of-life program. This would save overall healthcare organizational costs, as it would help prevent acute care admissions and help support individuals in their wish to die at home.

Volunteering in Palliative Care

Volunteering in palliative and end-of-life care was another theme observed in the literature. A qualitative study conducted by McKee, Kelley, and Guirguis-Younger (2007) in Northwestern Ontario examined the motives for hospice volunteering, how volunteers understand their role compared to their urban counterparts, and who they serve. A phone interview was conducted with 13 rural hospice volunteer coordinators in the region. Themes were identified from the interview data. These included "being there" and "just listening". Simply being present with end-of-life patients was identified as an important role as a palliative volunteer. Their ideal role was described as providing companionship and support to individuals in rural areas who were at risk for dying alone without adequate care. An important piece of their volunteer work was noted to establish a therapeutic relationship. Therefore, the coordinators identified the importance of receiving a referral early and not days before a patients's death when they would find it difficult to establish a relationship. The volunteers noted that their part is not to replace health care professionals, but to complete tasks they did not have time to do. Motivation for volunteering stemmed from an obligation to the elderly in their community. Many of the volunteers acknowledged that if it was not for palliative volunteers, many of the elderly would be at risk of dying alone and keep spending their last years without care and companionship. Rural and urban differences were also found. Volunteers recognized that their rural patients were not the typical “palliative patient”. Volunteers found they may have palliative patients for months to years, due to the large number of chronic conditions in rural areas. Caring for individuals at the end-of-life with chronic conditions may be prolonged in comparison to individuals with acute care illnesses whereby the illness takes on a different course such as different forms of cancer compared to dementia or cardiovascular disease. This needs to be taken into consideration when caring for individuals in rural areas especially in relation to caregiver burnout and the quantity of rural volunteers willing to provide long term care to community residents.

A similar study by Whittall, Lee, and O'Connor (2016) examined Austrailian and international literature for factors that impact palliative care and volunteering in rural communities. They found that many palliative care volunteers do not agree with the term “palliative care” as they feel it expresses imminent death of an individual. They feel the term influences their role especially in rural communities where many individuals have chronic illnesses. Moreover, Whittall et al. (2016) suggest that more palliative care volunteers are needed to meet the needs of an aging population. This was also identified as a strategy to help assist with equal provision of palliative health care services in both rural and urban communities.

Education

In December 2018, the federal government passed a bill to create a framework for palliative care in Canada. The *Framework of Palliative Care in Canada* was created on December 4, 2018. According to the Government of Canada (2018b) the framework acts as a guideline for all palliative care stakeholders, and it focuses on important issues such as: Training and education for healthcare professionals; promoting research; supporting health care professionals; and ways to support access to palliative care regardless of location. This is a significant step for palliative care in Canada as it sets out a specific plan to help streamline palliative care services across the country. Throughout this review, the literature discussed the requirement for healthcare professionals to have specialized palliative care knowledge, especially in rural communities. This is understandable given the unique demographics and limited number of health care professionals to provide the necessary care. Hence, it is a positive movement by the Government of Canada to recognize the need to improve palliative care education and access across the country.

Additionally, Kelley et al. (2004) found that palliative care providers in rural communities are “generalists”, as palliative care is only one aspect of their work. They determined that palliative care education is very important in helping develop not only knowledge and skill but also in increasing respondents comfort level in providing end-of-life care after the educational program. Respondents also stated they were able to better communicate with patients and their families, acknowledge a patients’s emotional and spiritual needs, and provide better emotional support. Wilson et al. (2009) found as a result of their ethnographic study that rural health care professionals face unique challenges in gaining current end-of-life knowledge as often there were no replacements available and their absence would be felt by the community. This is an unfortunate scenario, as lack of current educational guidelines for physicians, nurses, and other health care providers directly disadvantages rural communities. In order for health care professionals to provide quality care as evidenced by Kelley et al's. (2004) study, health care organizations and governments have to recognize the impact palliative care education has on improving patient outcomes.

Conclusions and Future Research

It is now evident through a review of the literature that there is sufficient evidence to suggest that rural communities do face disparities compared to urban regions in end-of-life care. It has been illustrated that rural areas face obstacles in relation to accessibility to end-of-life services, equipment, and medications. Travel has been identified as a significant obstacle for individuals, especially the elderly and individuals struggling financially. Research findings indicate that individuals enrolled in a palliative care program in rural areas face significantly higher costs than their urban counterparts. This may impact a patients's ability to stay at home to palliate, and may influence an individual's decision to die in an acute care setting. Specialized educational programs surrounding palliative care has been found to improve health care professionals knowledge on end-of-life care, and how they treat end-of-life patients. Further, palliative care volunteers have been shown to have a positive impact on palliative patients, and may be a solution to help support individuals in their decision to remain at home. While we are clear on the obstacles rural communities endure, future research is required to understand how palliative care programs in rural communities can be strengthened to overcome the many challenges in accessing end-of-life care.

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Literature Summary Tables

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: "Examining palliative care program use and place of death in rural and urban contexts: a Canadian population-based study using linked data" (Lavergne et al. 2015) Purpose: To examine the factors associated with enrollment in a palliative care program (PCP), and place of death across urban and rural districts of Nova Scotia, Canada.	Setting: Three districts in Nova Scotia. Nova Scotia vital statistics data were used to make connections. Sample: All residents of Cape Breton (CB), Capital Health (CH), and Colchestor East Hants (CEH) who were 20 years and older and died between 2003 and 2009 were included. Exclusion criteria were residents who died of mental health, accidental death, and unclassifiable causes as the researchers determined that they are typically not candidates for palliative	Design: Retrospective population study. Methodology: Descriptive statistics using logistic regression at a 95% CI were used to analyse the demographic, geographic, and socioeconomic predictors of PCP enrollment. Place of death was also analyzed using logistic regression. Analysis was completed initially with all study participants and then stratified by	Results: Overall, 40.3% of study subjects were enrolled in the PCP. 73.4% died in hospital. Women and participants younger than 85 were more likely to be enrolled. Urban residents had higher enrollment rates than their rural counterparts (OR: 1.51; 95% CI: 1.29, 1.77). Residents who had greater	Strengths: Large sample size. Appropriate statistical tests were used. Logistic regression used to control for confounding. Odds ratio were used by researchers. Research was approved by an ethics board. Data collection was controlled, and exclusion criteria was acceptable for the study's purpose.	Conclusion: The overall quality of the study is rated as high according to the Public Health Agency of Canada (2014).

	care. N= 23,860 were included in the study.	the three districts. PCP enrollment was a predictor of decreased likelihood of dying in hospital (OR: 1.05; 95% CI: 0.99, 1.12). This effect was not found to be a significant factor in the district of CEH.	distances from a PCP had lower odds of enrollment (OR:0.33; 95% CI: 0.27, 0.40).	<u>Limitations:</u> Sample was drawn from three districts in Nova Scotia. Generalizability of study findings is unknown. The inclusion of other provinces/ districts could improve generalizability.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: "Does access to end-of-life homecare nursing differ by province and community size?: A population-based cohort study of cancer descedents across Canada" (Seow et al. 2017) Purpose: To examine the utilization patterns of end-of-life homecare nursing among cancer decedents in three Canadian provinces: Ontario (ON), British Colombia (BC), and Nova Scotia (NS).	Setting: Cancer patients who received homecare nursing in three Canadian provinces ON, BC, and NS between 2004 and 2009. Sample: The sample included N= 83,746 cancer decedents who met the inclusion criteria of 19 years and older, at least one homecare nursing visit from their diagnosis and at least one within 6 months of their death.	Design: Retrospective population-based cohort study. Methodology: A calculation of the proportion of patients receiving end-of-life homecare nursing was calculated for each province. A comparison between provinces also took place. An examination of statistical difference between three time points: 26, 13, and 1 week prior to death was completed between the three provinces. Statistical significance	Results: All patients included in the study had at least one home visit in the last 6 months of life. In all three provinces, the smallest community size (<10,000) had the lowest proportion of patients receiving end-of-life homecare nursing. The second largest city in each province had the highest proportion	Strengths: Large sample size, including three Canadian provinces. Limitations: Unknown if control of demographic variables was completed. No regression analysis was mentioned. However, demographic numbers/ percentages were listed. No mention of ethical conduct details in study. Unclear of statistical	Conclusion: The overall quality of the study is rated as medium according to the Public Health Agency of Canada (2014).

		was set at p< 0.05 using Cochrane-Armitage test of significance.	of patients receiving end-of-life nursing. In all three Canadian provinces, patients receiving end-of-life homecare nursing increased from week -26 to -1 before death.	tests used in study. Limited to cancer patients.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: “Building capacity to provide palliative care in rural and remote communities: Does education make a difference?” (Kelley et al. 2004) Purpose: To evaluate an interdisciplinary education program delivered by the Northern Educational Centre for Aging and Health (NECAH) Lakehead University, Ontario. NECAH sought to understand to what extent the palliative care education had reached their educational goals of: Improving knowledge and skills of practitioners, having delegates function as trainers for their co-workers, and contributing to the development of	Setting: Northwestern Ontario. Sample: 353 palliative care providers (nurses, physicians, social workers, support workers, allied health professionals, volunteers, and spiritual advisors) who completed at least 30 hours of NECAH’s palliative care education between 1994 and 2001. Fifty-seven questionnaires were undeliverable (16%). Of the 296 that were deliverable, 125 were completed and returned for a	Design: Descriptive cross-sectional study. Program evaluation. Methodology: A survey was used to collect data. A four-page questionnaire comprised of 26 questions was used. Both open and closed questions were included.	Results: Results from the survey support that the goals of the educational program were met in that rural communities reported a greater capacity to provide palliative care. The majority (83%) reported the education provided by NECAH was either significant or very significant compared to other sources of learning. 70% reported that they were better able to	Strengths: Good data collection. Survey comprised of 26 questions. Good variety of health care professionals incorporated in study. Large sample size. Sent surveys to all available participants who completed at least 30 hours of NECAH’s palliative care education between 1994 and 2001.	Conclusion: The overall quality of the study is rated as medium according to the Public Health Agency of Canada (2014).

palliative care programs.	response rate of 46%.		provide emotional and psychological support. 74% identified lack of home visits as the biggest obstacle in providing end-of-life care.	<u>Limitations:</u> Low response rate (46%). However, good quantity of surveys completed (125). No mention of ethical conduct.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
<u>Title:</u> “So no one dies alone: A study of hospice volunteering with rural seniors” (McKee & Kelley, 2007). <u>Purpose:</u> To examine the role and contributions hospice volunteers have in rural communities.	<u>Setting:</u> Northwestern Ontario including the districts of Thunder Bay, Rainy River, and Kenora. <u>Sample:</u> 13 rural hospice volunteer coordinators were contacted to participate. All 13 agreed to partake in the study.	<u>Design:</u> Qualitative grounded theory design. <u>Methodology:</u> Phone interviews were conducted lasting from one to two hours. Interview questions were used as a guide; however, the interviews were loosely structured. Interviews were tape recorded with permission and were transcribed for analysis.	<u>Findings:</u> Seven broad themes emerged from the data, with several subthemes under each. The broad themes included: “The coordinators”, “The volunteers”, “What the volunteers do”, “The ideal role for volunteers”, “Relationships with health care professionals”, “Motivations for doing his work”, and “Perceived difference between rural and urban volunteering”. A surprising finding from the interviews	<u>Strengths:</u> All coordinators in the study region agreed to participate in the study. Data collection methods were appropriate for the study’s purpose. Data analysis including thematic coding was appropriate. Questions included in the interview were objective and appropriate.	<u>Conclusion:</u> There are many identified strengths of this study. However, the authors could have improved their ethical requirements for this study (Donna Moralejo & Memorial University of Newfoundland, 2016).

			included that many coordinators identified differences from their urban counterparts in that palliative patients in their programs often included elderly individuals dying from chronic conditions associated with age. Coordinators felt the need to revise the term “palliative” to include individuals in this category.	Limitations: No identification that the researchers received approval from a research ethics board. The authors did not indicate the process of keeping participants information confidential after the interview process.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
<u>Title:</u> "Factors affecting rural volunteering in palliative care-an integrated review" (Whittall et al. 2016) <u>Purpose:</u> To complete a literature review containing literature from Australia and international literature identifying issues related to volunteering in rural palliative care.	<u>Setting:</u> Australian and international literature was incorporated. <u>Sample:</u> Sixty-eight articles were identified as meeting the inclusion criteria.	<u>Design:</u> Comprehensive integrative literature review. <u>Methodology:</u> Thematic analysis was conducted.	<u>Findings:</u> Themes were found: Geography, aging rural populations in palliative care practice, psychosocial impact of end-of-life care in rural communities, palliative care models of practice and volunteering in rural communities.	<u>Strengths:</u> Clear inclusion and exclusion criteria were presented in Table 1. The authors performed a comprehensive search of many databases using several search terms. Inclusion of grey literature was used. <u>Limitations:</u> No major weaknesses were identified.	<u>Conclusion:</u> N/A

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: "The "Good" rural death: A report of an ethnographic study in Alberta, Canada" (Wilson et al. 2009) Purpose: To examine what is meant by the "good death" in rural and remote areas.	Setting: Rural Alberta Sample: The first strategy involved observation and taking field notes in communities/ People who did not live near the city were invited to tell their personal stories on the good rural death. The second strategy involved selecting two rural communities that included volunteers who were willing to tell their stories. Focus groups involving community	Design: Qualitative ethnographic study. Methodology: Interviews were conducted until data saturation was met-13 interviews. Two focus groups were used with 9 and 12 participants. Coding and categorization were completed separately by each researcher.	Findings: Four themes emerged: (1) Rural people feel they have unique perspectives on end of life care, (2) rural people care deeply about their community and they are highly motivated to ensure EOL services exist, (3) a loose network of EOL care providers has developed, and (4) rural areas face unique challenges in developing and maintaining EOL services in	Strengths: Ethical conduct was completed; informed consent was obtained prior to data collection. Two researchers were identified as qualified to complete ethnographic research/data collection. Data collection was appropriate. An in-depth literature review on the topic was discussed. Appropriate research design to answer research question/purpose.	Conclusion: There are many identified strengths of this study. The researchers could have further described how the data were analyzed to better understand how the findings were derived (Donna Moralejo & Memorial University of Newfoundland, 2016).

	leaders and health care providers were conducted. Participants included home care nurses, hospital administrators, family physicians, clergy, counsellors, accountants, lawyers, dentists, health sector secretaries, and local tradespeople.		providing for good deaths.	Limitations: Limited detail surrounding how the data were analyzed.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
<u>Title:</u> "Health care accessibility for chronic illness management and end-of-life care: A view from rural America" (Artnak et al. 2011). <u>Purpose:</u> To describe the similarities and differences between rural and urban areas while focusing on the challenges of bringing quality, affordable chronic disease management and end-of-life care to total communities.	<u>Setting:</u> Not clearly stated. Rural America. <u>Sample:</u> Not clearly stated.	<u>Design:</u> Literature review: Narrative. <u>Methodology:</u> Not clearly identified.	<u>Results:</u> Themes were identified in the literature: Chronic illness, cost, communication, rural America, rural health is different, managing chronic illness, negotiating care at the end of life, and solutions for rural communities.	<u>Strengths:</u> Clear research question and purpose. <u>Limitations:</u> No inclusion or exclusion criteria were identified. Unknown what databases the researchers used to gain literature on topic. Unknown how rigorous the review process entailed.	N/A

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: “Palliative care costs in Canada: A descriptive comparison of studies of urban and rural patients near end of life” (Dumont et al. 2015) Purpose: To compare rural and urban areas in relation to costs that occurred over 6 months of participation in a palliative care program.	Setting: Participants were selected from three provinces: Nova Scotia, Quebec, and Manitoba. Sample: The urban sample consisted of 125 patients, and 127 informal caregivers. The rural sample consisted of 80 patients and 84 informal caregivers. The participants were enrolled in a palliative care program. Data on the rural and urban samples were collected from a replication of two study’s the authors had conducted previously.	Design: Quantitative longitudinal prospective study design. Methodology: Data were collected from 2005-2006 for the urban regions and 2009-2011 for the rural regions. Interviews were used to collect data every 2 weeks until the patients’ death, or when the patient and informal caregiver wanted to end follow-up. Statistical analysis SAS 9.2 software was used to determine mean costs	Results: The overall mean total cost per patient for a 6-month participation in a palliative care program reached CAD $ 26,652 +- $1704 in urban regions as compared to CAD $31,018 +- $1159 (16.4% higher) in rural areas. These costs included hospital care, equipment, prescription medication, home care and long-term care costs, transportation, and out of pocket costs. The Public Health Care System assumed 76.6% and	Strengths: Prospective study design. Clear research question. From reviewing the two previous studies where data was collected inclusion criteria clearly stated and reasonable. Refer to (Dumont et al. 2009) and (Dumont et al. 2014). Statistical analysis was appropriate with a high confidence interval CI 95%. Trained research assistants were	Conclusion: The overall quality of the study is rated as medium according to the Public Health Agency of Canada (2014).

		associated with each participant in the palliative care program. 95% CI was used.	77.7% of the mean total cost per patient in urban and rural areas. The family paid the remainder 20.8% and 21.9% of costs in the rural and urban areas.	used to collect data. Data collection methods were reliable and valid. <u>Limitations:</u> Control for confounding was not completed due to the use of nonparametric testing. Risk on internal validity. However, baseline demographics were conducted on both rural and urban counterparts. The researchers did note that rural participants were on average older. Urban and rural participants were selected in different settings and at different times.	

				Convenience sampling was used. Limits generalizability. However, understandable for the study's purpose and feasibility. Low response rate in both previous studies, however mainly due to death of participants throughout the study.	

Title/Author/Purpose	Setting/Sample	Design & Methodology	Results & Findings	Strengths & Limitations	Conclusion
Title: "Dying in hospital: Medical failure or natural outcome?" (Middlewood, Gardner, & Gardner, 2001). Purpose: To draw upon the documented practices in patients records to describe patterns of medical and nursing practice in the care of patients dying in an acute care setting in Australia.	Setting: Australian Capital Territory (ACT) Canberra Hospital. Sample: 100 consecutive patients' charts were surveyed who died in hospital before August 1999 from an oncological or a hematological malignancy.	Design: Retrospective population-based cohort study. Methodology: A sampling frame of one year was conducted. A sample of 100 patients' charts were surveyed who dies in hospital before August 1999. The study was designed to replicate a previous American based project. An abstraction tool was utilized to survey 60 items of information on medical records. These included:	Results: Of the 100 patients in the sample, 88 were documented DNR prior to death. 27% of patients had palliative care goals instigated with a cessation treatment and investigations more than 48 hours prior to death. Forty-six patients were documented DNR 2 days or less prior to death, and of these 12 were documented DNR on the day of death.	Strengths: Retrospective study design. Clear research question. Data was collected by an experienced oncology nurse. Validity and rater reliability were completed on the collector. Appropriate chart abstraction tool was utilized. Limitations: No mention of ethical conduct details except for permission to use chart	Conclusion: The overall quality of the study is rated as medium according to the Public Health Agency of Canada (2014).

		demographics, diagnosis, reasons for admission, occurrence and timing of DNR orders, whether the patient was dying, documentation of palliative care goals, the withdrawal or non-withdrawal of life sustaining treatment, and the use of diagnostic tests. Data were analyzed using SPSS Windows software.		abstraction tools. Limited ability to generalize findings as results are limited to one hospital in Australia.	

Appendix C

Consultation Report

Catherine Noseworthy

Memorial University

Consultation Report

The palliative end-of-life (PEOL) program is provided by Eastern Health to assist patients and families in accessing palliative care services in the home and community setting. These services include home visits by Registered Nurses to provide supportive services to eligible patients who are dying and want to stay at home or be discharged home from an acute care facility. The overall goal of the program is to provide comfort measures, and to support patients and their families. Services included under the PEOL program include: Nursing visits, home care, medical equipment and supplies, financial coverage for pharmaceuticals for pain and symptom management, consultative services (e.g. social work, occupational therapy), and grief and bereavement counselling (Eastern Health, 2017).

Eligibility into the program is based on the following criteria: (1) The patients have a terminal illness or end stage diagnosis, (2) the patient requires palliative end-of-life home care and expresses a wish to palliate at home, (3) treatment is based on comfort measures only and death is anticipated. Entry into the program is typically initiated when death is anticipated within the last four weeks of life. However, community health nursing support and equipment may be provided prior to the four weeks upon consultation with the PEOL coordinator (Eastern Health, 2017).

Consultations

The overall purpose of this practicum project is to complete a formal evaluation of the PEOL program offered by Eastern Health in the rural district. Through my own observations and self-assessment, I have identified a need for a review of the program. In my own work experiences, I see the unique challenges rural communities face when accessing palliative care services in the home and community setting. Additionally, to my knowledge there has not been a formal evaluation of the PEOL program since its implementation.

This program evaluation project is important as Newfoundland and Labrador is currently experiencing costly healthcare challenges with a growing aging population, a high incidence of chronic disease, and large rural populations (Government of Newfoundland & Labrador, 2018). Providing quality, timely access to end-of-life care services in the community setting can help alleviate undue suffering, prevent unexpected visits to emergency departments, and reduce overall costs to healthcare organizations. An evaluation of the PEOL program is needed so that recommendations can be made on how to improve the program so that patients feel secure and supported in their decision to stay at home.

Consultations were completed with key stakeholders that provide and support the end-of-life care in the rural district. Data collection included in-person interviews and over the phone interviews. Interviews were identified as the most appropriate and beneficial methods for data collection to receive meaningful responses from all participants. A discussion of the participants included in the interview process will follow.

A total of 7 participants were recruited and interviewed. Participants included: a primary care physician in the area; a social worker; two Registered Nurses; a PEOL coordinator; an occupational therapist; and a nurse practitioner.

Data Management

All data including in-person and over the phone interviews were collected at the community health office located at the health care facility. Permission was obtained by all participants prior to commencing the interviews. Participants were advised on the purpose of the interview (to evaluate the PEOL program). I advised all participants that their data would be kept locked and secure on a locked iPhone device that requires a 6-digit password. I also advised participants that all interviews would not be made accessible to any other persons unless permission is granted. Permission and consent were obtained from participants prior to being recorded on the iPhone device for the purposes of data collection. The plan for future data management will include transcribing the data and using Microsoft Excel on my own personal computer. The computer is password protected.

Results

In total seven interviews were completed, two in-person and five over the phone. Interviews lasted from four minutes and thirty-six seconds to twenty-nine minutes and three seconds. Questions were left open-ended, and participants were encouraged at the end of the interview to add information they felt would benefit the evaluation. Interestingly, some of the participants highlighted similar conclusions to the questions, with other participants highlighting unique aspects of the program, especially when it came to limitations of the program. The common themes will be discussed below.

Physician Support

A major theme that was identified throughout the consultations was a lack of physician support in assisting both the patient and their family in end-of-life care in their home. It was acknowledged that many physicians do not make home visits, and this provided challenges when a patient needed assistance of a physician. Access to family physicians in rural areas were also identified as a limitation when providing end-of-life care in the community. Many individuals may not have a family physician, therefore making home palliation difficult if there is no prescriber. One participant identified that patients often must present to their local emergency department to receive pain medication if they are experiencing a pain crisis if there is no one available to prescribe the required medications. Signing of a death certificate and pronouncement of death was another barrier identified. It was recognized that registered nurses can now pronounce and sign a death certificate in a physician's absence. However, given the RN working time constraints of 0830-1630, only being able to provide on call support until 2200 hrs, and no weekend availability made this challenging.

Lack of prescribers was another barrier when providing end-of-life care. One participant identified nurse practitioners as a potential solution to this problem, especially in rural areas where physician shortages exist, and prescribers are needed. Nurse practitioner's scope of practice is expanding and they can now prescribe narcotics under the approval of the *New Classes of Practitioners Regulations* under the *Controlled Drugs and Substances Act* (Association of Registered Nurses of Newfoundland and Labrador, 2013). This is particularly important when dealing with end-of-life patients that require pain management control. Nurse practitioners can make home visits and help prevent a possible pain management crisis that otherwise would require emergency care. One participant identified that another solution would be the development of "standing orders" for certain medications when a patient is discharged from an acute care setting to a community health care setting. This would also include an attached "DNR" certificate so that community health staff do not have to find a physician willing to prescribe certain medications with the potential downfall that certain palliative patients may not have a family physician.

Access to Equipment

Availability of necessary equipment was another barrier identified throughout the consultations. While PEOL equipment is available to help support patients during the end-of-life, one participant identified that not all recommended equipment is covered under the program such as transfer belts and certain bathing equipment. Timely access of equipment was identified as a strength of the program, and that once paperwork is completed, equipment is often delivered the following day. Another participant identified that timely access to equipment was a barrier in rural areas, as equipment do not arrive as quickly to rural homes in comparison to urban areas.

Financial and Time Constraints

Timely access to staff was identified as a barrier. One participant identified that often it is difficult to see patients as quickly as they would want given their large caseloads. Lack of staff including registered nurses and nurse practitioners was identified as a significant barrier to timely access to PEOL services. Travel time was another barrier to providing end-of-life care at home. It was discussed by many of the participants that the rural district is geographically dispersed which makes it challenging due to time constraints of travel. One participant indicated that in order to see one end-of-life patient in their home, they would have to cancel a full morning clinic where they could possibly see 20-30 patients in that same time frame. Time constraints for physicians was identified in the consultations. Waitlists for clinics were identified as typically 4-5 weeks in the rural district making it difficult for physicians to complete home visits for end-of-life patients. Financial constraints were also identified especially for fee for service physicians. Limited twenty-four-hour access to PEOL care from community health nurses was identified as a limitation, especially if a patient becomes ill during the night or on a weekend when service is not available. This may lead patients having to seek the necessary service from the a nearby emergency department.

Mental Health

Although not a common theme throughout the consultations, one participant identified limited mental health services for end-of-life patients. No grief counselling services in the area was identified as a barrier. Better connection with mental health and spiritual care would strengthen the PEOL program and assist patients and their families through the grieving process.

Interdisciplinary Team

Working as a member of an interdisciplinary team was identified as a strength of the PEOL program. It was identified that working as a part of a team was the best approach in providing end-of-life care. It was acknowledged that without a team approach it would be deemed “impossible”, as often health care professionals have to rely on one another to support an end-of-life patient.

Home Support Workers

Availability of home support workers in rural areas was identified as a significant barrier to the patients obtaining needed support. Often patients end up in an emergency department given the lack of formal support services to help families caring for loved ones. It was also identified that some home support workers do not want to drive long distances to provide PEOL support to patients, and this may make it challenging to recruit workers in rural geographically dispersed areas. Although not identified in the interviews, it is important to note that Eastern Health do not provide any formal educational support to home support workers. However, it is encouraged through the PEOL program that individuals wishing to receive home support services choose an approved home support agency compared to the self-managed option.

Palliative Care Education

Not understanding that a patient is “end-of-life” was identified as a barrier to providing end-of-life care. It was identified that more specialized education surrounding palliative care and having specialized registered nurses in end-of-life care in a community setting is needed to strengthen the PEOL program. Often, patients are not being referred in a “timely” manner to the program from an acute care setting to a community care setting. One participant identified that they did not receive the Pallium LEAP training and felt this would highly enhance their training in providing specialized palliative care, especially as a new prescriber.

Access to Medications

Access to medications in rural pharmacies was identified as a limitation, especially when end-of-life patients require subcutaneous medications (i.e. morphine vials). Often smaller pharmacies do not have all the palliative care medications and families must drive long distances to receive the necessary medication from a larger pharmacy. It was identified by one participant that this may cause delays in palliative patients receiving the necessary medication and would also cause extra workload on a prescriber when having to contact multiple pharmacies to see if a certain medication is in stock. Further, smaller pharmacies would often have to order certain medications in which would often delay service and could potentially lead to a palliative patient seeking service from an emergency department.

Implications

All key stakeholders who are important members of the interdisciplinary team in providing end-of-life care in the rural district were contacted and provided in-depth data surrounding palliative care in the community setting. This information will be used to evaluate the program in the next term, and I will provide recommendations to Eastern Health that will benefit patients, families, health care professionals, communities, and the Eastern Health organization in improving end-of-life care services for residents in the rural district.

It is important to note that that there is much to learn from the data collected through the interviews. As identified in both the literature review and the interviews, rural communities face unique obstacles when accessing end-of-life care services. The participants identified challenges to the current PEOL program delivered in the rural district. The regional health authority can learn from this and develop strategies on how to address these concerns by providing the following: palliative medications in local rural pharmacies; support home care agencies in recruiting and retaining home support workers in rural communities; provide specialized palliative care education for registered nurses and nurse practitioners; recruitment of more nurse practitioners; and increase access to mental health services for end-of-life patients and their families.

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Appendix D

Environmental Scan Report

Catherine Noseworthy

Memorial University

Environmental Scan Report

The palliative end-of-life (PEOL) program is provided by Eastern Health to assist patients and families in accessing palliative care services in the home and community setting. These services include home visits by Registered Nurses to provide supportive services to eligible patients who are dying and want to stay at home or be discharged home from an acute care facility. The overall goal of the program is to provide comfort measures and to support patients and their families. Services included under the PEOL program include: Nursing visits, home care, medical equipment and supplies, financial coverage for pharmaceuticals for pain and symptom management, consultative services (e.g. social work, occupational therapy), and grief and bereavement counselling (Eastern Health, 2017).

Eligibility into the program is based on the following criteria: (1) The patients have a terminal illness or end stage diagnosis, (2) the patient requires palliative end-of-life home care and expresses a wish to palliate at home, (3) treatment is based on comfort measures only and death is anticipated. Entry into the program is typically initiated when death is anticipated within the last four weeks. However, according to Eastern Health Policy, community health nursing support and equipment may be provided prior to the four weeks upon consultation with the PEOL coordinator (Eastern Health, 2017).

An environmental scan has been completed to identify current and existing palliative care programs within Newfoundland and Labrador (NL) and Canada. This will assist in the evaluation of the PEOL program in a small rural community in NL by strengthening recommendations to improve best practices in the delivery of palliative care in rural settings. The environmental scan will also help identify challenges other rural communities face within Canada, and how health care authorities address these concerns.

Objectives and Data Collection

Objectives of the environmental scan include: (1) to identify and examine current palliative care programs that address rural populations within Canada, (2) to identify and examine current palliative care programs in Australia, (3) to apply what I have learned from the environmental scan and prepare recommendations to Eastern Health on how to enhance the current palliative end-of-life program in a small rural community in NL.

Data have been obtained from various provincial and national websites, policies, and frameworks. Information concerning palliative care programs have been easily accessible through provincial websites that outline specific details of their palliative care programs. Furthermore, health care association websites such as the Canadian Hospice Palliative Care Association (CHPCA) and the Government of Canada website has been utilized to gain relevant information concerning best practices for palliative care approaches throughout Canada. Understanding how other health care jurisdictions provide palliative care services to individuals and families in rural community settings is important to consider in this evaluation. This will strengthen this evaluation as it will provide insightful information as to what works in other areas throughout Canada, and what does not seem to work.

Results

After a thorough review of provincial websites throughout Canada, it has been found that all provinces and territories have palliative care programs aimed at providing support to individuals and families in the community setting. Each province has specific program components and policies to address the needs of the community. In 2013 *The Way Forward* initiative was introduced as a National Framework to help streamline and integrate palliative care approaches throughout Canada. The focus of the initiative is to ensure that all Canadians have equitable access to palliative care services that focuses on a persons' spiritual, physical, and psychosocial needs throughout the trajectory of their illness not just at the end-of-life (Canadian Hospice Palliative Care Association, 2019). Furthermore, in December of 2017, the Canadian Parliament passed the *Framework on Palliative Care in Canada Act* to develop a national palliative care framework to help guide policy and programs throughout Canada, and to assist key stakeholders who are responsible for the delivery of palliative care services (Government of Canada, 2019).

Frameworks have been developed to help guide provincial and territorial governments, programs, and policies. However, disparities have been noted across provincial organizations on how palliative care programs are developed and delivered. In 2006, the Government of British Columbia developed a "Joint Protocol for Expected/Planned Home Deaths in British Columbia" outlining the processes and procedures when managing an expected home death in the community. One of the updated changes to the policy was the legal requirement to complete pronouncement of death. Unlike Newfoundland and Labrador, a "Notification of Expected Death" form may replace a need for pronouncement by a Registered Nurse or a General Practitioner. Under this protocol, families may decline to have a pronouncement of death completed. If a notification of expected death form is completed in advance by a physician, family will wait one-hour after breathing has ceased and call the funeral home to have the body transferred (Government of British Columbia, 2006).

Eligibility criteria into the British Columbia (BC) palliative care program include the following: (1) Living at home, (2) have been diagnosed with a life-limiting illness, (3) have a life expectancy of up to 6 months to live, and (4) focus of care on palliative rather than cure. It is also important to consider that the BC palliative care drug plan includes 100% coverage for all medications that provide pain/symptom control and increase quality of life. The drug plan also includes 100% coverage for certain over the counter medications that are deemed medically necessary for palliative care. It is also noted on their website that physicians throughout BC have 24/7 access to palliative care consultation that involves medical advised on end-of-life issues (Government of British Columbia, 2015).

The province of Manitoba has a well described palliative care program. According to the government website, palliative care is: “appropriate for any individual and/or family living with a life-threatening illness due to any diagnosis, with any prognosis, regardless of age” (Government of Manitoba, 2017, pars. 4-5). This is important to consider as certain provinces have different definitions of what constitutes “palliative care”. This may affect eligibility criteria for entry into a palliative program within the community. It is also mentioned on the Government of Manitoba website that the Winnipeg Regional Health Authority (WRHA) Palliative Care Program provides 24/7 access to care for individuals registered in the program, as well as consultative services to patients and health care professionals in other health care authorities throughout Manitoba.

The Ontario government has committed to the funding of an additional 70 hospice palliative care nurse practitioners across the province through the development of the “Hospice Palliative Care Nurse Practitioner Program (HPCNP)”. This is one of the key components of Ontario’s health human resource strategy. The goal of the program is to enhance the delivery of hospice palliative care delivery through a collaborative approach with patients and their families. This will be completed by direct care provided through the full scope of practice of the NP in the home setting, management of pain and other symptoms though prescribing of necessary medications, interventions to support patients and their families to reduce hospital admissions and unnecessary emergency department visits, and earlier diagnosis of palliative care needs (Ontario Local Health Integration Network, 2018).

A report was also recently completed by the Minister of Health in Ontario on palliative and end-of-life care. The report was based on several engagement sessions with patients, families, caregivers, communities, and health care providers across the province. Some of the key findings include the need for a better integrated health care system that is well connected to its community members. This will help improve access and equitable service to individuals seeking palliative care in rural communities. Specialized education surrounding palliative care was another key finding that participants identified. Educational supports such as mentorship programs, courses, and new training programs for all health care professionals and home support workers. Further, recommendations to expand the scope of practice for nurses and nurse practitioners directly involved in palliative care was identified to improve timely access to palliative care services. Caregiver support was another concern mentioned by participants. Often, family members experience caregiver burnout when delivering end-of-life care to loved ones. Increasing home support services for respite would help alleviate the stress and help support families to continue to care for their loved one at home. Participants also identified a need for better grief and bereavement services including more information, support groups, and counselling to help them throughout the continuum of care (Government of Ontario, 2016).

The government of Nova Scotia has taken steps towards meeting national palliative care guidelines as the province released a strategy in 2014, *Integrated Palliative Care: Planning for Action in Nova Scotia*. In 2015, the government completed a palliative care strategy implementation progress report outlining the strategy highlights. Some of the highlights include the addition of palliative care teams in areas of the province that were most needed. This included the addition of 4 full-time registered nurses, one full-time NP, and two social workers. In addition, paramedics in Nova Scotia have received specialized palliative care education, and the province have established special care protocols so that paramedics can now perform palliative care and respond to calls within their scope of practice. This will help alleviate unnecessary transportation to hospitals and emergency departments to receive care if it can be performed by a paramedic in the person's home. The government of Nova Scotia has also recognized the need to increase capacity and practice change in all healthcare settings using specialized palliative care education for health care professionals, first responders, home support workers, and volunteers. According to the provincial strategy report, there are three educational programs that are currently being used for palliative care: LEAP (Learning Essential Approaches to Palliative Care), EPEC-0 (Education in Palliative and End of Life Care-Oncology), and the Palliative Care Front Line Education Program (Government of Nova Scotia, 2015).

The government of the Northwest Territories provides palliative home care services to individuals in all regions of the NWT. Palliative care is recognized as an "approach" to care which begins earlier in a person's illness. The NWT government developed a service delivery model outlining the palliative approach to care that aligns with their strategic framework. Within this model it is discussed that the four largest communities in the NWT provide end-of-life care services to individuals in the community through home support services, and the involvement of a nurse. However, the smallest communities do not have the support of nurses, and therefore no community end-of-life nursing services are available. Basic end-of-life care needs can be met by home support workers and the remote support from a nurse (Government of the Northwest Territories, 2018).

International Results

Australia is one of the leading countries when it comes to a strong commitment to research in palliative and end-of-life care. According to the government website, palliative care is offered in various health care settings and at home. Australia like the Canadian health care system has a publicly funded health care system, referred to as Medicare. The costs of receiving palliative care are mostly covered by the Medicare system, however private health insurance may be needed to cover costs such as specialized equipment at home, medications, paying for nursing staff if you decide to stay at home to palliate, accessing respite services, and accessing private health professionals (i.e. physiotherapists). Further, ambulance coverage may be an out of pocket expense depending on the state you reside in (Government of Australia, 2019). Access to palliative care services are made through a referral from your family physician, medical specialist or another health care professional.

A National Palliative Care Strategy was developed in 2018 in Australia to ensure that all people have access to the highest possible level of palliative care services. It is recognised in the foreword of the strategy that not all people living in Australia have the same access to palliative care services due to geography, accessibility, workforce, economics, and awareness of services. It is also understood that certain aboriginal groups in Australia face unique barriers to accessing palliative care, and people living in rural and remote locations (Government of Australia, 2018). One of the outlining goals in the report is to increase capacity by building on caregivers’ and health care professionals’ palliative care knowledge. This will assist health care professionals in recognizing who is in need of palliative care services, and when to start the conversation so that informed decisions can be made. Increasing access to underserved groups is another goal defined in the report. The government recognizes the need to decrease barriers to palliative care through commitments to work with health care providers, engage in research to identify barriers that exist, and to develop and support ongoing community palliative care services.

Conclusion

It is now identified through an environmental scan that there are many palliative care programs that exist throughout Canada, and internationally including Australia. Through a search of government websites, policies, frameworks, and strategies, it is now clear that palliative and end-of-life programs do exist. Unfortunately, disparities do occur across palliative programs, provinces, and communities, especially in relation to community-based palliative care. Although there is a National guiding framework for palliative care across Canada, more work needs to be done to integrate and standardize palliative care across the Nation. Some provinces have taken great strides in developing their own frameworks, strategies and policies surrounding palliative and end-of-life care. However, other provinces, including Newfoundland and Labrador have not developed a framework specifically for palliative care. More work needs to be done by governments, policy makers, and organizations to recognize the importance of community-based palliative care and to develop frameworks and strategies on how to improve palliative care programs for individuals wishing to die at home.

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Appendix E

Towards end-of-life in the community setting: An evaluation report

Catherine Noseworthy

Memorial University

Towards end-of-life in the community setting: An evaluation report

The palliative end-of-life (PEOL) program is provided by Eastern Health to assist patients and families in accessing palliative care services in the home and community setting. These services include home visits by Registered Nurses to provide supportive services to eligible patients who are dying and want to stay at home or be discharged home from an acute care facility. The overall goal of the program is to provide comfort measures, and to support patients and their families. Services offered under the PEOL program include: Nursing visits, home care, medical equipment and supplies, financial coverage for pharmaceuticals for pain and symptom management, consultative services (e.g. social work, occupational therapy), and grief and bereavement counselling (Eastern Health, 2017).

Eligibility into the program is based on the following criteria: (1) The patients have a terminal illness or end stage diagnosis, (2) the patient requires palliative end-of-life home care and expresses a wish to palliate at home, and (3) treatment is based on comfort measures only and death is anticipated. Assessment for eligibility into the program also includes the completion of the Palliative Performance Scale version 2 (PPSv2), Palliative Prognostic Index (PPI), and the Edmonton System Assessment Scale. Entry into the program is typically initiated when death is anticipated within the last four weeks of life. However, according to Eastern Health Policy, community health nursing support and equipment may be provided prior to the four weeks upon consultation with the PEOL coordinator (Eastern Health, 2017).

Through my own observations and self-assessment, I have identified a need for a formal evaluation of the PEOL program in Rural Avalon. I have worked as a Community Health Nurse (CHN) in various community health sites, and currently I work in a one nurse community health office in a rural district. Through my own work experiences, I see the unique challenges rural communities face when accessing palliative care services in the home setting. Additionally, to my knowledge there has not been a formal evaluation of the PEOL program since its implementation. Currently, there is an undertaking of a formal review of palliative care services throughout the organization. However, I have identified that the focus of the review is broad and encompasses acute care, long-term care, and community services. A detailed review of community services will not include an in-depth evaluation of the end-of-life program.

This project is important as Newfoundland and Labrador are currently experiencing costly healthcare challenges with a growing aging population, a high incidence of chronic disease, and large rural populations (Government of Newfoundland & Labrador, 2018). Providing quality, timely access to end-of-life care services in the community setting can help alleviate undue suffering, prevent unexpected visits to emergency departments, and reduce overall costs to healthcare organizations. An evaluation of the PEOL program is needed so that recommendations can be made on how to improve the program so that patients feel secure in their decision to stay at home.

Background

Objectives

The main goal of this evaluation is to formally evaluate an existing PEOL program offered in a small rural community in NL. There has been evidence in the literature to suggest that rural communities face unique challenges in accessing palliative and end-of-life services compared to their urban counterparts. The key practicum objectives for this evaluation are:

1. To identify areas within the end-of-life program in Rural Avalon that require improvement by completing consultations with key stakeholders including community

health nurses, nurse practitioners, physicians, social workers, occupational therapists, and end of life coordinators that work in the rural district.

2. To complete a comprehensive literature review and environmental scan to identify evidence in the literature to help support this evaluation and the recommendations made to the Eastern Health authority.
3. To evaluate the effectiveness of the end-of-life program in meeting the programs stated goal "To comfort and support clients and their caregivers through a combination of active and compassionate services that enable the client to stay at home or to die at home if that is their wish" (Eastern Health, 2017, para. 1). This will be completed by analyzing the data collected from key informants' interviews and offer recommendations to Eastern Health on how to improve the program so that patients and families feel secure in their decision to stay at home.

Methods

Literature Review

A comprehensive literature review was completed to understand more on the topic of end of life care in the community setting. The search was conducted using two databases Pubmed and CINAHL. Search terms included "end of life" and "rural communities". Under "Subject: Major Heading" in the CINAHL database, "palliative care", "terminal care", "hospice care", "terminally ill patients", "rural health services", and "rural areas" was selected. The results from the CINAHL database included the retrieval of 21 articles. From the 21 results, 5 articles were included in the literature review. Unfortunately, many of the articles did not correspond with rural community-based palliative care and focused on in-patients, and medical assistance in dying. In the Pubmed database, 95 articles were recovered in total using the same search terms. Additional filters used included: species “Humans”, text availability “Free Full Text”, and publication dates “10 years”. Three articles were incorporated in the literature review. Many articles were excluded for the same reason using the CINAHL database. Additionally, several articles did not translate with palliative care and focused on chronic conditions. To be congruent with the intentions of this literature review, end-of-life care needed to be the forefront of the literature. After this literature was examined, five major themes were identified.

Access to end-of-life care. Access to end-of-life care in rural communities was a major theme identified in the literature. Physician unavailability, lack of home care workers to assist with activities of daily living, recruitment and retainment of healthcare professionals including community health nurses (CHNs), and long driving distances to access services were some of the key barriers that patients and families experienced when attempting to access palliative and end-of-life services in rural settings. Wilson et al. (2009) completed an ethnographic study in Alberta, Canada on the issue of dying in rural communities. Of importance was that rural areas faced unique challenges in developing and maintaining end-of-life services in communities. One of the reasons for this was the recruitment and retainment of health care professionals providing end-of-life services. It was identified that the loss of even one health care professional could have a profound impact in a small remote community, as it might take years to find a replacement. Individuals within study reported that if they wanted a second opinion from another physician, or did not have trust in a physician, they would have to travel long distances to another community to seek the service. These driving distances acted as barriers themselves. Often, taxi services were limited in remote areas, creating obstacles for the elderly to receive access to required health care services. Although not specifically mentioned in the literature, access to public transportation in rural areas may be limited or non-existent in comparison to urban areas. Even if available, obstacles remain, as many end-of-life patients may be physically incapable of using public transportation as a method of travel.

Inequitable service delivery in the form of the number of visits made by community health nurses to end-of-life patients were found in the literature. Seow et al. (2017) completed a retrospective cohort study in three Canadian provinces: Ontario (ON), British Colombia (BC), and Nova Scotia (NS) to examine the utilization patterns of nursing homecare services between the provinces. They found that the smallest community sizes had the lowest proportion of patients receiving nursing homecare services each week compared to larger community sizes. As expected, as death approached, the number of nursing visits increased in both the small and larger communities. However, the gap in services remained as a person's death approached. A similar retrospective study by Lavergne et al. (2015) studied palliative care program (PCP) enrollment data in three districts in Nova Scotia, Canada. The findings from this study indicate that urban residents had higher odds of enrollment in a PCP than their rural counterparts. Likewise, those living a greater distance from a PCP had a higher chance of hospitalization. The findings from both studies may relate back to evidence found in the literature that there is a lack of health care professionals, including community health nurses (CHNs) available to provide services. Further, long driving distances due to the geographical makeup of rural communities may also be a limiting factor nurses face when providing care to end-of-life patients.

End of life planning. End-of-life care planning also known as advanced care planning (ACP) was another identified theme in the literature. Several challenges were found that created barriers in timely, and effective end-of-life care planning. According to the Canadian Nurses Association (2018), effective end-of-life care planning starts with having the conversation early and revisiting the topic through an individual's life. Nurses are key in starting the conversation to help encourage individuals to reflect on their wishes. Middlewood, Gardner, and Gardner (2001) completed a retrospective research study to examine the medical records of inpatients who died in a hospital in Australia. They found from a sample of 100 patients that 46 of those patients were documented as having a DNR completed within two days or less of the patient's death. Of the 46 patients, 12 had their DNR signed on the same day of death. Artnak. McGraw, and Stanley (2011) state that often the discussions with patients regarding their wishes are not discussed. This may lead to unfortunate circumstances where a patient might be too ill to make their own decisions especially regarding resuscitation measures. Cultural values and religion may impact a patients' desire to engage in early end-of-life conversations and adequately prepare for ACP. This could lead to unexpected medical decision making and undue suffering for patients and their families.

A report by Fowler and Hammer (2013) highlights the barriers clinicians have with their patients concerning end-of-life care plans. The identified barriers may be related to lack of time for discussions concerning end-of-life care, and the clinician's skill and interest in having difficult discussions surrounding the topic. Disagreements concerning a patient's wishes may be another challenge when planning for end-of-life care. Historically, family physicians were often identified as the "decision maker". Recently, a shared decision-making approach has evolved and includes the patient, their support network, and the health care team. Unfortunately, disagreements do arise when a patient's wishes are unknown, and the patient can no longer provide consent. Therefore, this emphasizes the importance of early end-of-life care planning so patients' wishes are clearly understood, and disagreements do not arise that may lead to undue suffering and stress on both patients and families.

As well, family physicians are often the primary and initial contact for individuals with a terminal illness. It is therefore paramount that physicians have opportunities to the knowledge and skills surrounding palliative care so patients have early access to palliative care options. The Canadian Institute for Health Information (2018) released a report that few Canadian physicians specialize in palliative care, with just 12% of medical students required to complete a clinical rotation in a palliative care field. Even more surprising, is that three out of five physicians stated that they did not feel well prepared in caring for individuals in need of palliative care. These statistics are concerning, as ACP should begin after the diagnosis of a life-threatening illness. If health care professionals are not comfortable discussing palliative care options, it may limit a patient's access to quality, timely palliative care.

Financial barriers. Literature examining the costs associated with end-of-life care illuminate the financial barriers and inconsistencies between rural and urban communities in Canada. The *Canada Health Act* is Canada's federal legislation for publicly funded health care insurance. The Act's primary objective is to "protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Government of Canada, 2018a, pars. 2-4). A Canadian quantitative longitudinal prospective study by Dumont, Jacobs, Turcotte, Turcotte, and Johnston (2015) compared the total costs associated with a 6-month participation in a palliative care program (PCP) between rural and urban areas in the provinces of Nova Scotia, Quebec, and Manitoba. Their goal was to evaluate the costs shared between the public health care system (PHCS), the family, and not-for-profit organizations. The urban sample consisted of 125 patients enrolled in a PCP and 127 informal caregivers, and the rural sample consisted of 80 patients enrolled in a PCP and 84 informal caregivers. The authors found that the total cost for a 6-month participation in a PCP reached CAD $26,652 (± 1.704) in urban regions, and CAD $31,018 (± 1159) in rural regions (a 16.4% increase). Costs related to medical equipment and aids were found to be 63.3% higher in rural regions. Further, prescription medication costs were higher in rural regions (20.1%), while urban regions had higher home care costs (25.8%). In total, families paid 20.8 % and 21.9% in the rural and urban areas, with the PHCS assuming 76.6% and 77.7% of the mean total costs.

Strengthening palliative care programs to include financial coverage for all required equipment, medications, and home care costs will help eliminate disparities among both urban and rural areas and allow all individuals to participate in an end-of-life program. This would save overall healthcare organizational costs, as it would help prevent acute care admissions and help support individuals in their wish to die at home.

Education. Specialized education for health care professionals surrounding end-of-life and palliative care have been found to be key elements in the delivery of end-of-life services in rural community settings. In December 2018, the federal government passed a bill to create a framework for palliative care in Canada. The *Framework of Palliative Care in Canada* was created on December 4, 2018. According to the Government of Canada (2018b) the framework acts as a guideline for all palliative care stakeholders, and it focuses on important issues such as: Training and education for healthcare professionals; promoting research; supporting health care professionals; and ways to support access to palliative care regardless of location. This is a significant step for palliative care in Canada as it sets out a specific plan to help streamline palliative care services across the country. Throughout this review, the literature discussed the requirement for healthcare professionals to have specialized palliative care knowledge, especially in rural communities. This is understandable given the unique demographics and limited number of health care professionals to provide the necessary care. Hence, it is a positive movement by the Government of Canada to recognize the need to improve palliative care education and access across the country.

Although this is an important milestone, evidence in the literature illustrate that disparities continue to exist. Wilson et al. (2009) found as a result of their ethnographic study in Alberta that rural health care professionals face unique challenges in gaining and remaining current in palliative and end-of-life knowledge. This was found to be a result of no available replacements for rural health care professionals to attend educational events, and without a replacement their absence would be highly felt by the community. Furthermore, it was found that mental health professionals, counsellors, and psychologists were rare in rural settings meaning that available health care professionals had to be “generalists” and a “jack of all trades”. This is an unfortunate finding, as although educational sessions may be available, health care professionals working in rural areas are disadvantaged as they face unique barriers to attending these events.

Additionally, Kelley, Habian and Aegard (2004) completed an evaluation of an interdisciplinary education program delivered by the Northern Educational Centre for Aging and Health (NECAH) in Lakehead University, Ontario. They found that palliative care providers in rural communities are “generalists”, as palliative care is only one aspect of their work. They determined that palliative care education is very important in helping develop not only knowledge and skill but also in increasing respondents comfort level in providing end-of-life care after the educational program. Respondents of the study also stated they were able to better communicate with patients and their families, acknowledge a patient’s emotional and spiritual needs, and provide better emotional support.

It is therefore founded in research that specialized education for health care professionals on palliative and end-of-life care can have a profound impact on palliative health care delivery in all community settings. It is important for health care organizations to understand the potential impact educational interventions will have on improving end-of-life care outcomes for all individuals seeking to remain home near the end of life.

Volunteering. It has been suggested in the literature that hospice volunteers are needed to meet the needs of an aging population and can benefit rural communities. A qualitative study conducted by McKee, Kelley, and Guirguis-Younger (2007) in Northwestern Ontario examined the motives for hospice volunteering, how volunteers understand their role compared to their urban counterparts, and who they serve. A phone interview was conducted with 13 rural hospice volunteer coordinators in the region. Themes were identified from the interview data. These included “being there” and “just listening”. Simply being present with end-of-life patients was identified as an important role as a palliative volunteer. Their ideal role was described as providing companionship and support to individuals in rural areas who were at risk for dying alone without adequate care. An important piece of their volunteer work was noted to establish a therapeutic relationship. Therefore, the coordinators identified the importance of receiving a referral early and not days before a patient’s death when they would find it difficult to establish a relationship. The volunteers noted that their part is not to replace health care professionals, but to complete tasks they did not have time to do.

Environmental Scan

An environmental scan was completed as a method of this evaluation. The objectives of the environmental scan included: (1) to identify and examine current palliative care programs that address rural populations within Canada, (2) to identify and examine current palliative care programs in Australia, (3) to apply what has been learned and prepare recommendations to Eastern Health on how to enhance the current end-of-life program in a small rural community in NL.

After a thorough review of various provincial and national websites, policies, and frameworks provincial and national websites, policies, and frameworks, data was collected on all palliative care programs across Canada. All provinces and territories have palliative care programs. However, it is evident that services are not streamlined nationally, with certain provinces, territories, and jurisdictions offering different palliative and end-of-life care services and coverage options. It has also been noted certain provinces and territories have different frameworks and policies guiding palliative health care delivery in the community setting. For the purposes of this evaluation report, only certain programs in comparative jurisdictions to NL will be discussed.

Results

In 2013 *The Way Forward* initiative was introduced as a National Framework to help streamline and integrate palliative care approaches throughout Canada. The focus of the initiative is to ensure that all Canadians have equitable access to palliative care services that focuses on a persons' spiritual, physical, and psychosocial needs throughout the trajectory of their illness not just at the end-of-life (Canadian Hospice Palliative Care Association, 2019). Furthermore, in December of 2017, Parliament passed the *Framework on Palliative Care in Canada Act* to develop a national palliative care framework to help guide policy and programs throughout Canada, and to assist key stakeholders who are responsible for the delivery of palliative care services (Government of Canada, 2019).

Frameworks have been developed to help guide provincial and territorial governments, programs, and policies. However, disparities have been noted across provincial organizations on how palliative care programs are developed and delivered. In 2006, the Government of British Columbia developed a “Joint Protocol for Expected/Planned Home Deaths in British Columbia” outlining the processes and procedures when managing an expected home death in the community. One of the updated changes to the policy was the legal requirement to complete pronouncement of death. Unlike Newfoundland and Labrador, a “Notification of Expected Death” form may replace a need for pronouncement by a Registered Nurse or a General Practitioner. Under this protocol, families may decline to have a pronouncement of death completed. If a notification of expected death form is completed in advance by a physician, the family will wait one-hour after breathing has ceased and call the funeral home to have the body transferred (Government of British Columbia, 2006).

Furthermore, the province of Manitoba has a well described palliative care program. According to the government website, palliative care is: “appropriate for any individual and/or family living with a life-threatening illness due to any diagnosis, with any prognosis, regardless of age” (Government of Manitoba, 2017, pars. 4-5). This is important to consider as certain provinces have different definitions of what constitutes “palliative care”. This may affect eligibility criteria for entry into a palliative program within the community. It is also mentioned that the Winnipeg Regional Health Authority (WRHA) Palliative Care Program provides 24/7 access to care for individuals registered in the program, as well as consultative services to patients and health care professionals in other health care authorities throughout Manitoba. This is an important consideration, as currently individuals eligible for and receiving end-of-life care services offered by Eastern Health do not have access to 24/7 care. If individuals encounter unforeseen health events, they must access care through their local emergency department after community health office hours.

The Ontario government has taken initiative to improve palliative and end-of-life care with the commitment to fund an additional 70 hospice palliative care nurse practitioners across the province. This will be accomplished through the development of the "Hospice Palliative Care Nurse Practitioner Program (HPCNP)", which is described as a key component to Ontario's health human resource strategy. The goal of the program is to enhance the delivery of hospice palliative care delivery through a collaborative approach with patients and their families (Ontario Local Health Integration Network, 2018). Nurse practitioners will use their full scope of practice to provide direct care in the home setting. These services include management of pain and other symptoms though prescribing of necessary medications, interventions to support patients and their families to reduce hospital admissions and unnecessary emergency department visits, and earlier diagnosis of palliative care needs. Just recently, Eastern Health has hired one half-time nurse practitioner position for the Rural Avalon district under the Community Supports Program (CSP). This is a small step forward, and more nurse practitioners are needed to respond to the demand of a lack of physicians in the area. Further, many physicians choose not to deliver end-of-life care services in the community setting for various reasons.

The government of Nova Scotia has taken steps towards meeting national palliative care guidelines as the province released a strategy in 2014 entitled, *Integrated Palliative Care: Planning for Action in Nova Scotia*. In 2015, the government completed a palliative care strategy implementation progress report outlining the strategy's highlights. These include the addition of palliative care teams in areas of the province that were most needed (4 full-time registered nurses, one full-time NP, and two social workers). In addition, paramedics in Nova Scotia have received specialized palliative care education, and the province have established special care protocols so that paramedics can now perform palliative care and respond to calls within their scope of practice. This will help alleviate unnecessary transportation to hospitals and emergency departments to receive care if it can be performed by a paramedic in the person's home. The government of Nova Scotia has also recognized the need to increase capacity and practice change in all healthcare settings using specialized palliative care education for health care professionals, first responders, home support workers, and volunteers. According to the provincial strategy report, there are three educational programs that are currently being used for palliative care: LEAP (Learning Essential Approaches to Palliative Care), EPEC-O (Education in Palliative and End of Life Care-Oncology), and the Palliative Care Front Line Education Program (Government of Nova Scotia, 2015).

Australia is one of the leading countries in demonstrating a strong commitment to research in palliative and end-of-life care. According to the government website, palliative care is offered in various health care settings and at home. Australia, like Canada has a publicly funded health care system referred to as Medicare. While the costs of receiving palliative care are mostly covered by the Medicare system, private health insurance may be needed to cover costs such as acquiring specialized equipment at home, medications, paying for nursing staff if one decides to stay at home to palliate, accessing respite services, and availing of private health professionals (i.e. physiotherapists). Further, ambulance coverage may be an out of pocket expense depending on the state in which one resides (Government of Australia, 2019). Access to palliative care services are made through a referral from the person's family physician, medical specialist, or another health care professional.

A National Palliative Care Strategy was developed in 2018 in Australia to ensure that all people have access to the highest possible level of palliative care services. It is recognised in the foreword of the strategy that not all people living in Australia have the same access to palliative care services due to geography, accessibility, workforce, economics, and awareness of services. It is also understood that certain aboriginal groups in Australia face unique barriers to accessing palliative care, and people living in rural and remote locations (Government of Australia, 2018). One of the outlining goals in the report is to increase capacity by building on caregivers' and health care professionals' palliative care knowledge. This will assist health care professionals in recognizing who is in need of palliative care services, and when to start the conversation so that informed decisions can be made. Increasing access to underserved groups is another goal defined in the report. The government recognizes the need to decrease barriers to palliative care through commitments to work with health care providers, to research to identify barriers that exist, and to develop and support ongoing community palliative care services.

While the environmental scan identified many palliative care programs that exist throughout Canada, and internationally including Australia, disparities do exist across palliative programs, provinces, and communities, especially in relation to community-based palliative care. Although there is a National guiding framework for palliative care across Canada, more work needs to be done to integrate and standardize palliative care across the nation. Some provinces have taken great strides in developing their own frameworks, strategies, and policies surrounding palliative and end-of-life care. However, other provinces, including Newfoundland and Labrador have not developed a specific framework. More work needs to be done by governments, policy makers, and organizations to recognize the importance of community-based palliative care and to develop frameworks and strategies on how to improve palliative care programs for individuals wishing to die at home.

Consultations

Data collection for this evaluation included interviewing key stakeholders who are directly involved in end-of-life care delivery in the rural district. Interviews in person and over the phone were identified as the most appropriate and beneficial methods for data collection to receive meaningful responses from all participants. Recruitment included directly contacting participants either through email or in-person contact to identify interest. All participants were advised that the purpose for the interview was to obtain meaningful data on end-of-life care delivery in the community setting to formally evaluate the end-of-life program in the rural district. All participants stated they were eager to participate and provided consent prior to commencing the interviews. All participants were asked 5 questions (see appendix A) and interviews were recorded using a secure password protected personal Apple iPhone device. Consent for recording was verbally obtained by all participants. All recordings were sent to a secure, password protected personal computer, and interviews were then deleted from the iPhone device.

A total of 7 participants were recruited and interviewed. Participants included: a primary care physician in the area; a social worker; two Registered Nurses; a PEOL coordinator; an occupational therapist; and a nurse practitioner.

Data Management

All data including in-person and over the phone interviews were collected at the community health office in the rural district. Permission was obtained by all participants prior to commencing the interviews. When participants were advised on the purpose of the interview (to evaluate the PEOL program), all participants were informed that their data would be kept locked and secure on a locked iPhone device that requires a 6-digit password and then moved to a secure computer. I also advised participants that all interviews would not be made accessible to any other persons unless permission is granted.

Data Analysis

Data were analyzed and completed by listening to the tape recordings numerous times and coding for themes.

Results

In total seven interviews were completed, two in-person and five over the phone. Interviews lasted from four minutes and thirty-six seconds to twenty-nine minutes and three seconds. Questions were left open-ended, and participants were encouraged at the end of the interview to add information they felt would benefit the evaluation. Interestingly, some of the participants highlighted similar conclusions to the questions, with other participants highlighting unique aspects of the program, especially when it came to limitations of the program. The common themes will be discussed below.

Physician Support

A major theme that was identified throughout the consultations was lack of physician support in assisting both the patient and their family in end-of-life care in their home. It was acknowledged that many physicians do not make home visits, and this provided challenges when a patient needed this care. Access to family physicians in rural areas were also identified as a limitation when providing end-of-life care in the community. Many individuals do not have a family physician, therefore making home palliation difficult if there is no prescriber. One participant identified that patients often have to present to their local emergency department to receive pain medication when experiencing a pain crisis if there is no one available to prescribe required medications in the community. The signing of a death certificate and pronouncement of death was another barrier identified. It was recognized that Registered Nurses can now pronounce and sign a death certificate in a physician's absence. However, given the working time constraints of 0830-1630, only being able to provide on call support until 2200, and the lack of weekend availability made this challenging. One participant identified Nurse Practitioners as a potential solution to this problem, especially in rural areas where physician shortages exist, and prescribers are needed. Nurse Practitioners' scope of practice is expanding and now includes prescription of narcotics under the approval of the *New Classes of Practitioners Regulations* under the *Controlled Drugs and Substances Act* (Association of Registered Nurses of Newfoundland and Labrador, 2013). This is particularly important when dealing with end-of-life patients who require these medications for pain management control. Nurse Practitioners can make home visits and help prevent a possible pain management crisis that otherwise would require emergency care. One participant identified that another solution would be the development of "standing orders" for certain medications when a patient is discharged from an acute care setting to a community health care setting. This would also include an attached "DNR" certificate so that community health staff do not have to find a physician willing to prescribe certain medications.

Access to Equipment

Availability of necessary equipment was another barrier identified throughout the consultations. While PEOL equipment is available to help support patients during the end-of-life.

One participant identified that not all recommended equipment is covered under the program such as transfer belts and certain bathing equipment. Timely access of equipment was identified as a strength of the program, and that once paperwork is completed, equipment is often delivered the following day. Another participant identified that timely access to equipment was a barrier in rural areas, as equipment does not arrive as quickly to rural homes in comparison to urban areas.

Financial and Time Constraints

Lack of staff including Registered Nurses and Nurse Practitioners was identified as a significant barrier to timely access to PEOL services. One participant identified it is often difficult to see patients as quickly as they would want, given their large caseloads. One participant indicated that in order to see one end-of-life patient in their home, they would have to cancel a full morning clinic where they could possibly see 20-30 patients in that same time frame. Travel time was another barrier to providing end-of-life care at home. It was discussed by many of the participants that the rural district is geographically dispersed which makes it challenging due to time constraints of travel. Time constraints for physicians was also identified in the consultations. Waitlists for clinics were identified as typically 4-5 weeks in the rural district making it difficult for physicians to complete home visits for patients. Financial constraints were also identified especially for fee for service physicians. The lack of twenty-four-hour access to PEOL care from community health nurses was identified as a limitation, especially if a patient becomes ill during the night or on a weekend when service is not available. This may lead patients having to seek the necessary service from the a nearby emergency department.

Mental Health

Although not a common theme throughout the consultations, one participant identified limited mental health services for end-of-life patients. In addition, the lack of grief counselling services in the area was identified as a barrier. Better connection with mental health and spiritual care would strengthen the PEOL program and assist patients and their families through the grieving process.

Interdisciplinary Team

Working as a member of an interdisciplinary team was identified as a strength of the PEOL program. This was viewed as the best approach to providing end-of-life care. Participants acknowledged that without a team approach, care provision would be deemed “impossible”, as often health care professionals must rely on one another to support an end-of-life patient.

Home Support Workers

Availability of home support workers in rural areas was identified as a significant barrier to patients obtaining needed support. Often patients find themselves in an emergency department given the lack of formal support services to help families caring for loved ones. It was also identified that some home support workers do not want to drive long distances to provide PEOL support to patients, and this may make it challenging to recruit workers in rural geographically dispersed areas. Although not identified in the interviews, it is important to note that Eastern Health do not provide any formal educational support to home support workers. However, it is encouraged through the PEOL program that individuals wishing to receive home support services choose an approved home support agency compared to the self-managed option.

Palliative Care Education

Not understanding that a patient is “end-of-life” was identified as a barrier to providing end-of-life care. It was identified that more specialized education surrounding palliative care and having specialized registered nurses in end-of-life care in a community setting is needed to strengthen the PEOL program. Often, patients are not being referred in a “timely” manner to the program from an acute care setting to a community care setting. One participant identified that they did not receive the Pallium LEAP Training and felt this would highly enhance their training in providing specialized palliative care, especially as a new prescriber.

Access to Medications

Access to medications in rural pharmacies were identified as a limitation, especially when end-of-life patients require subcutaneous medications (i.e. morphine vials). Often, smaller pharmacies do not have all the palliative care medications and families must drive long distances to receive the necessary medication from a larger pharmacy. It was identified by one participant that this may cause delays in palliative patients receiving the necessary medication and would also cause extra workload on a prescriber when having to contact multiple pharmacies to see if a certain medication is in stock. Further, smaller pharmacies would often have to order certain medications, which would often delay service and could potentially lead to a palliative patient seeking service from an emergency department.

Recommendations

The following recommendations are made with the goal of improving the end-of-life care program in the rural district, such that it will benefit patients, families, health care professionals, communities, and the Eastern Health organization in the provision of improving end-of-life care services for residents in the rural district. It is important to note that there is much to learn from the data collected through this evaluation. As identified in both the literature review, environmental scan, and the interviews, rural communities face unique obstacles when accessing end-of-life care services. The participants identified challenges to the current PEOL program delivered in the rural district. The regional health authority can learn from this and develop strategies on how to address these concerns. The following are a list of recommendations that have been derived from the evaluation.

Nurse Practitioners

Hiring more nurse practitioners under the Community Supports Program (CSP) for Rural Avalon is a key solution to the physician shortage that the rural district currently is encountering. Nurse Practitioners are trained professionals who are equipped to deal with all aspects of end-of-life care delivery in the community setting. This would prevent individuals from seeking necessary palliative and end-of-life care needs in emergency departments, and individuals would be able to stay at home longer. Individuals who do not have a family physician would not be discriminated against and would be able to access all services offered by the end-of-life care program, including receiving necessary medications. Further, nurse practitioners would be able to make home visits allowing individuals to remain at home and not forcing them to access care from a clinic or hospital, such a service would alleviate suffering and stress on families and the patients themselves.

Appropriate Access

Continuous 24/7 access to a palliative health care provider in the community setting is needed to improve the current end-of-life program. Presently, as key informants describe, if an emergency health event happens over a weekend there is no on-call community health nurse to contact. Therefore, patients must access care to their local emergency department. This can be alleviated by expanding service delivery to all hours. As well, there is only one community health nurse working in the rural district. To make this a feasible and possible solution, the hiring of another Registered Nurse is needed so that services can expand.

Paramedics

Specialized education for paramedics to provide palliative and end-of-life care would help individuals, families, and health care organizations. If an end-of-life patient experiences an emergency after community health hours, trained paramedics would support the patient at home instead of bringing the patient to the nearest emergency department. This would prevent undue suffering and unnecessary health care costs. As identified in the environmental scan, Nova Scotia has already developed a strategy which includes paramedics receiving specialized palliative care education. The province is also developing special care protocols so that paramedics can perform palliative care and respond to calls within their scope of practice.

Specialized Education

The provision of specialized palliative and end-of-life education is important for all health care professionals including: Registered Nurses, Nurse Practitioners, Physicians, Social Workers, Occupational Therapists, and Home Support Workers. This strategy also includes mandatory Pallium LEAP training, something that is currently not consistently done. One participant in the consultations identified they did not receive the Pallium LEAP training. Further, staff need to be relieved in order to attend educational events and training especially in rural areas. It has been identified in the literature that it is often difficult to receive relief in rural communities, and the absence of even one health care professional may be highly felt by the community. Therefore, this would require careful strategizing in order to facilitate this necessary training.

It is also important to identify and provide end-of-life training and education for home support workers. Often, as identified through consultations, it is difficult to recruit home support workers to provide respite for families, largely due to geographically dispersed rural areas and driving distances. However, it may also be a result of a lack of knowledge and comfort in home support workers ability to provide end-of-life care. They may feel intimated by the task and require more skill and education in providing care. Eastern Health could collaborate with home support agencies and develop educational resources for home support workers on how to deliver end-of-life care, thus potentially increasing recruitment, and retainment.

Interdisciplinary Teams

Although interdisciplinary teams currently exist, there must be ongoing improvements to the integration of interdisciplinary teams to enhance end-of-life care for patients and their families. Developing a better understanding of each others' roles in providing end-of-life care is required to improve collaboration among health care members. This would result in streamline services and better outcomes for both the patients and health care professionals involved. Communication could be enhanced with having regular team meetings either in person or through tele/video conferencing software such as Skype. This would be beneficial as geography and distance is a challenge in rural areas.

Discharge Planner

It was identified in the consultations that often patients are not being referred in a "timely" manner to the program from an acute care setting to a community care setting. The hiring of a discharge planner who is specialized in palliative care delivery would better streamline the process when patients wish to be discharged in the community setting to die at home. Currently there is no liaison or discharge planner hired at the hospital in the rural district. The hiring of a discharge planner even a 0.5 position would ensure continuity of care from the acute care setting to the community health setting. The hiring of a discharge planner who is specialized in palliative care delivery would better streamline the process when patients wish to be discharged in the community setting to die at home.

Standing Orders

The development of standing orders for palliative and end-of-life care patients would benefit both patients and health care organizations. This would prevent the need to receive care from an emergency department if a patient requires a prescription for morphine, for example. Further, a "DNR" form attached to the standing order would prevent the need to find a physician or a nurse practitioner to write an order when a patient is discharged from an acute care setting to the community.

Mental Health

It was identified that a better connection with mental health and spiritual care would strengthen the PEOL program and assist patients and their families through the grieving process. Currently in the rural district, there are no bereavement services offered beyond the local clergy. There is a walk-in mental health "Doorways" program which provides walk-in counselling services at the hospital. Unfortunately, for many end-of-life patients, they are physically incapable of availing of a walk-in service and would require a home visit. Providing a service that includes home visits for individuals under the end-of-life program to receive these services would highly benefit the program and could possibly prevent worsening psychological distress or caregiver burnout.

Pharmacies

Collaboration among small rural pharmacies is needed to improve access to medications used in end-of-life care such as morphine and scopolamine. These are often required subcutaneously when a person is near death. Collaboration with pharmacies to ensure that adequate stock is available when needed would enhance the patients access to pain control and prevent patients requiring to visit the local emergency department to receive the necessary medication.

Conclusion

It is evident that action is required to improve end-of-life care services in the community setting in the rural district. Providing quality, timely access to end-of-life care services can help alleviate undue suffering, prevent unexpected visits to emergency departments, and reduce overall costs to healthcare organizations. An evaluation of the end-of-life program has been completed and recommendations made on how to improve the program so that patients and their families can feel secure in their decision to stay at home. Please consider the findings from this evaluation and move forward with the recommendations that have been made which can enhance the current end-of-life program and ensure those at this vulnerable stage have access to a good death.

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Appendix A

Interview Questions:

1. Describe your current role as a health care provider in the delivery of end of life care in the community setting.

2. Identify limitations to your practice when providing palliative care services under the end of life program.

3. What value do you place as a health care provider on end of life services in the community setting?

4. Explain areas of the end of life program that work well, and areas you would like to see modified?

5. In your experiences with the end of life care program, what challenges have rural families faced when choosing to stay at home to palliate?

Appendix B

Health Research Ethics Authority Screening Tool

Question	Yes	No
1. Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review		X
2. Are there any local policies which require this project to undergo review by a Research Ethics Board?		X
3. Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?		X
4. Is the project designed to answer a specific research question or to test an explicit hypothesis?		X
5. Does the project involve a comparison of multiple sites, control sites, and/or control groups?		X
6. Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?		X

7. Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectation		X
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses	0	
8. Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	X	
9.Is the project intended to define a best practice within your organization or practice?	X	
10. Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	X	
11. Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	X	
12. Is the current project part of a continuous process of gathering or monitoring data within an organization?	X	
LINE B: SUBTOTAL Questions 8 through 12 =	5	

(Count the # of Yes responses		

Interpretation

• If the sum of Line A is greater than Line B, the most probable purpose is research. The project should be submitted to a REB • If the sum of Line B is greater than Line A, the most probable purpose is quality/evaluation.

Proceed with locally relevant process for ethics review (may not necessarily involve an REB). • If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

Conclusion: The sum of line B is greater than Line A, therefore the probable purpose is quality/evaluation.