

**DEVELOPMENT OF AN EDUCATION RESOURCE FOR FAMILIES AND CLIENTS
NAVIGATING THROUGH END-OF-LIFE CARE WITH AT-HOME PALLIATION**

by

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ABSTRACT

Background: Community health nurses (CHNs) play a pivotal role in providing end-of-life care to clients diagnosed with a life-threatening illness. Providing quality end-of-life care is an ethical obligation. Eastern Health's palliative end-of-life care program (PEOLC) offers nursing care, equipment, services, and support. However, the caregiver's need for practical information about end-of-life issues is not addressed. **Purpose:** To develop an educational resource to assist clients and families during end-of-life and to provide a framework for new CHNs in home palliation. **Methods:** An informal Needs Assessment, a literature review, an environmental scan, and consultations with four CHNs involved with home palliation. **Results:** An educational resource was developed to address the practical end-of-life issues identified in the literature review and consultations. **Conclusion:** An improved delivery of care for at-home palliation in the community for clients and families, and a framework for new CHNs.

Key words: end-of-life, at-home palliation; educational resource; CHNs

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Educational Resource for Clients and Families Navigating through the End-of-Life with At-Home Palliation

Providing quality end-of-life care recognizes death as a normal aspect of life and encourages support to both the client and their family. Therefore, providing quality end-of-life care during home palliation should not be marginalized. The goal of palliative care is to provide quality of life to clients and their families who are facing a life-threatening illness (WHO, 2015). This encompasses the prevention of complications, providing a supportive environment (Paice, Ferrell, Coyle, Coyle & Calaway, 2007), assessment of the psychological problems, and the management of legal and spiritual problems associated with a life-threatening illness (Open Society Foundations, 2011). While the terms palliative care and end-of-life care are often used interchangeably, the palliation process begins with the diagnosis of a terminal illness, continues until death, and then afterward with family bereavement. Similarly, end-of-life care occurs when the individual is actively dying, continues until the individual dies, and then concludes with family bereavement (CNA, 2015).

At the end of life, most people wish to die at home. For terminally ill patients, the desired place of death is recognized as a key component to achieving a good death (Kinoshita et al., 2015). The CHN plays a central role in providing quality end-of-life care to terminally ill clients and families with at-home palliation. Since caring for a loved one can be stressful, caregivers can experience psychological, physical, emotional, and financial stress (Fujinami et al., 2014). As well, caregivers can have impaired cognitive ability (Mackenzie, Smith, Hasher, Leach & Behi, 2007). To properly care for clients and meet the needs of caregivers, it is imperative the CHN feel comfortable in this role.

The purpose of this practicum is to develop an educational resource to help improve the quality of end-of-life care for clients and families during at-home palliation. This report will discuss the background and the rationale of the project. In addition, I will provide a summary of the methodologies that were used in the development of this resource. The conceptual and theoretical framework will be examined in relation to the content of the final practicum project. The attainment of advanced nursing practice (ANP) competencies will be reviewed for this practicum. Finally, the next step - involving the implementation of the resource - will be discussed.

Background

With age there is deterioration in health and an increase in life-limiting illness. As the baby boomer generation continues to mature, it is estimated that by 2036, 25% of the Canadian population will be over 65 years of age. Newfoundland and Labrador has the oldest population in Canada (Statistics Canada, 2015). In 2012, 16.6% of Newfoundland and Labrador's population's mean age was over 65 (Statistics Canada, 2015). With the impending challenges of providing quality end-of-life care, the ten bed palliative care unit at the L.A. Miller Center cannot meet the potential demand of this cohort population. The alternatives include an acute care facility, a long-term care institution, or at-home palliation. The quality of death was regarded as highest at home, followed by palliative care units, and then finally in hospitals (Kinoshita et al., 2015).

Eastern Health has a community-based PEOLC program that offers support and services through home palliation. Through the program, the client can receive 100%

coverage for comfort medication; home oxygen; limited home support services; bereavement counselling; equipment; physiotherapy; and occupational therapy. In 2013-2014, there were 125 individuals admitted to the PEOLC program in the St. John's metro area (D. Pynn, personal communications, September 11, 2015). See Appendix A for PEOLC statistics from 2008-2014. Currently, when diagnosed with a life-threatening illness, a CHN will visit with client and their family, and the palliative care team will visit weekly. The transfer of information is relayed verbally from the CHN to the caregiver and family. While the current resources for end-of-life do provide some information on the care of a loved one at home, it neglects to address the practical needs of end-of-life care. The information received is dependent on the knowledge and comfortable level of the CHN.

Rationale

The idea of the educational resource stemmed from my own personal experience with at-home palliation as a CHN. As a new CHN to the community, I noticed a lack of printed information for both the families and the nurses. Since caregivers and clients are very vulnerable at this time, the information can be very overwhelming and caregivers experienced a lack of memory recall. The role of the CHN is to help prepare the client and family as they transition from illness to death.

McKechnie, Macleod and Keeling (2007) identified a shortfall in the lack of education provided by the CHN to clients and families about palliative care and hospice services. This educational resource directly involves the family with the CHN as they

navigate through end-of-life care. Practical and relevant issues are addressed including: preparing Wills and funeral planning; pain and symptom management; accessing resources; and obtaining financial assistance; and what to do at the time of death. This educational resource will provide a valuable guide and create a standard that is needed in the community to promote a quality of life for both the loved one and the caregiver, and provide a framework for CHNs during home palliation.

Practicum Goal and Objectives

The overall goal for this practicum project is to create an educational resource for caregivers and families who choose to palliate their loved ones at home. This goal was accomplished through the following objectives:

- To assess the need for an educational tool for families who choose to palliate their loved ones at home and for CHNs.
- To collaborate with my practicum supervisor and with the coordinator of the PEOLC program in the development of an educational resource based on the literature review and data collected through consultation with key informants.
- To propose an implementation plan for the educational resource in the community setting.
- To assess the available resources currently in use by consulting with Eastern Health.
- To fulfill the following ANP competencies: clinical; research; consultation; and leadership.

Overview of Methods

Four methodologies were used to collect evidence to support the need for this educational resource. This included an informal Needs Assessment, an environmental scan, an integrative literature search, and consultation with CHNs directly involved in the home palliation process.

Informal Needs Assessment

An informal Needs Assessment was conducted prior to starting the practicum. In the informal Needs Assessment, I spoke with the CHNs at the Conception Bay South office, the clinical educator, and the PEOLC coordinator; all identified a need for an educational resource to assist clients and families with at-home palliation.

Environmental Scan

An environmental scan proved that the ARRNL did not have a policy to support end-of-life care. Eastern Health policy is a brief overview of the PEOLC program, but does not provide a tangible list of resources and available community supports. To determine if a pre-existing educational resource already existed outside of Eastern Health, I contacted the nursing manager of home and community care of Central Health. Furthermore, I contacted the Nova Scotia Hospice Care Association resource line for information on palliative care resources to determine if a resource existed in the province of Nova Scotia. The outcomes of my search indicated that a current resource did not exist in circulation.

Literature Review

The literature review provided supporting evidence for the resource and identified the desired content for the practicum project. I consulted with the librarian and we conducted a literature search using the CINAHL Advanced database. Relevant literature was located to support the need for the resource, however, there was little supporting evidence identifying the desired content of the resource. Grey literature was searched for statistics. The Health Canada site helped identify the caregivers' needs for home palliation.

Four common themes emerged from the literature review: the need for home palliation; caregiver stress; lack of CHN's comfort level with home palliation; and the need for an education resource to assist with home palliation. The complete literature review can be found in Appendix C, with the literature summary tables are found in Appendix C1.

Literature Summary

The Need for Home Palliation

The need for improved palliative care services has been recognized worldwide (WHO, 2015). In 2009, Canada has put forth a strategic plan to improve palliative care services and end-of-life care (Health Canada, 2009). According to Statistics Canada (2015), Newfoundland and Labrador has the highest increase in the aging population over age 65 with chronic illness. In addition, the Canadian Cancer Statistics (CCS) reports that there is an increased incidence of cancer with advanced age and that 29% of deaths in Canada are related to cancer (CCS, 2010). This means cancer clients will make up an important group of people who will benefit from end-of-life care.

McAteer and Wellberry (2013) found clients who receive hospice care have an improved quality of life, less depression, better symptom management, feel more in control, and are able to avoid risks associated with hospitalization and treatment. If the individual is unable to palliate at home or the palliative care unit is full, then the client may have to die in a hospital setting. Since hospitals are intended for treatment and not comfort care, a client may receive sub-optimal care (Decker, Lee & Morphet, 2015).

Caregiver Stress

The quality of life of a caregiver changes as the care needs of their dying loved one increases. The theory of caregiver stress proposes that “caregivers with stressful life events will experience a higher level of caregiver stress than caregivers without stressful life events” (Tsai, 2003, p. 140). While caring for a loved one is rewarding, the caregiver may have feelings of physical exhaustion, anxiety, emotional stress, social isolation, and depression. As well, caregivers feel overwhelmed with incurred financial burdens related to end-of-life care (Fujimami et al., 2013; Kuei-R, 2000). Furthermore, caregivers may experience frustration, anger, and guilt (Angelo & Egan, 2015). Researchers identified that caregivers experience impaired cognitive functioning, making it difficult for them to process information (Mackenzie et al., 2007).

Lack of CHN’s Comfort Level with Home Palliation

Providing quality competent nursing care for home palliation was identified as a challenge for CHNs. This was attributed to inexperience, inadequate training, and a lack of emotional support (Meirelles & Dornelles, 2015). The role of the CHN has been

misrepresented as being the nurse who set up the client with just equipment, rather than providing emotional support. Because of the lack of comfort with at-home palliation, the spiritual and emotional needs of the caregiver are often neglected (Health Canada, 2006).

The Need for an Educational Resource for At-Home Palliation

The literature identified that caregivers requested a single entry point for all services or a guide that would help them navigate to what services are available and how to access them. This included how to co-ordinate care from various professionals and how to obtain assistance agencies to relieve some of the financial burdens associated with caring for a loved one at home (Osse, Vernooij-Dassen, Schadé & Grol, 2006). A Web-based reading or a printed pamphlet was identified as a useful supplement to personal communication with health professionals (Health Canada, 2006).

Consultation Summary

The consultation process involved conducting semi-structured interviews with four CHNs involved at different levels of end-of-life care. I strategically selected a novice, a seasoned nurse, team lead CHN, and the PEOLC coordinator. After the interview contents were analyzed, the following three themes emerged: a lack of standardization for end-of-life; current resources are inadequate; a need for printed resources to assist for families during end-of-life care and to provide a framework for CHNs. See Appendix D for the complete consultation report. In the development of this project, I consulted with Doctor Cheryl Hurley, a palliative care physician, and Denise Pynn, the PEOLC coordinator, to review the content of the resource. As well, I consulted with key individuals in the community to ensure the accuracy of the information.

Lack of Standardization

The care received is dependent on the comfort level of the nurse with at-home palliation. Since it is difficult to measure the amount of psychological and emotional support provided, families and clients may be receiving suboptimal end-of-life care. Furthermore, the need for better community services was identified, including 24/7 access to palliative care services and a specialized palliative team of CHNs in the community. This is not available at this time.

Current Resources are Inadequate

All interviewees identified that the current resources, the book “Caregiver’s Guide for End-of-Life Care” and the pamphlet issued by Eastern Health, were inadequate for clients palliating at home. Because of the length of the book, it was described as being “overwhelming” and not practical at this stressful time. In addition, this resource did not account for individuals who may not have a high literacy level. While the central focus of both the book and pamphlet is the care of a dying loved one at home, they fail to provide practical information related to end-of-life care, especially at the local level.

Need for a Printed Resource for Families/Framework for Nurses

The CHN is the primary individual providing care to clients and families during end-of-life care for at-home palliation. The information communicated to the clients and families is passed verbally from the CHN. Their processing of the information depends on their preparedness and cognitive ability at that time. Currently, a practical printed resource does not exist for families and clients. The transfer of knowledge regarding home palliation by the CHN is often from CHN to CHN. The general consensus is that

you also “learn as you go”. The resource would provide a framework for both novice CHNs and CHNs who are new to at-home palliation.

Educational Resource

After the literature review and the consultation, it was clear that there was a need for an education resource to help caregivers navigate through the end-of-life care at home. The resource provides a single point of entry for caregivers to access health care professionals, agencies, and community resources. The resource is a small booklet that is written at a grade six to eight reading level, according to the SMOG readability test. After weighing the evidence from the literature and consultations, the educational resource begins with an acknowledgement of the difficulty of being diagnosed with an end-of life illness. This is followed up with a description of the PEOLC program. The educational resource is written from the third person narrative to facilitate interaction between the CHN and the client and family. A section for goal setting is created in the resource to encourage conversation between the CHN and the family.

Because of the end-of-life care is a multidisciplinary approach, the roles of the CHN, the palliative care team, the family doctor, bereavement counsellor, and the caregiver are explained. The caregiver is made aware of available equipment and resources offered through the program; available home supports; and local community resources such as the Red Cross and the Nurse Next-Door. The end-of-life discussion addresses a “do not resuscitate” order, advanced health care directives, Last Wills and Testaments, and pre-planning a funeral. The resource is intended to facilitate end-of-life

conversation.

Furthermore, the resource explores pain and symptom management in terms of what to expect at the end-of-life and as the end-of-life becomes closer. The caregiver is provided with an easy to read chart that identifies the symptoms, the reason for the symptoms, and how to manage them. Because the PEOLC program does not offer 24/7 access to palliative care services, the resource addresses potential crises, actions to take to prevent a crisis, and what to do in the event of a crisis. In addition, the resource addresses the multifaceted dimensions of death and spirituality. It encourages coming to terms with this present life and finding a spiritual release.

Finally, the resource provides a list of frequently used numbers for organizations and important contacts. There is a section for clients and families to ask questions about the content once reviewed.

Theoretical Framework

The principles of the Knowles Adult learning theory was used in the development of the educational resource. The principles of adult learning include: adults need to know why they are learning; adults are motivated to learn by the need to solve problems; an adult's previous experience must be respected and built upon; the learning approaches should match the background and diversity of the adult; and adults need to be actively involved in the learning process (Knowles, 1978).

Need to be Involved in the Learning Process/Self-Directed

The adult learning is based on the principle that adults are autonomous self-directed learners and are capable of independent study (Knowles, 1978). The literature review found that caregivers lacked information from health care professionals; a lack of service coordination; a lack of 24/7 service; a lack of appropriate and timely information; a reluctance to ask for emotional and spiritual support; and rushed or overworked health care professionals (Health Canada, 2006). In addition, caregivers requested a single entry point for all services or a guide that would help them navigate to what services are available and how to access them (Brown et al., 2011; Health Canada, 2006). The caregivers wished to be informed of the physical signs of decline, how to deal with pain control, and how to obtain assistance with financial burdens (Osse et al., 2006). The findings from searching the literature became the crux of the resource. In addition, the resource includes a list of websites for the caregiver to access, if they desire more information.

Need to Know Why they are Learning/Relevance to Lives

Adults will invest more time and energy learning when they are aware that there is a reason for learning. Adults are willing to learn, if it will improve their current situation (Knowles, 1978). The literature identified the concept of caregiver stress. The challenges associated with caring for a loved one with a life-threatening illness becomes the motivation behind the need to learn. Furthermore, caregivers want to honor the wish of their loved one to die at home.

Need to Solve Problems

A need for basic information related to end-of-life care was identified in the literature review and the consultation process. Based on Knowles (1978), the information is problem-centered, rather than content-centered. From my own clinical experience, caregivers and clients have many concerns as the end-of-life approaches. A large aspect of end-of-life care is preparing for the time of death and even after death. This includes having proper documentation and plans implemented prior to the passing of the loved one. Having a legally valid Last Will and Testament is particularly important, especially in the situation of common-in-law spouses. Another common concern of caregivers is what to do when the loved one passes away in the home. In the resource, this is addressed so the caregiver do not find themselves in a precarious situation.

Previous Experience

Adult learning theory is draws from previous experience (Knowles, 1978). The home palliation process builds on the caregiver's previous experience of caring for others and incorporates skills that they have acquired. The CHN assesses the previous experience of caregivers because they are responsible for medication administration, providing personal care, and assessing the effectiveness of pain medication.

Background and Diversity

Adults accumulates a broad range of life experiences throughout their life span and have adults have diverse styles of learning (Knowles, 1978). In designing the educational resource, the resource is written at a grade six to eight reading level to reach a variety of the adult population. The resource respects individuality and the diverse nature

of spirituality. Caregivers requested that information be provided in stages corresponding to their rate of understanding, and they did not want too much detail regarding the future of the illness or death (Brown et al., 2011). The resource is intended for the caregiver to learn at their own pace based on the need.

Conceptual Framework

The PRECEDE-PROCEED model (PPM) was used as the conceptual framework for the development of this project. The first five steps of the model focus on the planning aspect of the project, whereas the last four focus on the implementation and evaluation aspects of the project (see Appendix B for PRECEDE-PROCEED MODEL). The focus was on the PRECEDE aspect of the conceptual framework. The Needs Assessment is an integral component of program development; the PPM identified the existing gap in knowledge needed to achieve an optimal level of operation (McKenzie, Neiger, Thackeray, 2013).

Phase 1: Social Assessment

Social assessment and situational diagnosis seek to define the quality of life, including the problems and priorities of the target population (McKenzie et al., 2013). To facilitate a quality death at home, competent health professionals are needed to provide support and provide knowledge that will assist with the palliation process. Since the cognitive ability of caregivers can be impaired, they need to be informed of the role of the nurse, how to access available resources, and how to care for a dying loved one at home.

Phase 2: Epidemiological Assessment

As more individuals are choosing to palliate at home, there will be an increased demand for nursing services and access to resources. Informal caregivers identified a lack of necessary resources or abilities to provide end-of-life care in their own home. Among the needs identified were home care resources, financial assistance, paid time off from work, and home modifications (Statistics Canada, 2014). In 2013-2014, there were 125 individuals admitted to the PEOLC community based program in the St. John's metropolitan area (D. Pynn, personal communications, September 11, 2015). It is expected with the aging population, more individuals will opt to die at home (Statistic Canada, 2015), therefore increasing the demand quality end-of-life care.

Phase 3: Behavioural and Environmental Assessment

This phase identifies and classifies predisposing, enabling, and reinforcing factors. These factors have the potential to influence an individual and provide the motivation for health behaviour. Predisposing factors include knowledge, attitude, and beliefs that help or hinder health behaviours (McKenzie et al., 2013). Enabling factors are barriers or resources that hinder or help in the access to health-related services. Thirdly, reinforcing factors influence the motivation for behaviour change.

In the palliation process, knowledge about death and dying can help decrease the anxiety and stress of caregivers. Access to resources are enabling factors than can assist with more independence at home and being able to palliate in the community. In contrast, lack of communication with health professions, a lack of resources, a lack of education on end-of-life care, and a lack of preparation for end-of-life can hinder effective palliation at

home. The reinforcing factors, such as quality of life for both the caregiver and individual, can influence the decision to palliate at home. In addition, the choice of dying at home is preferred over a hospital death.

Phase 4 –Educational and Ecological Assessment

A barrier to quality of care identified by caregiver is not knowing what information they need or the right questions to ask (Kristjanson, 2004). To date, there is no information resource that explains the community resources that are available to the clients or the purpose of the palliative care team. A practical resource was deemed to help caregivers navigate through end-of-life care.

Phase 5- The Administrative Assessment and Policy Assessment

The administrative assessment evaluates the current resources to develop and implement the proposed project (McKenzie et al., 2013). The current policy for end-of-life care outlines the eligibility criteria for the program and services that the client may receive through the program (Eastern Health, 2013). The policy is accessible to nurses, but it is limited in detail. Much of the knowledge is acquired through word-of-mouth and experience.

ANP Competencies

The demonstration of the ANP competencies of clinical research, and consultation and collaboration, as per the Canadian Nurses Association (CNA, 2008), was identified as a core objective in the development of the practicum.

Clinical Competence

In the development of this project, I have relied on my own clinical competence and experience as a CHN. As a new CHN to home palliation, I would ask questions when I had a palliative client on my caseload. In retrospect, because there is no set list or framework, I know that I could have provided better care to my clients. The information transferred to client and families was dependent upon my knowledge and experience. This results in a lack of standardization, and providing less than optimum quality care. Furthermore, new graduate nurses and CHNs new to home palliation are reluctant to go into the home of someone dying because palliation makes them uncomfortable. Overall, this resource will improve the clinical competence of CHNs in the community.

Research

Research competencies involve using evidence-based practice to guide the care of a particular population (CNA, 2008). My research competencies were demonstrated through a review of the literature, a Needs Assessment, the consultation process, and by conducting an environmental scan. In addition, in the development of the research project, I explored what was available at the local community level to ensure the information was relevant and accurate. The research identified a current gap in practice: the learning needs of caregivers and the uncertainties of CHNs in practice regarding home palliation. The caregiver stress theory was identified as having impact on the caregiver during home palliation. Also, the Knowles Adult Learning theory and the PRECEDE-PROCEED model were also researched as to their applicability to this project.

Leadership

ANPs are “agents of change, consistently seeking effective new ways to practise, to improve the delivery of care, to shape their organization, to benefit the public and to influence health policy” (CNA, 2008, p. 24). This was demonstrated by taking the initiative to address the current need in home palliation. With the completion of this project, the leadership competency will be evident by advocating for families and clients in the community; the resource will facilitate a better quality home palliation, reduce the stress of caregivers and others, and enhance the quality of care provided by CHNs.

Consultation and Collaboration

Consultation and collaboration competencies have been extremely important to date in the development of this project. Consultation and collaboration with clients and other health care team members is vital to effective nursing practice (CNA, 2008). I have collaborated and consulted with my course professor, Dr. Khraim, who provided input and edification on my work. I completed the consultation plan and interviewed four key individuals who confirmed the need for the educational resource and provided input with what information should be included in the resource. I also contacted individuals outside Eastern Health to determine if other educational resources exist to assist with home palliation. Furthermore, I consulted with key stakeholders in the community to ensure the availability of outside resources such as the Red Cross. I checked with the palliative care unit to clarify the role of the palliative care unit in the home palliation process. I also consulted with Ed Tapper, ambulance driver with Eastern Health, to determine the proper protocol for the removal of the loved one if they pass after hours.

Next Step

Implementation

Since the development of the resource, I have met with Denise Pynn for review. The resource was also reviewed by Doctor Cheryl Hurley. The resource will be presented to the end-of-life committee. Once approved by this committee, it will be presented to the Home and Community committee where it will be further edited, as necessary, and signed off by Karen Milley, the regional director responsible for Public Health and Home and Community Care at Eastern Health. Following her approval, the resource will be then presented to the education committee. There it will be evaluated for content and readability. This process can take up to two years (C. Gosse, personal communications, March 10, 2016).

Once the final modifications have been made, the educational resource will be introduced to Eastern Health CHNs that are in contact with palliative clients and their caregivers, so that they can be familiar with the information. This will be done via Webinar so that all CHNs employed by Eastern Health can be aware of the resource. While the resource will be self-explanatory, the CHNs should be aware of the caregiver's needs as identified in the literature. They ought to be aware of the importance of how the information is delivered, e.g. not to be rushed, presented in small amounts, and that repetition may be necessary. The distribution of the resource will be to the primary points of contact: all five community health zones in the St. John's metropolitan area. The reinforcement of the resource will be made via e-mail to the PEOLC representative at the individual offices, and the CHN team leads at all five community health offices. In

addition, support staff will be informed of the resource and asked to place the resource on the referral of all palliating clients.

Conclusion

The practicum report has explored key aspects of the development of the education resource for helping clients and client navigating through end-of-life care with at-home palliation. In this report, the objectives of the practicum project were met. This was evident through an assessment for the need for the resource, the collaboration process, proposing an implementation plan for the resource, and fulfilling the ANP competencies. As discussed in the report, the implications for this resource have been strongly supported through the various methodologies.

This report provided a summary of the literature review, and the consultation process. The findings of the literature review and the consultation process were then incorporated in the final practicum project. The application of Knowles Adult Learning theory and the PRECEDE-PROCEED model were used in the development of the project. This was examined and applied to the practicum project. Based on the time constraints presented in this course, it is challenging to implement the educational resources in such a short period of time that is both theoretically and practically sound. Therefore, the next step of the project was explored through consultation with key individuals. In the development of this education resource, I hope that the misconceptions surrounding end-of-life care will be dispelled and this resource will encourage an open conversation about end-of-life planning. With the final goal being met, this resource will improve the quality of life for clients and families who choose to palliate at home. Furthermore, this resource will change the current delivery of care of CHNs and encourage a new comfort level

among CHNs with end-of-life care.

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Appendix A

Palliative End-of-Life Care Statistics Eastern Health (2008-2014)

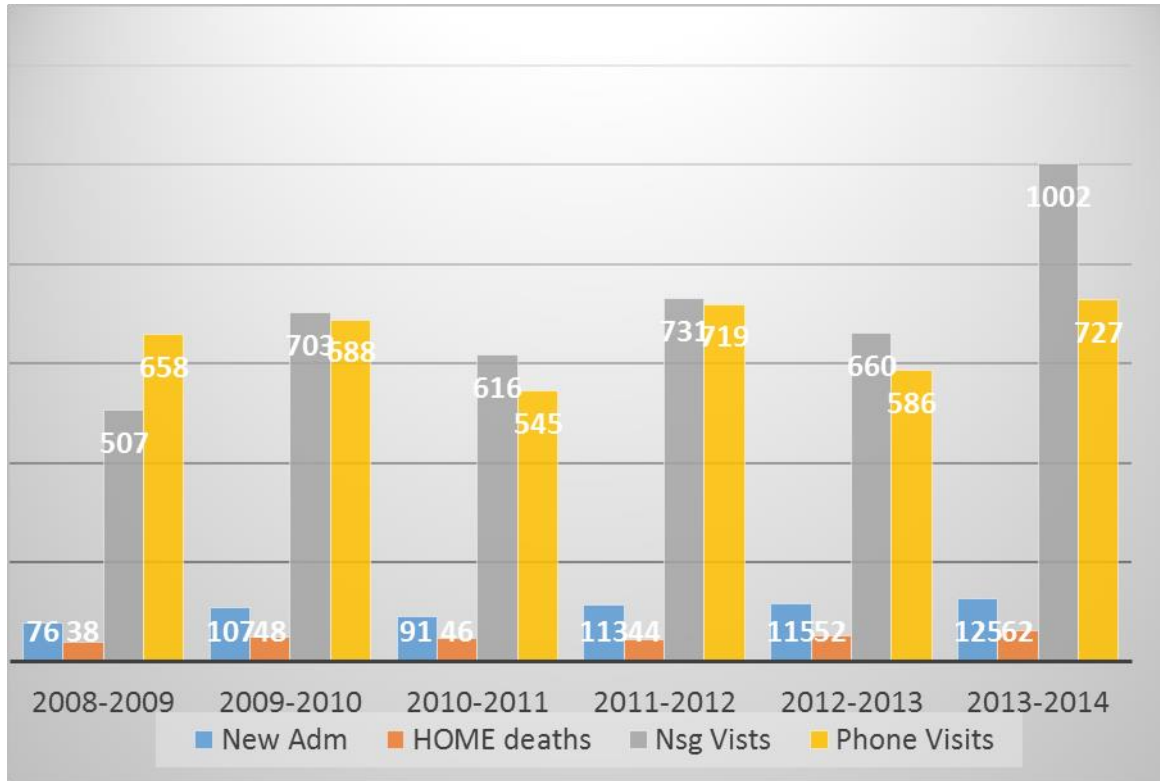
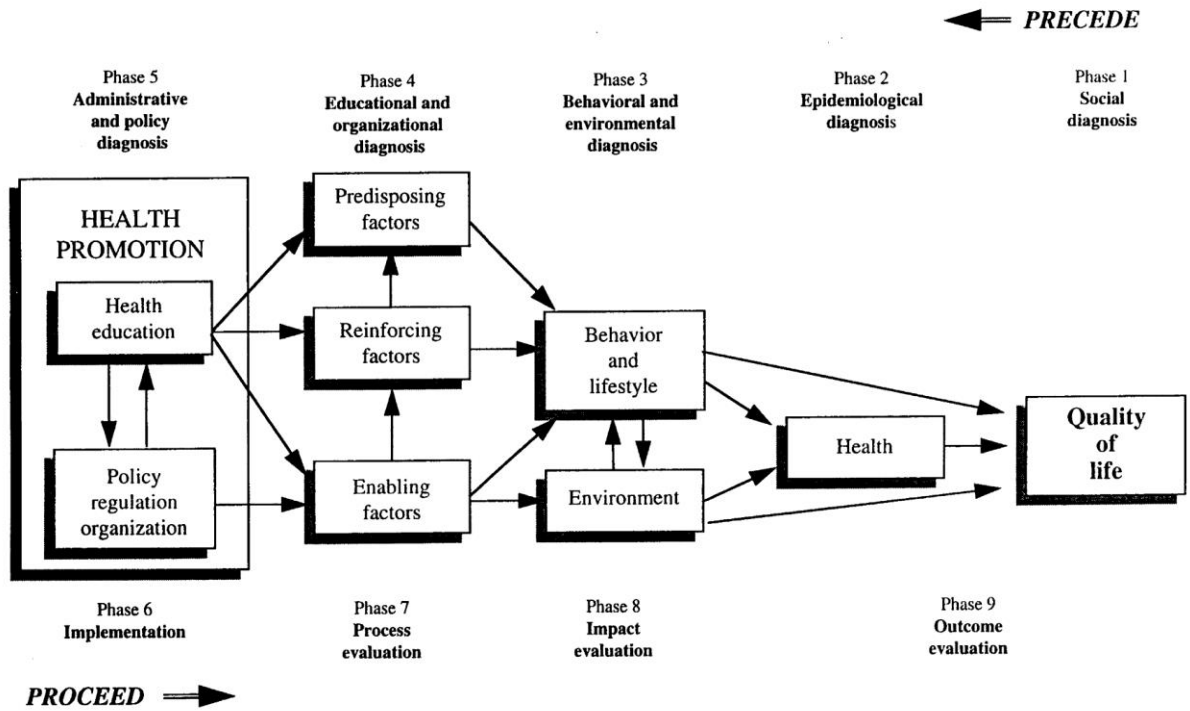


Figure 1: PEOLC stats for Eastern Health (2008-2014). Retrieved from Denise Pynn (PEOLC coordinator)

Appendix B
 PRECEDE-PROCEED MODEL



The Precede-Proceed model of health promotion planning [adapted from (Frankish et al., 1998)].

Appendix C

Literature Review

Integrative Literature Review: Palliation at Home

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Abstract

The diagnosis of a terminal illness can be overwhelming for both the individual and their family. Providing end-of-life care can be emotionally taxing and physically exhausting for the caregiver. The uncertainty of not knowing what to expect and what resources are available can place unnecessary demands on the family unit. As more people are choosing to die at home, there is a need for guidance in the community setting. The community health nurse (CHN) is of paramount importance in assisting clients and their families through the home palliation process. The purpose of this paper is to promote better understanding of the palliation process at home and the need for guidance and support at the end-of-life stage. An integrated literature review was completed to examine the following factors: palliation in the home; the role of the CHN and the palliative care team; the caregiver's needs; and how the CHN can meet those needs. The PRECEDE-PROCEED Model will be discussed as the conceptual framework in relation to identifying the need. The principles of Knowles Adult learning theory will be explored in the creation of the educational resource.

Key words: palliative care in the home; integrated literature review; community resources; educational resource

Integrative Literature Review: Palliation at Home

The World Health Organization (WHO) defines palliative care as a means to provide better quality of life to patients and their families who are facing life-threatening illness. Access to palliative care services is recognized as a human right to health (WHO, 2015); it is not limited to the end-of-life, but also includes care during the treatment phase of the illness (Paice, Ferrell, Coyle, Coyle & Calaway, 2007). The palliation process begins with the diagnosis of a terminal illness, continues until death, and then afterward with family bereavement. Similarly, end-of-life care occurs when the individual is actively dying, continues until the individual dies, and then concludes with family bereavement (CNA, 2015).

Despite misconceptions, palliative care affirms life and views death as a normal process; it does not hasten or prolong the dying experience, rather, it is highly effective in pain and symptom management (Open Society Foundations, 2011). Furthermore, a palliative care approach includes prevention of complications, providing supportive environment (Paice et al., 2007), assessment of the psychological problems, and the management of legal and spiritual problems associated with a life-threatening illness (Open Society Foundations, 2011).

As more individuals are choosing to palliate at home, there will be an increased demand for nursing services and access to resources. Since the community health nurse (CHN) plays a pivotal role in providing end-of-life care, the CHN should be knowledgeable about the end-of-life process, the clients and family's needs and what resources are available in the community setting. As nurses, we have an ethical

responsibility to support accessible, high quality palliative and end-of-life care (CNA, 2015).

Since the focus of this paper will be on palliative end-of-life care, I will provide an integrative literature review examining the concept of end-of-life care and the need for better end-of-life care on a local level. The terms palliative care and end-of-life care will be used interchangeably throughout this paper. The PRECEDE-PROCEED Model will be discussed in identifying the needs of client's and families palliating at home and the CHNs who attend to those needs. In addition, I will discuss the principles of Knowles Adult Learning theory associated with developing a competent educational resource. Literature summary tables will be provided for research studies relevant to the topic of the paper.

Integrative Literature Review

Background and Topic Relevance

According to the WHO (2015), 48 million people worldwide require palliative care. By the year 2036, it is estimated that seniors will comprise 23% to 25% of the Canadian population (Statistics Canada, 2010). With advanced age, there is a deterioration in health and an increased risk for illness, resulting in a higher number of Canadians diagnosed with chronic life-limiting illnesses. According to Canadian Cancer Statistics (CCS), there is an increased incidence of cancer with advanced age. Approximately 29% of deaths in Canada are related to cancer (CCS, 2010). Therefore, individuals with cancer make up an important group of people who will benefit from end-

of-life care. While cancer is the leading cause of death in Canada (CIHI, 2015), clients with other life-threatening illnesses are also candidates for home palliation. Palliative care is also suitable for a wide range of life-threatening illnesses including: HIV/AIDS; advanced cardiovascular disease; end-stage renal or liver disease; dementia; neuromuscular disorders; upper motor neuron disease (Paice et al., 2007); and advanced COPD (Teno et al., 2004).

To improve the quality of end-of-life care, there needs to be a better understanding of the experience of patients and their families. Caregiver stress is not uncommon when caring for a loved one at home. The theory of caregiver stress proposes that “caregivers with stressful life events will experience a higher level of caregiver stress than caregivers without stressful life events” (Tsai, 2003, p. 140). Essentially, because of the challenge of providing end-of-life care, caregivers may experience emotional and physical exhaustion.

Of all healthcare professionals, nurses spend the most time with the clients and families. The nurse provides care through the course of the individual's lifespan and serves as clinician, advocate and educator, even in the last stage of death (Paice et al., 2007). In the palliation process, most of the knowledge regarding end-of-life care is taught by other nurses (Paice et al., 2007). In order for nurses to provide a quality of care that will meet the needs of the client and their family, it is vital for the nurse to be equipped with the proper knowledge and tools for end-of-life care.

Currently, the palliative end-of-life care program (PEOLC) in St. John's, Newfoundland and Labrador, provides a book to caregivers entitled “A Caregivers Guide:

A Handbook About End-Of-Life Care” and distributed by the Canadian Hospice Palliative Care Association. This book includes information on how to tend to physical needs, recognize spiritual needs, and create a supportive home environment while a loved one is palliating at home. In addition, the home and community program of Eastern Health has a booklet entitled “Toward an Understanding of the Final Days of Life”. While both of these resources are useful, they do not address the immediate and practical needs of the client and caregiver during end-of-life care. The accurate transfer of information is the responsibility of the CHN. An educational resource is needed to provide caregivers with guidance on how to tap into in to community resources and navigate through end-of-life care (Angelo & Egan, 2015).

Literature Review Strategy

In searching for relevant literature regarding palliation at home, I consulted with a librarian at the Health Sciences Center. We searched the CINHALL Advance Database to locate both quantitative and qualitative articles. Initially, the search terms "terminal care" or "palliative care" or "terminally ill patients" or "hospice and palliative nursing" and "community health nursing" or "community health services" or "home health care" or "home nursing, professional" or "home visits" and "caregivers" or "caregiver burden". This resulted in 162 outcomes. In addition to the above terms, we entered “quantitative studies”, “cross-over design”, “non-experimental studies”, “quasi-experiments”, and “retrospective design.” This yielded 207 results. So, to narrow the search, I entered the term “caregiver” and this reduced the results to 58. To help identify "barriers" or “facilitators” to palliation at home, the same initial search terms were entered, to yield

provided 66 results. In addition to the above search, I entered “caregivers”, “educational needs” and “end-of-care”. This provided 20 results.

The research articles were assessed and reviewed, so that the most relevant and pertinent were selected. Research studies of a qualitative design were evaluated for methodology, scientific merit, clarity, and rigour. These studies were rated using the Public Agency of Canada (PHAC) quality rating tool. Literature summary tables were created for many of the studies.

I searched grey literature for relevant statistics, and for educational resources that are currently being used in home palliation. I contacted the nursing manager of home and community care in central Newfoundland to determine what resources were used in palliation. In addition, I contacted the Nova Scotia Hospice Care Association resource line for information on palliative care resources that are in circulation in the province of Nova Scotia.

PEOLC Programs

While evidence shows that most people want to die at home (WHO, 2015), this may not always be a realistic option. As indicated earlier, one main prerequisite to home palliation is a willing family caregiver. Other barriers identified by WHO (2015) include: access to resources and implementing services; a lack of knowledge and training of health care professionals; a lack of community volunteers; and lack of national policies identifying the need for palliative care and end-of-life (WHO, 2015).

In 2011, there were only twenty countries with well-integrated PEOLC programs (WHO, 2015). Recently, the Economist Intelligence Unit (EIU) ranked the United Kingdom as the best place to die in the 2015 Quality of Death Index. This is related to the UK's comprehensive national policies, the extensive integration of palliative care into the National Health Service, a strong hospice movement, and deep community engagement on the issue. The financing of the program is through government funding and charitable donations (EIU, 2015). Australia and New Zealand rank in second and third place, respectively, as the best place to die, while the USA ranks ninth, and Canada is in the eleventh place (EIU, 2015).

Over the past five years, Canada has put forward a strategy supporting palliative and end-of-life care (PEOLC). The overall goal of the PEOLC is to improve the quality of living and dying for those facing life-threatening illness. The PEOLC program offers the following services: pain and symptom management; psychological, social, emotional and spiritual support; support for caregivers; and bereavement support (Health Canada, 2009). To support a quality PEOLC, the project recommended accessibility to 24/7 care, continuity of care, caregiver satisfaction, and client and caregiver goal setting (Health Canada, 2009).

In Newfoundland and Labrador, Eastern Health has a PEOLC program that services the St. John's metropolitan area. Through the program, the client can receive 100% coverage for medication; oxygen; home support services; bereavement counselling; equipment; physiotherapy; and occupational therapy. Nursing services are provided by

the CHN, and the palliative care team will visit once per week. The palliative care team is composed of a physician and a nurse. In addition to the PEOLC, the St. John's metropolitan area program has a ten bed palliative care unit located at the Dr. Leonard A. Miller Center. Often, families and clients will choose to stay at home and then decide to go to the palliative care unit to die. The closest hospice to the St. John's area is located in Halifax, Nova Scotia. In the event of a crisis, the family may have to proceed to the emergency department. The very nature of an emergency department is a high-stress, fast-paced and chaotic environment that is not equipped to provide quality end-of-life care. Decker, Lee and Morphet (2015) found the emergency department to be noisy, busy, lacking in privacy, and lacking palliative care expertise. This caused distress for the families and clients. Nurses also realized that the emergency department was not the ideal place for death and the client received suboptimal care.

Under the services of Central Health in Newfoundland and Labrador, there are twenty designated palliative beds throughout the region. These beds are located on medical units or in long-term care facilities. The individuals who palliate at home do not have 24/7 access to palliative care services. The educational resources that are provided to end-of-life clients and families includes "A Caregivers Guide; A Handbook About End-Of-Life Care", by the Canadian Hospice Palliative Care Association. The palliative care team was first developed in the past five years (V. House, personal communications, October 23, 2015).

To meet the need of the palliative population, Halifax has launched the "speak up" campaign that promotes Advance Care Planning. This program is advocated by the

Canadian Hospice Palliative Care Association (CHPCA) and is part of Canada's larger national initiative to promote advanced directives. Individuals are encouraged to have a discussion with family and friends about their health and personal care wishes, in the event they become incapable of verbalizing their choice of care (CHPCA, 2015). There are also advanced planning tools for cancer patients, families, and healthcare professionals. Halifax has a "death café" where clients who are dealing with death can meet and openly discuss their feelings. If clients need help with medication dosing, paramedics are available after hours through the palliative program to increase their medication dosage. Volunteers are involved with providing transportation and going into homes during palliation to provide support. Furthermore, there is a "death midwife" that visits the home and provide guidance for funeral arrangement (K. Woolstenholme, personal communications, October 22, 2015).

Hospital Death and Home Death

Since the goal of palliative care are to provide quality end-of-life care and lessen caregiver stress (CNA, 2015), dying at home should provide satisfaction for both clients and caregivers. A good death is defined by Kehl (2006) as "one that is free from avoidable distress and suffering for patients, families and caregivers..." (p. 227). Home-based palliative care programs provide services through community care teams consisting of physicians, nurses, personal support workers, and case managers. The quality care at the end-of-life depends on the agreement and cohesiveness of the interdisciplinary health team, requiring strong interpersonal skills, clinical knowledge, technical competencies, and respect for individuals (Masucci, Guerriere, Zagorski & Coyte, 2013). These teams

are better able to identify and deal with the needs of patients and their families as compared to conventional care. The place of death is important for terminally ill patients because being in a preferred place is recognized as a key component to achieving a good death (Kinoshita et al., 2015).

In acute care facilities, where death occurs infrequently, the individual may not receive the same standard of care as compared to a setting that is accustomed to palliation. Hospitals are intended for treatment and recovery. A palliative individual often receives inappropriate treatment, poor pain and symptom management, and undergoes prolonged suffering (CNA, 2015). In contrast, specialized palliative care services improve patient outcomes with pain control, reduced anxiety, and avoiding unnecessary hospital admission (Jack, Hillier, Williams & Oldham, 2015; Paice et al., 2007). Studies have shown that the caregiver's perceptions of the quality of life care received by their loved ones differs between those who die at home as compared to dying in an institution (Kinoshita et al., 2015; Teno et al., 2004). The quality of death was regarded as highest at home, followed by palliative care units, and then finally in hospitals (Kinoshita et al., 2015).

Teno et al., 2002 found that loved ones of family members who die in a nursing home, at home with nursing services, and in a hospital had more unmet needs for pain than with home hospice services. Furthermore, family members reported more respect from home hospice care and expressed fewer concerns about emotional support. Providing quality of life for terminal patients through home-specialist services are intended to meet the needs of patients towards end-of-life with physical symptoms and

distress (Dhiliwal & Muchaden, 2015). Comparably, clients who receive hospice care have an improved quality of life, less depression, better symptom management, feel more in control, and are able to avoid risks associated with hospitalization and treatment (McAteer & Wellberry, 2013).

The lack of access to services increased the number of palliative deaths in hospital (Dhiliwal & Muchaden, 2015). In addition, research indicated that a diagnosis of cancer increased the use of hospice services, whereas a diagnosis of COPD usually transitions to a hospital setting, and individuals diagnosed with dementia were admitted to a nursing home (Teno et al., 2013). In Canada, low socioeconomic status is not a factor in determining the place of death.

Palliative Care and Service Use

For the PEOLC program, certain criteria has to be met, including: diagnosis with a terminal/life limiting illness; an estimated time of death of thirty days or less; a caregiver; and a family doctor willing to assist with palliation.

In Canada, if you are diagnosed with a terminal illness and wish to die at home, there is an increased likelihood of that happening if you are female and living with someone, as compared to being a male and living alone (Masucci, Guerrier, Richard & Coyte, 2010). In addition, there is an increased use of services in older adults as compared to someone who is younger. As well, older individuals with lower functioning ability are more likely to receive more nursing visits and support workers. Male caregivers tend not to have many nursing visits as compared to females. Furthermore, low socioeconomic

status tends to intensify the use of home-based nursing services (Masucci et al., 2012).

Caregiver

Caregiver Demographics

Being able to die at home is dependent on the capability of the family caregiver to provide care. Approximately 77% of all caregivers are female, with 70% of those being 45 years of age or older. With the vast majority of family caregivers in Canada being female, they are most likely to be retired or homemakers (Health Canada, 2012).

Caregiver's Need

For the dying individual, home can bring a sense of comfort and control because they are surrounded by familiarity and cherished memories. However, for the family member, the decision to honor a loved one's request can be accompanied by an increase in physical demands, anxiety, emotional stress, social isolation, depression, and financial burdens (Fujimami et al., 2013; Kuei-R, 2000). The quality of life of a caregiver changes as the care needs of their dying loved one increases. The caregiver's quality of life is affected by caregiver burden, disruptiveness, positive adaptation, and financial concerns (Connell et al., 2013; Fujimami et al., 2015). As a result, in addition to their physical exhaustion, caregivers may experience frustration, anger, guilt, and loneliness (Angelo & Egan, 2015).

The greatest needs identified by the caregivers were an unpredictable future and accepting the patient's disease (Osse, Vernooij-Dassen, Schadé & Grol, 2006). Other concerns included: a lack in competent care; not being informed of the physical signs of

decline; or how to deal with pain control (Osse et al., 2006). Considering about 80% of all care at home is provided by family care (Stajduhar, 2013), it is not surprising that caregivers often feel physically and emotionally exhausted (Fujimami et al., 2015; Osse et al., 2006). Regrettably, caregivers struggle with co-ordinating the care of different professionals and getting help from agencies and assistance with financial burdens (Osse et al., 2006). This indicates a need for guidance and advocacy.

Mackenzie et al., (2007) noted that because of the increased physical and mental health risk associated with caregiving, caregivers demonstrated cognitive impairment. Not surprisingly, caregivers had difficulty with memory recall, acquiring new items, and switching from one task to another. Brown, Johnston & Åstlund (2011) found that when educating caregivers, the pace of giving information was important. Caregivers requested that information be provided in stages corresponding to their rate of understanding, and they did not want too much detail regarding the future of the illness or death. Osse et al., (2006) reported 23% of the caregivers lacked information in writing, and more than 50% of them wanted more information about elementary issues such as preparation for problems as the disease progresses. Since palliation of a loved one at home can be very stressful, information should be provided in gradual amounts and consistently.

Caregivers Perceived Service Barriers

The goals set by Health Canada (2009) are well-intended, in reality caregivers identified gaps in the current system. These gaps create barriers to implementing quality care to families and clients. The gaps identified by caregivers include: lack of information

from health care professionals; lack of service coordination; a lack of 24/7 service; lack of appropriate and timely information; a reluctance to ask for emotional and spiritual support; and rushed or overworked health care professionals (Health Canada, 2006).

Research provided by Health Canada (2006) indicated that caregivers reported a lack of coordination between hospitals and the community setting in providing services when their loved one is discharged home to die. In addition, caregivers have voiced frustration with trying to access services and not knowing where to access those services. Caregivers had difficulty locating information, and therefore, they requested a single entry point for all services or a guide that would help them navigate to what services are available and how to access them. Caregivers identified that nurses had limited time to spend with the client and caregiver because of their busy schedule (Brown et al., 2011; Health Canada, 2006). A Web-based reading or a printed pamphlet was identified as a need by caregivers as a supplement to personal communication with health professionals (Health Canada, 2006).

Community Health Nursing and Palliative Care

The palliative care process involves teamwork and collaboration. The role of the community health nurse is often wrongly defined as the nurse who focuses on practical issues, such as equipment, whereas the clinical nurse specialist is more directed to psychosocial issues (O'Brien & Jack, 2009). Unfortunately, some CHNs have the same perceptions. Arnaert and Wainwright (2009) identified that CHNs often feel threatened by palliative nurse specialists and may be reluctant to involve them in the client's care. Comfort with the palliation process is acquired through experience and knowledge. It is

not unusual for CHNs to be insecure with dealing with the complex needs of palliative individuals (Arnaert & Wainwright, 2009). CHNs have identified that individuals with complex needs were being discharged in the community without appropriate resources being implemented by hospital staff (O'Brien & Jack, 2009), resulting in the individual being re-admitted to hospital and then being more likely to die there (Teno et al., 2012).

Competent Health Nursing services

Competency is central to caring for patients dying at home. To assist CHNs in the palliation process, the expertise and knowledge of palliative care specialists is often required. For novice nurses, other senior staff may be a source of knowledge (Arnaert & Wainwright, 2009). Overall, a lack of experience, and inadequate training and a lack of emotional support, are seen as obstacles to providing quality of care to patients at the end of their lives (Meirelles & Dornelles, 2015).

Competencies identified in the palliative care process include: recognizing client's autonomy; maintaining dignity; effective communication; establishing a relationship between patients and health care professionals; accessing the multidisciplinary approach; ensuring quality of life; having a position in relation to life and death; identifying loss and grief; and public education regarding networking to meet the complex needs of patients (Brown et al., 2011; Meirelles & Dornelles, 2015). In providing care, the spiritual and emotional needs of the caregiver are often neglected. Caregivers often feel guilty about their own personal needs (Health Canada, 2006), and nurses need to recognize this need and provide support. This can be done personally or through a bereavement counsellor. Support, both physical and emotional, can come from friends, family, and professionals

(Brown et al., 2011). To provide quality end-of-life care to palliative patients, nurses need to be competent to ensure the continuity of the care process.

Conceptual and Theoretical Framework Guiding Clinical Practicum

Adult Learning Theory

The principles of adult learning will be used in the development of the informational resource for caregivers palliating at home. This resource will further expand on the CHN's knowledge base and promote continuity of care. Knowles (1978), felt that the heart of education is learning, and not teaching. As the individual matures, his or her ability to be self-directed improves, and there is a decreased dependency on others (Knowles, 1978). The principles of adult learning include: adults need to know why they are learning; they are motivated to learn by the need to solve problems; their previous experience must be respected and built upon; the learning approaches should match the background and diversity of the adult; and they need to be actively involved in the learning process (Knowles, 1978).

The target population is adult caregivers. There is a need identified in the literature for basic information related to end-of-life care. The module will be designed with a table of contents for simply looking up frequently asked questions and answers related to end-of-life care. Furthermore, there will be a checklist to serve as a reminder of the information that has been communicated.

Knowles (1978) believed that adults are able to utilize their experiences, identify their readiness to learn, and organize their learning around life issues. The experience of

taking care of a dying loved one is a difficult experience, and a desire to gain knowledge regarding the illness may help the patient gain a sense of control over the situation. By providing information regarding end-of-life issues, the client and caregiver should be able to cope more effectively and have less anxiety. The experience of death can be intimidating when resources are limited and when one does not know what to expect. While the concept of home palliation is well-explored in the literature, caregivers are reporting an unmet need related to practical end-of-life care and not knowing how to access resources.

PRECEDE-PROCEED Model

The PRECEDE-PROCEED model (PPM) will be used as the conceptual framework for the development of this project. Planning interventions and strategies for a project are created through systematic models designed to provide organization and structure (McKenzie, Neiger, & Thackeray, 2013). The acronym PRECEDE-PROCEED model is composed of nine steps which are used in the organizing and planning process. The first five steps of the model focus on the planning aspect of the project, whereas the last four focus on the implementation and evaluation aspects of the project.

The acronym PRECEDE, which stands for Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation, creates the diagnostic and assessment aspects of the model. The second aspect, PROCEED, is Policy, Regulatory and Organizational Constructs in Educational and Environmental Development, and describes the intervention and evaluation phases (Tramm, McCarthy & Yates, 2012). The model begins with the desired outcome, and then designs interventions to reach that

desired goal. Since a Needs Assessment is an integral component of program development, the PPM will identify an existing gap in the skills and knowledge needed to achieve an optimal level of operation (McKenzie et al., 2013).

Phase 1: Social Assessment

Social assessment and situational diagnosis seek to define the quality of life, including the problems and priorities of the target population (McKenzie et al., 2013). For a palliating client who is dying, research shows that they are experiencing a decreased quality of life (Connell et al., 2013). In addition, their caregivers are stressed physically, emotionally, financially, and socially (Fujinami et al., 2014). To facilitate a quality death at home, competent health professionals are needed to provide support and provide knowledge that will assist with the palliation process. Since the cognitive ability of caregivers can be impaired, they need to be informed of the role of the nurse, how to access available resources, and how to care for a dying loved one at home. Researchers identified that information in a written form is a need identified by caregivers (Osse et al., 2006).

Phase 2: Epidemiological Assessment

As more individuals are choosing to palliate at home, there will be an increased demand for nursing services and access to resources. Statistics Canada (2014) identified 35% of Canadians surveyed in 2012 had provided care for their terminally ill relative or friend in the home. The respondents identified a lack of necessary resources or abilities to provide end-of-life care in their own home. Among the needs identified were home care resources, financial assistance, paid time off from work, and home modifications

(Statistics Canada, 2014). In 2013-2014, there were 125 individuals admitted to the palliative end-of-life care (PEOLC) community based program in the St. John's metropolitan area (D. Pynn, personal communications, September 11, 2015). It is expected with the aging population, more individuals will opt to die at home (Statistic Canada, 2015), therefore increasing the demand for services.

Phase 3: Behavioural and Environmental Assessment

This phase identifies and classifies predisposing, enabling, and reinforcing factors. These factors have the potential to influence an individual and provide the motivation for health behaviour. Predisposing factors include knowledge, attitude, and beliefs that help or hinder health behaviours (McKenzie et al., 2013). Enabling factors are barriers or resources that hinder or help in the access to health-related services. Thirdly, reinforcing factors influence the motivation for behaviour change. In the palliation process, knowledge about death and dying can help decrease the anxiety and stress of caregivers. Access to resources are enabling factors than can assist with more independence at home and being able to palliate in the community. In contrast, lack of communication with health professions, a lack of resources, a lack of education on end-of-life care and a lack of preparation for end-of-life can hinder effective palliation at home. The reinforcing factor such as quality of life for both the caregiver and individual can influence the decision to palliate at home. In addition, the choice of dying at home is honored versus a hospital death.

Phase 4 –Educational and Ecological Assessment

While most people would choose to die at home, the reality is dependent on several factors, including the willingness and availability of a caregiver, and a community-based palliative care program. In addition to nursing services, the PEOLC program requires that the dying individual have a primary caregiver. A barrier to quality of care identified by caregiver is not knowing what information they need or the right questions to ask (Kristjanson, 2004). Research indicates that families who are well-informed are able to be better caregivers and experience less anxiety (Health Canada, 2009). Providing the most appropriate information and implementation resources can facilitate an uneventful death and alleviate caregiver stress. A printed information resource would be a valuable asset in the community setting for the family and the nurse in the community.

Currently, clients are provided with “A Caregiver’s Guide” by the Canadian Hospice Care Association. While, the book is a valuable resource, it is 168 pages in length. The amount of information can be overwhelming and there may not be sufficient time to absorb a lengthy book when there are other pressing needs at hand. In addition, when caring for a loved one, many caregivers may not be able to cognitively process the information (Mackenzie et al., 2007). In planning an educational resource, the information needs to be simple, concise, and relevant to the caregiver’s needs. To date, there is no information resource that explains the community resources that are accessible to the clients or the purpose of the palliative care team. A practical resource is needed to help caregivers navigate through end-of-life care. This resource would include the

following: the role of the CHN; the role of the palliative care team; community resources that are available and how to access the resource; advanced care directives; what is financially covered; do not resuscitate (DNR); what to do when the loved one passes in the home; preparing for funeral arrangements; caring for a loved one at home; and contact information.

Phase 5- The Administrative Assessment and Policy Assessment

The administrative assessment evaluates the current resources to develop and implement the proposed project (McKenzie et al., 2013). By consulting with the clinical coordinator of home and community care, Carolyn Gosse, it was determined that the need for the development of an information resource for home palliation was on the agenda. The Eastern Health policy for end-of-life care outlines the eligibility criteria for the program and services that the client may receive through the program (Eastern Health, 2013). The policy is accessible to nurses, but it is limited in detail. The services that the client and families receive depends on the knowledge and competency of the nurse. There is an identified need for an information resource to be provided to the client and families.

The PROCEED phase of the PPM focuses on selecting strategies for intervention and implementation of the program (McKenzie et al., 2013). For the purposes of this practicum project, I will not be implementing this program. However, once the development is completed, I will arrange for Carolyn Gosse to deliver the project to Eastern Health for approval and implementation.

Discussion

A number of key themes and concepts were revealed through the integrated literature review. Firstly, with the increase in the ageing population, there is also an increase in chronic diseases and the diagnosis of cancer. With medical advancements, people are living longer; however, when diagnosed with a terminal illness their quality of life deteriorates. Subsequently, for individuals choosing to die at home, a caregiver is needed to provide care at home to their dying loved one.

A dominant aspect of this literature review is a discussion of the concepts surrounding the emotional, psychological, and physical needs of the caregiver. New literature is exploring the impact that caregiver stress has on their cognitive ability. Caregivers often experience barriers to accessing resources, not knowing what questions to ask, and how to care for the needs of their loved one during end-of-life. To respond and meet the needs of caregiver caring for dying loved ones at home, nurses need to communicate effectively. This can be done through providing small amounts of appropriate information at a slow pace, so that the information is not overwhelming. A printed resource can reinforce the information.

Another theme is that nurses may not be comfortable with palliation at home and lack adequate knowledge about providing quality palliation at home. Knowing that the role of the CHN is not for equipment only, but to provide quality of care to the client and improving the quality of life of the caregiver. Being comfortable with palliation comes with experience and since most palliative care knowledge is passed from nurse to nurse, further education on palliation should be implemented in the community setting. Even if a nurse has many years of experience, they may still need additional education regarding

home palliation. Clients and families in the community may have complex needs, and therefore nurses must provide competent care to ensure optimal outcomes and a quality death at home. While caring for the client and families in the home, the CHN must ensure both are comfortable and understand what is happening; that is, providing holistic care.

Lastly, there is a need for an education resource for clients and families in the community that focuses on end-of-life care. Eastern Health is lacking an educational tool that will assist with navigation of end-of life care. The usefulness of this learning resource is just a starting point to improving local end-of-life care at home, as compared to other centers such as Halifax. In addition, the education resource will assist nurses in providing relevant information to client and families in the home. In addition, it will help ensure a continuity in care.

Relevance to Practice

In reflecting on the literature, it is evident that caring for a dying loved one at home can be stressful on caregiver and can result in depression, anxiety and social isolation Kuei-R, (2000). In Canada, the quality of end-of-life care an individual receives will be dictated by geographical location, availability of a community resources, palliation programs, and government funding. In 2002, Canada launched a national strategy promoting PEOLC programs. However, health care services and end-of-life services received by the individual are dependent on the individual provinces and territories (Health Canada, 2009). The PEOLC program in St. John's provides a number of services that can assist with home palliation, but the barrier exist with knowing the availability and the accessibility of the resources. In addition, the lack of 24/7 access to care can hinder quality of care after regular working hours and on the weekends.

In 2006, research by Health Canada indicated that caregivers requested practical information relating to end of life care. Now, nine years later, there still exist a need for such a resources. In the literature, the need is identified by both CHNs (Arnaert & Wainwright, 2009) and by the caregivers (Brown et al., 2011; Health Canada, 2006).

Not surprising, my own comfortable level with palliation has increases with exposure to home palliation. As supported in the literature, most of my knowledge about community resources and services available through the PEOL program has been learned from other nurses. Even with my experience of approximately 20 clients with home palliation over the past 20 months, it would be presumptuous to think that I am an expert in end-of –life care. Merelles et al. (2015) found that nurses with expert palliative care experience did not feel the need to acquire additional knowledge on end-of-life care or a need to develop palliative care competencies. This was in direct contrast to the response of CHN, which indicated a lack of knowledge and experience regarding palliative care and adequately transferring information (Arnaert & Wainwright, 2009).

Assuming the role of a caregiver can be daunting, especially in the home environment. Since the amount of client and family support is individualized, it is important for the nurse to assess the needs of the family and tailor the care to fit the need (Masucci et al., 2012). The literature strongly supported the caregivers burden can be alleviated through psychological support (Connell et al., 2012; Fujinami et al., 2015) and through services and education (Connell et al., 2012). It is also is important to note that family caregivers live with the memories of the final stage of the care recipient's life. Supportive and informative contacts that may help families navigate through

the final stages of death using visual materials and concrete explanations (Waldrop, Kramer, Skretny, Milch & Finn, 2005). This allowing time for family members to process information. This is the responsibility of the CHN.

Caregivers identified a need for more a more effective transfer of information and for the CHN not to be rushed (Arnaert & Wainwright, 2009; Health Canada, 2006): Information that is relevant and not overwhelming in content. A printed resource would improve the transfer of knowledge between the CHN and families and encourage open discussion. With the client's and family's needs at the forefront of this project, the resource will be left in the client's home where it can be shared between the CHNs and families and clients.

Conclusion

This literature review provided supporting evidence for the bases of this practicum project. With the aging population, and more people choosing to die at home, there will be an increased need for palliative services in the community setting. Unfortunately, those who do not have a caregiver cannot palliate at home. This will result in a death at a hospital or in a long-term care facility. This correlates with a poorer quality of death. Although St. John's has a specialized hospital-based palliative team, it does not have a hospice center or 24/7 access to palliative care services. The palliative care team is a multi-disciplinary team that works together with the community to provide quality end-of-life care to clients and caregivers. A quality home palliation program, education resources and access to services will decrease hospital deaths for terminally ill individuals

and better deaths; this means dying with dignity and better quality of care for the terminally ill.

This literature review has several important implications for this practicum project, as an educational resource would benefit clients and families, new nurses, and more experienced nurse in the community setting. Firstly, an educational resource will help navigate through end-of-life care. It will answer questions pertaining to end-of-life care and direct client on how to access resources that will helping in providing home palliation. Studies indicated nurses struggle with a lack knowledge regarding home palliation; such knowledge deficits would certainly need to be addressed in an educational resource (Meirelles et al., 2015; O’Brein & Jack, 2009). For a nurse, providing end-of life care can also be unnerving: palliative clients often present with complex needs and demands. Secondly, the resource serves a dual role for both caregivers and nurses, containing information about access to community resources for the client and family, what to expect, access to community personnel, and a general navigational guide through the end-of-life.

The literature also supports that the transfer of education often occurs from nurse to nurse and then from nurse to client. An education resource will allow the transfer of consistent information as well as improved continuity of care. Together with the nurse, it will also help client and families to identify and implement strategies to meet needs. Lastly, this literature review revealed that the cognitive ability of caregivers can be impaired with the stress of caring for a terminally ill loved one. The involvement of the CHN is paramount in providing quality care and proving support for the family. Palliation at home can be overwhelming for the caregiver, incurring an increasing physical,

emotional, and financial burden. A learning resource will allow clients and families to learn on their own time at their own pace.

In this paper, I have provided an integrative literature review that identifies the caregiver's burden and the need for competent nursing care during the palliation process. Both the PRECEDE-PROCEED Model and Knowles' Adult Learning Theory were discussed in terms of their applicability to creating an information resource for both caregivers and nurses. Literature summary tables of several research studies surrounding the topic of this paper have been included in Appendix C1.

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Appendix C1

Literature Summary Tables

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Providing care and sharing expertise: Reflections of nurse-specialists in palliative home care (Arnaert, & Wainwright, 2009)</p> <p>Objective: To explore the experiences, views, and reflections of five nurse-specialists in palliative home care in relation to caring for patients and sharing their knowledge, skills, expertise, and experiences with other CHNs.</p> <p>PC-palliative care</p>	<p>5 female PC nurse specialists working for NOVA-Montreal, Quebec</p> <p>Age from 38 to over 60 years Experienced from 18 and 44 years of nursing practice</p> <p>4 nurses have worked for 8 or more years as a nurse-specialist in PC within NOVA-Montreal and 1 nurse with 20 months.</p> <p>All nurses attended PC workshops /conferences 2 nurses followed a course in PC, and one a specialized training program</p>	<p>A qualitative explorative research design</p> <p>Ethical approval</p> <p>Semi-structured 40 minute interviews conducted by the same interviewer at a location of the Nurse’s choice. French or English and translated into English by the researchers</p> <p>Interview consist of open ended questions</p> <p>Audit trail</p> <p>The contextual data analyzed for content using the constant comparative method to identify main themes</p>	<p>Three main themes with sub themes: 1-Recognizing one’s own limitations and humanness: calling for backup; learning as we go; coping with emotional demands; interacting with family members 2-Building a collaborative partnership: working collaboratively; sharing information; guiding CHNs because they lack knowledge re PC; being nonjudgement-some CHNs feel threatened by PC specialist. 3- Teamwork and implementing Palliative home care teams Informal education is need for CHN’s from PC specialist.</p>	<p>Strengths: Open-ended question allowed participants to express their experience. Research question answered via appropriate methods and rigor. Has good generalizability Objective met</p> <p>Limitations; Some of the meaning of the interviews may have been lost in translation Not a homogeneous sample- can introduce bias</p>	<p>All themes conveyed that the personal and formal knowledge held by nurse specialists can be shared with CHNs</p> <p>Relevance: Study of high quality and relevance to practice as it indicates CHNs lack knowledge and experience re palliative care clients and a transfer of information is needed</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Identifying care to conserve dignity in end-of-life care (Brown, Johnson, Ostlund, 2011)</p> <p>Objective: This study is a part of multi-phase project developing and testing a care pathway. The pathway suggest care action based on CHNs experiences aimed at conserving dignity during end-of-life care</p>	<p>West –Scotland, UK-rural setting.</p> <p>Purposive sampling- local hospital nurse of patient, caregivers, and GP’s nurses</p> <p>Five focus groups: Two with CHNs, one with GP’s, eight patients and five caregivers The caregivers were considered the experts</p> <p>Patients Life threatening illness six months or less 18 years or over Able to read and write English Deemed be physical and psychologically fit</p> <p>Caregivers 18 years and over Caregiver affected by Terminally illness Able read and write English</p> <p>Nurses and GPs Member of the multidisciplinary team- caring for patients with advanced illness at end-of life 18 years or over Read and write English</p>	<p>Qualitative descriptive design</p> <p>The Chochinov Model of dignity was used for collecting and analyzing the data</p> <p>Research from literature on how to conduct focus groups</p> <p>Semi-structured 60 minute interview and questions developed to include all themes included in the Chochinov Model</p> <p>The interview was piloted with one group of CHNs and modified</p> <p>Interview by researchers –one was the moderator and the other was the observer.</p> <p>All interviews were tape-recorded and transcribed verbatim</p>	<p>Themes and subthemes</p> <p>Level of independence Symptom distress Dignity conserving perspectives Dignity conserving practices Social dignity boundaries</p> <p>Continuity of care is important in maintaining dignity in the end-of-life for patients, carers</p> <p>The pace of giving information was important: given in stages corresponding to rate of understanding.</p> <p>Request not want too much detail regarding the future of the illness or death.</p>	<p>Strengths; Model is empirically based and validated</p> <p>Ethical Approval was obtained from Scotland research center and R&D</p> <p>Research carried out with rigor</p> <p>Counsellors available</p> <p>Limitations: Results from caregivers may be bias because of sensitivity at the time and vulnerability of the caregiver</p> <p>Some missing data- , all groups provided data on all themes</p> <p>The results lack generalizability to other cultures</p> <p>Open ended results need to be interpreted with caution</p> <p>Groups were too small-lead to skewed results</p>	<p>Study of high quality and relevance to practice of CHNs providing end-of life care in the home setting.</p> <p>Relevance: CHNs have to fill comfortable with palliation.</p> <p>CHNs need to let the caregiver and client be the guide to what they need rather than take over the situation.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Quality of life of community-based palliative clients and their caregivers (Connell et al., 2012)</p> <p>Objective: To investigate health related Quality of life of palliative care (PC) clients and their caregivers at baseline, following a referral to Community PC service</p> <p>This study is part of a larger study by Connell, 2010 and Connell et al., 2012</p>	<p>49 clients and 43 carers at baseline and 22 clients and 13 carers at follow-up Mean age-68.3 of patient and 60% male</p> <p>Patient with a life threatening illness recruited from five PC services in metropolitan Sydney, Australia.</p> <p>Exclusion Criteria: Newly referred client to palliative care with an estimated > 30 days of life (based on a ECOG score of 1-4); life limiting illness; access to a phone at home; living within the study geographical area; caregivers willing to participate.</p>	<p>Descriptive cohort design cross-sectional survey design-Quantitative</p> <p>Screening by PC nurses. Researcher contacted client and met in the home.</p> <p>8 week follow-up</p> <p>HRQoL of the client was measured by the MQoL and the CQoLC measured quality of life for caregiver</p> <p>Alpha set at 0.05 Student paired t-test-base-line and follow-up</p> <p>SPSS software</p>	<p>No statistical significant difference between the paired t-test for both clients and caregivers</p> <p>Overall HRQoL-rated poorly by client</p> <p>Higher score for HRQoL evident in Support, psychological well-being and existential well-being And lowest in physical symptoms</p> <p>Overall CQoLC rated high by caregiver</p> <p>Higher score CQoLC for the caregivers; caregiver burden and psychological morbidity, Disruptiveness, Positive adaptation, and financial concerns</p>	<p>Strengths; Consent obtained</p> <p>The reliability and validity of the MQoL and CQoLC</p> <p>Ethical approval obtained</p> <p>Methodological rigour</p> <p>Accommodations made for those who could not read well</p> <p>Privacy and confidentiality during data collection</p> <p>Good generalizability</p> <p>Limitations: high attrition rate-21 related to death</p> <p>30% participation rate</p> <p>Researcher primary investigator and completed all aspects of study-possible bias</p> <p>English only</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality but has a moderate study design.</p> <p>Relevance:</p> <p>Need to address the psychological needs for clients and caregivers.</p> <p>Need to relieve the caregiver burden through services and education.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Impact of specialist home-based palliative care services in a tertiary oncology set up: A prospective non-randomized observational study (Dhiliwal & Muckaden. 2015).</p> <p>Objective: To study the impact of specialist home-based palliative care services on (a) Symptom control (b) psychosocial support (c) health-related communication (d) home-based death (e) Bereavement outcomes and (e) caregiver satisfaction.</p>	<p>Patients in Mumbai, India who live in 35 km radius from Tata Memorial Hospital that were: registered in Department of Palliative Medicine in 2012; and consented for home-based palliative care.</p> <p>A total of 690 new cases were registered and 506 received home based care (total of 1830 visits)</p> <p>Exclusion Criteria: 18 or older and ECOG >3</p> <p>216 caregivers</p>	<p>A prospective non-randomized observational study</p> <p>Family involvement and stage of grief assessed at the first visit.</p> <p>Socio-economic status and distress assessed by the social workers the team members</p> <p>Physical symptoms- ESAS scale</p> <p>ESAS scale compared between visit-1 to visit-2 at home. The Wilcoxon signed ranks test and non-parametric statistical hypothesis used to compare the two related samples.</p> <p>End-of-life care: delegations of task counselling; 24/7 access to a home care team; social/financial support; home visits; bereavement follow-up; and support groups</p>	<p>All patient has adequate pain control with palliative care input based on ESAS scale (p< 0.005)</p> <p>50.98 % were care for at home; 28.85% need for hospice care; 20.15% needed brief periods of hospitalization</p> <p>29% received medical equipment</p> <p>83.2 % received out of hours with GP; 42.68 % received home based bereavement; 91.66% good bereavement outcomes.</p> <p>57% died in the home; 19 % died in the hospital; 24% died in hospice</p> <p>Caregivers-198 acceptance stage of grief process- counselling provided</p>	<p>Strengths; low attrition rate -94 died before study completed</p> <p>Good generalizability</p> <p>Large sample</p> <p>Relevance of study noted and objective met</p> <p>validity and reliability of the ESAS reported</p> <p>Limitations:</p> <p>Feasibility dependent on economic resource of country</p> <p>Did not identify if study obtained ethical approval</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a moderate study design.</p> <p>Relevant: home based palliative care programs improve pain and symptoms management, decrease hospital based deaths and improve bereavement grief and caregiver satisfaction.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Family burden distress levels related to quality of life, burden, and preparedness (Fujinami et al., 2015).</p> <p>Objective: To explore the relationship between family caregiver distress (FCD) per the distress thermometer (DT) and the FCD QOL, burden and preparedness. To identify types of problems unique to FCGs in cancer care.</p>	<p>Purposive sampling-178 consented and 163 completed study</p> <p>Caregivers of patients recruited from the medical oncology adult care clinic in the USA</p> <p>18 years and older</p> <p>Mean age 57</p> <p>64 % caregivers-female (105)</p> <p>English speaking</p> <p>Occurred over 1 year</p>	<p>Quantitative - cross-sectional design</p> <p>Baseline - assessment of demographics were obtained in clinic, mail or at home-questionnaire</p> <p>DT screening tool for FCG distress-likert design (p < 0.001)</p> <p>City of Hope QOL scale-family version (p <0.05)</p> <p>Caregiver burden scale</p> <p>Preparedness for Caregiver Scale</p> <p>SSPS</p> <p>Audit for accuracy</p>	<p>Higher levels of distress related to: physical, psychological, social, spiritual, caregiver burden and caregiver preparedness.</p> <p>Three components;</p> <p>Self-care-related to FCG and maintained of QOL</p> <p>FCG-demand related to role preparedness and managing the role of a caregiver</p> <p>FCG and the emotional response of caring for loved ones</p>	<p>Strengths: no missing data</p> <p>Consent obtained</p> <p>Ethical approval</p> <p>Established screening tools reliability and internal consistency mentioned</p> <p>Carried out by researcher</p> <p>Limitations: Future research needed</p> <p>Limited diagnosis to lung cancer</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality but has a strong study design.</p> <p>Relevance: A need for nurses to provide respite; to anticipate the caregivers need prepare them for the new role; and provide emotional support through counseling</p>

Name, Author, Date, Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Cognitive functioning under stress: Evidence informed caregivers of palliative patients (Mackenzie, Smith, Hasher, Leach, & Behl. (2007).</p> <p>Objective: to explore the cognition among caregivers of palliative family members using multiple neuropsychological test</p> <p>To explore changes in cognition following caregiving through retesting</p>	<p>Purposive sampling-selected through the Temmy Latner Center for PC at Mount Sinai hospital in Toronto, Ontario Canada</p> <p>PC team provided the information</p> <p>English speaking with no neurological or debilitating health problems.</p> <p>27 subjects in first group-pretest</p> <p>22- retested-loved ones passed away within 6 months</p> <p>Testing in caregivers home-90 min interview</p> <p>μ – 58.78 years 19 –female 19- Married or CL 20 –English 16-spouse μ -15 yrs of education</p>	<p>Quantitative -Pre and posttest design</p> <p>-Ruff 2 & 7 Selective Attention test</p> <p>-California Verbal Learning Test II</p> <p>-Wechler Memory Scale II</p> <p>- Wechler Memory Scale III</p> <p>-Wechler Abbreviated Scale of Intelligence</p> <p>-Beck Depression Inventory</p> <p>-State-Trait Anxiety Inventory</p> <p>-Health and background information</p> <p>Scores compared with matched normalized test scores</p> <p>Not all test utilized the same normalized test scores-but adjustments made through z-scores with 95 % CI</p>	<p>n = 14 reported they were run down and had problems sleeping</p> <p>caregivers were faster (p = 0.001) and less accurate re attention regulation (p = 0.001)</p> <p>Recall- sign. lower (p = 0.05)</p> <p>Learning scope-sign. lower-acquiring fewer new items over 4 learning episodes</p> <p>difficulty switching from initialized learned task to a second task (p=0.005)</p> <p>Working memory- not significantly different (p=0.27)</p> <p>Posttest- depression improved Anxiety –still present</p> <p>-Attentional regulation returned to normal</p> <p>-Poorer long episodic memory Word list deteriorated, but able to recall meaningful stories</p> <p>-Spatial working memory sign wore (p =0.02) verbal-sign worse- (p=0.07)</p>	<p>Strengths:</p> <p>Objective mets</p> <p>Strong statistical testing</p> <p>Test were known</p> <p>Uses normalized bas-line results</p> <p>Moderate generalizability</p> <p>Researcher conducted interview</p> <p>Limitations:</p> <p>Did not explore why cognitive impairment is associated with caregiver stress</p> <p>Did not mention ethical approval</p> <p>Small sample</p> <p>Did not address if the caregivers in the study had CHN services</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a strong study design.</p> <p>Relevance</p> <p>Recognize caregiver stress and the effects that it has on the cognitive functioning and recall.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Predictors of Health Service Use Over the Palliative Care Trajectory (Masucci, Guettiere, Zagorski, & Coyte, 2012)</p> <p>Objective: To examine the predictors of propensity (the use of service) and the intensity (amount of service) of the five main health care service categories in the last three months of life for home-based palliative care programs factors.</p>	<p>Ontario, Canada</p> <p>169 family caregivers were recruited from Temmy Latner Center for Palliative care (TLCPC) by telephone</p> <p>Total sample 109 51 male and 71 female Means age 71.1</p> <p>Diverse in clinical, demographic and ethnic background</p> <p>27 older than 46 Inclusion criteria: primary caregivers; Dx with a malignant neoplasm; fluent English; > 18 age July 2005 to Sept 2005</p> <p>Median time for patient as 28 days</p>	<p>Quantitative Prospective cohort design</p> <p>Phone call every 2 week-recall of the health service use in two weeks</p> <p>Five services assessed in the last three months of life: Home based physician visits; nurse visits; personal support visits; ambulatory physician visit; and other ambulatory/ home visits.</p> <p>Predictor variable guided by Andersen and Newman's Behavioural Model of Health Services Predisposing factors; age and sex of caregiver and patient, socioeconomic status; enabling factors; and need-based factors.</p> <p>-Ambulatory and Home Care Record (AHCR) data for publicly financed health system cost. -Z score for enumeration area in Toronto -Palliative Performance scale (PPI-correlation coefficient 0.93 to 0.96)</p>	<p>Data analyzed by SAS software</p> <p>Multicollinearity and backwards stepwise regression for each service category</p> <p>92.1 % used Home nursing visits vs 15. 4%-home-based physicians visits</p> <p>Patients age most significant predictor of use of services ; younger patients (<61) more physician visits, and other ambulatory/ home based visits (OR 0.28) 62-72- more use of support worker -Male caregivers had a lower intensity of home nursing visit -Lower functioning-more likely receive nursing visits and use services (PPI) -Low socioeconomic higher intensity of home based nursing services.</p>	<p>Strength; The reliability and validity of AHCR - kappa as 0.41 to 1 (moderate to substantial agreement)</p> <p>Reliability of PPI Consent obtained Sample very diverse in clinical, demographic and ethnic background, therefore increase generalizability of the results</p> <p>Limitations: no ethical approval mentioned Few statically significant predictors of propensity and intensity of service use Did not evaluate symptom severity Potential for recall bias and Hawthorne effect</p>	<p>The design of the study is medium as per PHAC</p> <p>Relevance This study highlights the factors that influence the use of services and the amount of services. CHN's is one of the main providers of home palliative caregivers. Nurses can recognize uniqueness of each situation and assess the need for services.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Determinants of Place of Death for Recipients of Home-based Palliative care. (Masucci, Guerreire, Cheng & Coyte, 2010)</p> <p>Objective: To determine the place of death and its predictors among palliative care patients with cancer (home or in an institution)</p> <p>To identify the difference between individuals registered with a home-based palliative care program and those who died in a hospital</p>	<p>Subjected recruited from the Temmy Latner Center for Palliative Care (PC), Toronto, Canada</p> <p>137 patients and caregiver 7 excluded because date of death unknown and 20 interview > 2 monts</p> <p>Total- 110 subjects</p> <p>IPrimary caregivers of clients diagnosed with a malignant neoplasm who was admitted to Toronto PC program in past 7 years. 18 years or older Fluent English</p> <p>July 2005 to September 2007</p>	<p>Quantitative descriptive design</p> <p>Anderson and Newman model for Health service utilization. Predictors of death:</p> <p>Caregiver interviewed by researcher- telephone survey from admission to death-re demographic, socioeconomic status, health service utilization, unpaid caregiver time, and functionality of the patient.</p> <p>Ambulatory and Home Care Record- collect data on use of home care service (Kappa 0.41)</p>	<p>Results analyzed by SAS</p> <p>1stObj.- Gender and co-residency were predictors of home deaths; Home death were more likely in woman and Individuals who lived alone died in the hospital.</p> <p>Related to Access to home-based supports, attitudes, perceptions and preferences.</p> <p>2nd obj.-home deaths more likely to occur in older patient, receiving increase nursing visits, living with others, low functioning status. Low socioeconomic not a determine of place of death-more related to access to services</p>	<p>Strengths: Psychometric properties met the standard-reliable thereby reducing bia Written consent Minimal bias</p> <p>Limitations: Some of the data was collected by telephone interviews- subject to recall and social desirably bias Limited generalizability; not also countries have government funding</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a moderate study design.</p> <p>Relevance: Understanding predictors of place of death can assist in deploying resources of home-based services and reduce frequency of home deaths. It can also assist caregivers who think finances are a barrier</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Nursing competencies for palliative care in home care (Meirelles, Sousa & Dornelles, 2015).</p> <p>Objective To identify the competencies of nurses for palliative care in home care</p>	<p>Sample: Nurses linked to the Multidisciplinary Teams of Home Care (EMAD – Equipes Multiprofissionais de Atenção Domiciliar) of the Health Department of Distrito Federal (SES-DF)-Canada</p> <p>Sample: 20 nurses; 95% female, 5% male with a mean age of 38.5 years</p> <p>Nursing experience 65% < 10 years 25% -11-20 years 10% - 21-30 years</p> <p>65% participated in courses addressing the theme of palliative care</p> <p>March to June 2014</p>	<p>A descriptive, exploratory study with quantitative approach. Likert approach</p> <p>1st- researcher - a list of competencies based on national and international literature scientific articles, palliative care manuals and specific books on the subject 2nd- a jury of three Brazilian nurses with experience in palliative care and currently engaged in health care programs in palliative care analyzed the list 3rd-43 competencies that were presented to nurses at the in order to reach a consensus</p> <p>Delphi method defined the study location and the sample. Sample collected by purposive sampling</p> <p>First round-telephone interviews-survey method Second round not needed because a 70 % census reached</p>	<p>Cronbach’s alpha coefficient above 0.7 for all competencies</p> <p>Competencies central in palliative care are: autonomy; dignity; communication; relationship between patients and health care professionals; the multidisciplinary approach; quality of life; position in relation to life and death; loss and grief, and public education - network to meet the complex needs of patients e.g. equipment -A few nurses indicated the need to acquire more knowledge on palliative care and develop their own competencies</p>	<p>Strengths: study used experts to develop survey Informed consent Rigor No missing data</p> <p>Limitations: small sample</p> <p>Some lack of generalizability and feasibility</p> <p>All nurses selected had expert palliative care experience</p>	<p>The study is of strong quality and address the relevance nursing competencies in palliative care</p> <p>Research question answered</p> <p>There is a need to be a focused on the needs of patients and family for a better quality of life. This means working together as a team to meet the complex needs of the client and family.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Barriers to dying at home: the impact of poor co-ordination of community service for patient with cancer (O’Brein & Jack, 2009)</p> <p>Objective: to explore the views of district nurses (DN)and specialist palliative care nurses regarding end- of- life care and the place of death for patients with cancer.</p>	<p>Purposive sampling of DN and community specialist palliative care nurses- two focus groups</p> <p>North West England</p> <p>Research occurred over two primary care trust; nurses needed to have local practical of greater than six months</p> <p>11 palliative care nurses and 18 district nurses</p> <p>Data collection took place in 2006-2007</p>	<p>Qualitative Research design- Phenomenology</p> <p>DN attended a monthly palliative care interest group</p> <p>Separate focus groups; Two hour long focus groups were held; one with eight specialist palliative care nurses and one with eleven DNs</p> <p>Groups conducted by each researcher</p> <p>Open ended questions focusing on whether patients died where they had chosen to and the identification of influential factors that could affect choice at the end- of- life . Themes were identified post interview.</p>	<p>Data analysis and coded revealed two main themes; carer breakdown and and service provision (reported separately)</p> <p>Four subthemes concerning: provision of equipment, establishment of care packages, discharge planning and out of hours services. (Identified by both groups, but more discussion with DN)</p> <p>DN focused on practical issues regarding care the clinical nurse specialists’ focused on the psycho social factors for the patient and families</p>	<p>Strengths; Ethics approval obtained Consent obtained Separate focus groups allowed more open discussion. Different research conducted each focus group- decrease bias Two researchers- increase inter-rater reliability rigor</p> <p>Limitations: Feasibility dependent on economic resource of country Limited generalizability; not also countries have government funding</p>	<p>Study of high quality and address concerns for preparing for end-of-life care</p> <p>Research question answered</p> <p>Relevance: District Nurses spend more time in the home with patients than the nurse specialist. While holistic care is the focus of nursing, providing services in one avenue to help meet that need</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Problems experienced by Informal Caregivers of Cancer Patients and their needs for support (Osse, Vernooij-Dassen, Schadé, & Grol, 2006).</p> <p>Objective: to provide a complete picture of the problems that caregivers experience during palliation and identify how those problems they would benefit more professional attention.</p>	<p>A cross-sectional design descriptive study</p> <p>Setting: The home of clients with advanced care cancer in several cities and villages in the Netherlands</p> <p>Convenient sample: GP's, outpatient-clinic oncologists, and patient organizations selected cancer patients. The patients identified their caregivers</p> <p>76 informal caregivers consisted of 46 men and 30 women informal caregivers were included with the patients in the study</p> <p>Caregivers were divided into two group: under 60 and over 60</p>	<p>A cross-sectional design -descriptive study.</p> <p>Ethics approval from the University of Nijmegen .</p> <p>Informed consent was obtained and Anonymity was maintained</p> <p>The caregivers given the PNPC- checklist that identified potential problems at home. These checklists were used in a following consultation with their doctor.</p> <p>The PNPC-c was based on interviews with patients and their caregivers. The validity of the PNPC-c was confirmed and the reliability was acceptable</p> <p>Univariate statistics (2-sided Fisher exact tests</p> <p>SPSS</p>	<p>Frequent problems are listed in a "top 20": Hope for the future (68%); meaning of death (54%); and the caregiver's own physical symptoms</p> <p>Unmet need by health professionals: 1 in 4 re competence of care e.g. physical signs of decline (25%); pain control (21%).</p> <p>23 % identified lack of information in writing</p> <p>More than 50 % of the caregivers wanted more information for elementary preparation for problems as disease progresses.</p> <p>Difficulty in coordinating the care of different professionals (22%), Getting help from agencies (22%)</p> <p>Getting a second opinion (21%). extra cost with supplies (17%)</p>	<p>Strengths:</p> <p>Reliability and validity of instruments used in the study.</p> <p>Concise inclusion criteria.</p> <p>Low dropout rate</p> <p>Met objective of the study</p> <p>Limitations: not all items in the PNPC-c questionnaire were of are of equal weight.</p> <p>Possible underreporting to due to sensitivity of the issue</p> <p>Performed only a single measurement</p> <p>Limited generalizability because the Netherlands have good access to resources</p> <p>Limited to caregivers of cancer patients</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a moderate study design.</p> <p>Study is highly relevant for those CHNs who assist with palliation; It identifies the target needs of caregivers</p> <p>This study indicates the types of support to be given to caregiver by health care professionals in the community</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Family Perspectives on end- of- life care at the last place of Care (Teno et al., 2004)</p> <p>Objectives: To evaluate the US dying experience at home and in institutional settings.</p> <p>Outcome Measures: (1) the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care.</p>	<p>Purposive sampling of family members or other knowledgeable informants; 1578 deaths from chronic illness in the United States in 2000.</p> <p>Deaths from 22 states; this accounted for 70.4% of all annual deaths in the United States</p> <p>No differences by sex ($P = .32$), < 64 years were less likely to be interviewed (completion rate: 39.3% vs 50.6%; $P < .001$), as were Hispanic and African American respondents (35.6% vs 49.4%; $P < .001$).</p>	<p>Descriptive Quantitative study</p> <p>Mortality follow-back survey. Contacted information listed on the death certificate</p> <p>Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours. 72% of the interviews occurred 9 and 15 months after the patient died</p> <p>All analyses were performed using SUDAAN version 8.0</p> <p>Outcome measures were based on a conceptual model of patient-focused, family-centered medical care.</p>	<p>Nursing home or home with home health nursing services</p> <p>24. 2 % - reported patient did not receive any or enough help with pain or dyspnea (22.4%)</p> <p>Over 50.2 %- reported that the patient did not receive enough emotional support. 21.1%-reported did not receive respect</p> <p>Unmet needs for dyspnea did not differ by setting of care. Home hospice care 34.6% - had lower rates of unmet needs</p> <p>All subjects reported the patient was always treated with respect. fewer concerns regarding the amount of emotional support</p> <p>70.7% rated care as "excellent" vs less than 50% for the other settings of care ($P < .001$).</p>	<p>Strengths:</p> <p>Relevant to nursing practice Strong statistical analysis Large sample Objectives met</p> <p>Limitations:</p> <p>results based on memory recall Sample taken at one point in time External validity. Results may be difficult to generalize to other hospitals and location</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a moderate study design.</p> <p>Relevance: Insight in caregiver's perceptions allows nurses to gauge their care and actions in providing quality of care during end-of-life care.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results and Findings	Strengths/ Limitations	Conclusion and Rating
<p>Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009 (Teno et al., 2013)</p> <p>Objective: To describe changes in site of death, place of care, and health care transitions between 2000, 2005, and 2009.</p>	<p>Random sampling from the Medicare denominator file; a cohort of 20% of all fee-for-service Medicare beneficiaries who died in 2000, 2005, and 2009.</p> <p>A sub-cohorts diagnosis of cancer, dementia, or chronic obstructive pulmonary disease (COPD).</p> <p>Aged 66 years and older, who died in 2000 (n = 270 202), 2005 (n = 291 819), or 2009 (n = 286 282).</p> <p>USA</p>	<p>Quantitative Retrospective cohort study</p> <p>The Residential History file; place of death, places of care in the last 90 days of life, number of health care transitions, and patterns of transitions that experts would label as burdensome</p> <p>Medicare Denominator file for Socio-demographics: including patient age, race/ethnicity, sex, and state of residence.</p> <p><i>P</i> < .05. Descriptive statistical measures</p>	<p>68.9%-the last place of care was an institutional setting, either a hospital or nursing home. 36.1% died without any nursing services, 12.4% had home nursing services, and 51.5% had home hospice services</p> <p>Between 2000 and 2009, the ICU utilization rate, transition rate, and number of late transitions in the last 3 days of life increased.</p> <p>31% of these late transitions were to hospice services</p>	<p>Strengths: Informed consent procedures reviewed by the university of MA Large sample Random sample Taken over a period of time</p> <p>Limitations: results based on memory recall External validity Results may be difficult to generalize to other hospitals and location</p>	<p>In accordance with the PHAC quality-rating tool, this study is of medium overall quality and has a moderate study design.</p> <p>Relevance: The importance to have a high quality home palliation program to meet the needs of palliation individuals and families. The place of death will have long-term effects on the grief of caregivers.</p>

Appendix D
Consultation Report

Consultation Report: Navigating Through the End-of-Life
with Home Palliation

Nursing 6660

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School of Nursing
Master of Nursing Program

PRACTICUM: PLAN FOR CONSULTATION WITH COLLEAGUES

Student's Name: Student ID #: Karen Leyte (009017435)

Course Names and Numbers: Nursing 6660

Supervisor: Dr. Fadi Khraim

Title: Navigating Through the End-of-Life With At -Home Palliation

Date: November 14, 2015

1. Brief overview of the project

While the concept of palliation and end-of-life care was well explored in the literature, there has been a lack of focus on the educational needs of the client and caregiver. There was very little information on the type of educational material that is being currently provided to the families in the community setting. In searching the grey literature, the focus was on hospice care rather than home palliation. In 2013, along with the Canadian Hospice Palliative Care Association (CHPCA), Health Canada launched the new “Speak Up” campaign, which promotes advanced planning in the event you cannot speak for yourself (CHPCA, 2015). While this is a start in providing quality of care for clients and families, it does not prepare the family for when the loved one is dying in the home. This gap exists not only at a local level, but also at the national level (Health Canada, 2007).

The literature identified that caregivers struggled with co-ordinating care with different professionals and getting help from agencies to assistance with financial burdens (Health Canada, 2007; Osse, Vernooij-Dassen, Schadé & Grol, 2006). In helping to meet this need, caregivers requested more effective communication from health care professionals and that the information be provided in small amounts (Health Canada, 2007). Currently, caregivers in Eastern Health may receive a 168-page book entitled “A Caregiver’s Guide” to assist with end-of-life care. To help guide the home palliation process, caregivers indicated that they preferred a web resource or a pamphlet (Health Canada, 2007). Eastern Health provides a website with a synopsis of the end-of-life program and links the caregiver to relevant contacts. The purpose of this project is not to

develop a website, but to provide clients and families with a printed resource that will help them navigate through end-of-life care. Although the focus is on the clients and families, this resource will allow CHNs to better assess the client's and families' needs during home palliation.

The resource will include the following: contacts of the multidisciplinary team and their role; what resources are available and how to access them; information pertaining to advance health care directives; funeral home preparation; implementing a do not resuscitate order; what to expect when your loved one is dying; bereavement counselling; respite; identified goals of families and how to meet that need; volunteer services; and what do when your loved one passes at home.

Prior to meeting in June, 2015 with Dr. Donna Moralejo, Professor and Associate Dean of the School of Nursing, my informal Needs Assessment identified that there was a greater need for an educational resource for clients and families palliating in the home over a resource for the community health nurse (CHN). Although the focus of this project is predominantly on the educational needs of the client and families, the educational resource will also be an asset for the CHNs. The need for an educational resource was identified through the integrated literature review. The next step was consultation with direct care providers.

2. Specific objective(s) for the consultation

- To assess the available resources currently used in Eastern Health by consulting with the palliative end-of-life care (PEOLC) coordinator and with the clinical

educator for home and community services for Eastern Health.

- To gather information that will help identify the gap in the home palliation process and identify a way to change the current delivery of care.
- To seek feedback from CHNs and the PEOLC coordinator regarding what content should be included in the educational resource that would meet both the needs of the client and family in home palliation and the CHN.
- To seek feedback on the strategies on the implementation of the educational resource such as a pamphlet or a booklet from the clinical educator of home and community services.
- To demonstrate the advance practice competency of consultation and collaboration as per Canadian Nurses Association.

3. Setting and Sample

The consultation took place in two different settings: the home and community services office in Conception Bay South, and the home and community services office at Mount Pearl Square. Both of these community health offices are under the umbrella of Eastern Health. For the purpose of this practicum project, four individuals were interviewed: the PEOLC coordinator; the team lead CHN at the Conception Bay South office; an experienced CHN; and a newly hired graduate nurse to the community. Recruitment occurred by selective sampling; four of the above CHNs play an active role in home palliation. The purpose of the practicum project was explained to each selected

individual and each of them was asked if they were willing to participate. All four of the CHNs agreed to be interviewed. I also spoke with the clinical educator of home and community services regarding implementation and design of the educational resource.

The PEOLC coordinator was selected because of her position in the palliative care program. The PEOLC coordinator has 20 years of nursing experience and has been in her current position for three years. She has a community health nursing certification, as well as PEOLC nursing certification. I consulted her because of her expertise in home palliation. As well, she is the primary contact person for the community for the mobilization of resources and information on at-home palliation.

The team lead in Conception Bay South was selected because of her 15 years of nursing experience and because of her leadership ability in the area of community health. She is responsible for orientating nurses to the community health office in Conception Bay South. Because of her knowledge regarding community health issues, the team lead is also considered a resource person for other CHNs at the office.

In addition, an experienced CHN was selected because of her expert knowledge and her active involvement in home palliation. This CHN has ten years of community health nursing experience, and was recently awarded the CEO award of Excellence of Service for her work as a preceptor to students. In consulting with this senior CHN, I wanted to hear her perspective on the learning needs of clients and families in the community. I also wanted to learn about her viewpoint regarding the learning needs of CHNs who are new to community, and whether she felt further resources were needed to orientate them into home palliation. While a newly graduate nurse often occupies a casual position, he or she is not routinely involved in regular home palliation. However, there

are times when he or she may be assigned to visit a terminally ill client and their family in the community when the regular district CHN is unavailable. The perspective of a newly graduated nurse is important because I wanted to know if an educational resource would be beneficial in providing continuity of care and guiding the home palliation process. The resource would also benefit experienced nurses orientating to the community that may be novice to home palliation.

Additionally, the clinical educator for home and community services was consulted because of her active role in education and policy development. The clinical educator would be responsible for the implementation of the resource.

4. Data Collection

An interview allows the researcher into the other person's world (Streubert & Carpenter, 2011). The interviews took place in October, 2015 and occurred in the office of each participant with the exception of the novice nurse. This interview occurred in my office because this nurse did not have an office. The door closed to allow privacy and to avoid interruptions. The data was collected through semi-structured interviews. The writer used open-ended questions to facilitate a detailed description of the participants' experiences. A list of structured questions was used to guide the interview, however, there was time allowed for additional comments if the interviewee decided to elaborate (Young, 2004). The responses from the interview were repeated back to ensure accuracy. The interview questions were developed based on the findings from the integrated literature review and the informal Needs Assessment. A list of the questions used to guide these interviews can be found in Appendix D1.

5. Data Management and Analysis

Notes were taken during the interview and the results transcribed into a Microsoft Word 2013 document. The answers to the interview questions were analyzed for content and themes, and then each response was compared for similarities and differences. The data was stored on a password-protected laptop.

6. Ethical Considerations

The Health Research Ethics Authority (HREA) Screening Tool was used to determine if this project should be submitted to a Research Ethics Board for approval (see Appendix D2). It was determined this project does not need ethical board approval, because it is not a research project (see Appendix D3). Permission to interview the participants for this practicum project was discussed with the team lead of the Conception Bay South office. Selection of the subjects was conducted by purposive sampling and participation was completely voluntary. All four of the participants agreed to take part in the interview and their verbal consent was obtained. Since no patient information was involved, there was no need for agency permission.

Confidentiality and anonymity was maintained: no identifying information was attached to the data collected. The participants' names were translated into a sequence of numbers represented in codes rather than being identified directly. Prior to beginning each interview, the purpose of the interview was made known to the interviewee, and they were asked not to disclose any particular client information. The information gathered from the interview was only used for the purpose of this practicum project and the

identities of the interviewees were protected. Finally, prior to the beginning of the interview, the interviewees were advised that there was no obligation to answer any particular question.

7. Consultation Results

To reiterate, there were four CHNs interviewed and a brief discussion with the educator of home and community care regarding the implementation of the resource. Each of the four CHNs provided a different perspective on home palliation based on their job experience and stratification level in the organization. After reviewing the data collected through the interviews, the data was analyzed and grouped into major themes.

Current Policy

In consultation with the clinical educator, it was determined that the legislating body of the Association of Registered Nurses of Newfoundland and Labrador (ARNNL) does not have a policy on home palliation. The current Eastern Health policy entitled “Palliative Care at Home and in the Community,” provides a brief description of the program and what is available to the clients and families. On a national level, the PEOLC coordinator stated that “in the PEOLC programs, there is a discrepancy through all the provinces and there was definite room for improvement here in St. John’s”. In essence, the quality of the PEOLC program directly affects the quality of care received by home palliation clients and their families. While the PEOLC program does offer a variety of services, to date there is no succinct list of what is available.

Lack of standardization

The PEOLC coordinator felt that since a standard of care for palliation cannot be measured, as compared to wound care, for example, it makes it difficult to determine if the client and families are receiving the best possible care. It is easy to determine if a physical need has been met and whether best practice measures have been followed. This can be done through charting and seeing what products best suit the type of wound. Two of the participants believed that because nurses in general are often task orientated, the psychosocial aspect of palliation is often neglected. This was also supported in the literature. The PEOLC reports that because there is no set procedure to follow, it is difficult for someone else to determine by reviewing the charts whether the best possible psychosocial support has been provided to clients and families.

As of September, 2015, every client referred to the PEOLC program will be automatically be referred to the palliative care bereavement counsellor. To further improve the current PEOLC program, two of the interviewees would like to see a specialized palliative team of CHNs in the community, and all of the CHNs would like to see a hospice built in the area. Two CHNs identified the need for 24/7 access to palliative care services. This would be useful in the event of an emergency. Currently, if an individual needs advice regarding pain and symptom management after regular hours, they can call the palliative care unit at the Dr. Leonard A, Miller Center. The client may receive assistance from a doctor only if they have been previously consulted and seen by the palliative care team. If not, they are advised to proceed to the nearest emergency department.

Current Resources

All interviewees identified that the current resources the “Caregiver’s Guide for End-of-Life Care” and the pamphlet issued by Eastern Health were inadequate resources for clients palliating at home. The participants identified a need for an educational resource that would be easy to navigate end-of-life care. The book was described as being “overwhelming” and not practical at this stressful time. Due to the length of the book, it can be a deterrent for an individual who may not be a “reader”. In addition, there are individuals who may not have a high literacy level. In regards to the booklet, it does not provide practical information related to end-of-life care. As supported by the literature, two of the CHNs identified that caregivers do not want to read a large amount of information. They need information based on their particular needs. All the CHNs identified a lack of reference material for clients and families. Having a printed list of resources and how to access those resources will assist both the CHN and families in the home.

Caregivers wishing to seek resources independently on the Eastern Health Website can locate information under “Palliative Care at Home and in the Community.” The site provides a superficial description of the PEOLC program and a brief description of what is available to the clients and families under the PEOLC. For further information on the program, the family or client can contact intake, where their situation will be assessed and then referred to the appropriate department. The hours for intake are Monday to Friday, from the hours of 8:00 am to 4:00 pm. There so much is left to the caregiver to ascertain.

Transfer of Knowledge

The CHN is the primary source of information for the client and families. Two of the CHNs referred to a deficit in information from the hospital to the community. In the experience of two CHNs, families are not prepared for home palliation. Clients and families have a misconception of palliative care: it is viewed as “a place to die”. Clients do not realize that you can go to palliative care for pain and symptom management and then return home again. Furthermore, many clients may not be told that they are dying until palliative care unit (PCU) becomes involved. Most of the time the CHN is the first person to see the client after they are told “no more treatments”, and the rest of the information is left up to the CHN or the PCU. The CHN is often the liaison between the client and other healthcare professionals.

Two CHNs noted that the processing of information depends on the client’s preparedness and cognitive ability at that time. Some clients request that the CHN not talk about dying. This makes it very difficult to provide quality home palliation care. The caregiver still needs information that would assist with care of the loved one. While the client may not be ready for the resource at the time of the prognosis, making it available, can inform the caregiver of what is available to assist with end-of-life care e.g. a hospital bed or medication coverage. The caregiver can contact the CHN for assistance with implementing the resources.

Furthermore, the transfer of knowledge regarding home palliation by CHNs is often from CHN to CHN. The newly graduated CHN cited other CHNs and the PEOLC coordinator as a primary reference source for community resources and advice on home

palliation. The more experienced CHN also asked other CHNs for information, but stated that you also “learn as you go”.

Quality of Care

Since the transfer of knowledge is dependent on the assigned CHN, participants in the interviews correlated quality of care the client and families received with the knowledge and comfort level of the CHN with home palliation. All four of the CHNs interviewed felt there are disparities in the care provided, based on the assigned district CHN. If the CHN was comfortable with palliation and knowledgeable about the resources available in the community, then the client and family would likely receive better end-of-life care. The newly graduate nurse described feeling as though “she did not provide the best quality of care, because of a lack of knowledge about available resources”. This sentiment is not limited to the novice CHN; it was also echoed by CHNs with more experience. All participants identified a need for further education to increase confidence and decrease anxiety regarding home palliation.

Content of Resource

The CHNs, PEOLC coordinator, and clinical educator of home and community care each identified a need for education on the practical aspect of end-of-life care in the form of a pamphlet or small booklet. Clients come from a variety of vocational backgrounds. There is a requirement for the information to be simple and easy to understand. Therefore, the information should be designed at a grade six reading level for ease of comprehension (McKenzie, Neiger & Thackeray, 2013). The information will be tailored to the needs of individuals palliating at home. Furthermore, the transfer of

knowledge is the CHNs responsibility. The resource will allow an opportunity for clients and families to ask questions about the content once reviewed. A question and answer session would be after the CHN provided teaching based on the content of the resource. In addition, the booklet or pamphlet would be a reference for the client and caregiver between visits by the CHN.

Based on experience and need, the CHNs identified a need for the following content in the booklet: the role of the CHN and the palliative care team should be defined; frequently used numbers for organizations and important contacts; what to do in a crisis; available support, such as counselling; how to plan funeral arrangements; available equipment and resources; and pain and symptom management during the dying process. Two participants identified a lack of bereavement support in the PEOLC program. Once the client has passed, there may be a single follow-up phone call made the day after to the surviving caregiver. As mentioned earlier, recently the consultation of the bereavement counsellor in home palliation is automatic. Based on need, the counsellor would be responsible to follow the family after their loved one has died. The role and contact information of the bereavement counsellor would be included in the booklet. It is important for the caregiver to know that psychological support is available during the grieving process.

The experienced CHN discussed the importance of orienting newly graduate nurses and nurses novice to home palliation. Currently, resources are insufficient to prepare client and families for palliating in the home. If the proposed resource was presented in orientation, it would allow all nurses orientating to the community to review

and become familiarized with the information. With a strong underlying knowledge base, they will have more confidence and be able to better provide care to the palliating client.

8. Attainment of Objectives

Through the consultation process, the identified objectives were accomplished. The first objective required feedback from CHNs and the PEOLC coordinator regarding what content should be included in the educational resource. This objective was achieved by looking at the current delivery of care and through the CHNs reflecting on their own experience with home palliation. The second goal was achieved by examining the current resources used in Eastern Health, and realizing that they are inadequate to meet the needs of clients palliating at home. The third objective demonstrated the advanced practicing competency of consultation and collaboration. I also consulted with colleagues across sectors at the organizational level, provincial, and to some degree, at a national level. The PEOLC coordinator and the clinical educator of home and community care for Eastern Health was consulted to discuss the lack of policy surrounding home palliation. In reviewing the literature, I contacted the CHN manager of Central Health in Newfoundland and Labrador, and I also contacted the Halifax hospice to determine what is available for home palliation in their geographical areas. To meet the fourth objective, I collected information that identified the current gap in home palliation.

The findings of these consultations verify that a gap exists in the transfer of knowledge, a lack of knowledge regarding home palliation resources, a disparity in quality of care, and a need for specialized palliative team of CHNs and a hospice. Though this project cannot meet all the gaps identified, it can help with providing information that will influence the current delivery of care. Finally, by consulting with the PEOLC, the

clinical educator and the CHNs, it was unanimous that the information should be presented in an easy-to-read booklet or pamphlet containing relevant information.

9. Implications for Practice

Recognition of the caregiver's contribution to end-of-life care is important for the CHN in assessing the family caregiver's and client's needs in practice. Offering supports that can alleviate the psychological, physical and financial stress when caring for a dying loved one at home. It is the responsibility of the interdisciplinary team, which includes the CHN, to offer and share knowledge about palliation and what can be offered throughout the illness and bereavement experience (CHPCA, 2013).

Education regarding aspects of end-of-life care would be valuable for clients and families. The educational resource would improve the transfer of knowledge from CHN to clients and families. The resource will improve the current delivery of care because the knowledge the client receives will not be solely dependent on the knowledge and comfort level of their CHN.

In addition, the information will be shared in a printed form so that the CHN can review it verbally. The client and family can refer back to the educational resource and use it as a reference as their needs change. The education resource will help the CHN and family identify the palliative needs of the family together, and thereby work together to meet those needs. The resource may contain a checklist that will make it easier for continuity of care. When a different CHN visits the client, he or she will be aware of what resources have been implemented and what topics have been discussed.

By having the resource in print, it will guarantee standardization of knowledge being transferred. In addition, if all clients and families receive the same standard

information, there should be less disparity in the quality of care received by different clients. Each family will be aware of the services that are available and how to access them.

10. Conclusion

The results and information generated through consultation with key informants and stakeholders will contribute to the development of this project. It was vital to gain various perspectives from CHNs who are actively involved in the home palliation process. While all the interviewed individuals have experience in home palliation, they all presented unique perspectives.

Input from a newly hired graduate nurse indicated that a novice nurse to the community should be informed about PEOLC services available to clients and families so that he or she is able to provide better quality of care. While, the experienced CHN had more frequent and regular interactive relationships with palliating clients and families, she also felt uncomfortable with home palliation. Her understanding and involvement of the home palliation allowed a deeper understanding of what is needed to improve the quality of care for clients and families. She too felt that client and families should be fully aware of the scope of available resources. From a leadership viewpoint, a team lead CHN provided perspective on the delivery of home palliation and identified needs that are presented by the CHNs at her office. The PEOLC coordinator provided a broader perspective on improving palliation at a local level. All of them identified that there is a need for the development of a resource that would help improve the home palliation process and improve the care received by clients and families in the community.

The consultation process helped identify gaps in the current approach to the home palliation program, and helped to identify changes that will improve the delivery of care. Furthermore, the results from the consultations supported those derived from the review of the literature, and serve to validate the necessity of an educational resource. The interview from the consultation process and a review of the literature identified the content to be included in the educational resource and the design of that resource. The consultations identified a lack of standardization in home palliation and a lack of a legislative provincial policy on the home palliation process. This can lead to disparities in the care that is provided in home palliation.

Both the review of the literature and the consultation process identified a need for a practical end-of-life navigating tool to help clients and families have a quality home palliation. This was predominant in the consultations, however, the participants did not mention the need for advance directives as part of end-of-life care. While this was not directly addressed in the interview questions, the focus was on the “do not resuscitate order”. While it is often thought to be synonymous, it is not. In clarifying the need for an advanced directive, all agreed that it was necessary. The advance directive was predominant in the grey literature.

In meeting the educational needs of the CHN, the needs of the clients and families will also be met. It is important to provide quality and holistic care to clients and families palliating at home. If the CHN is adequately prepared, then the comfort level should improve. This will increase the family's comfort level at home and decrease their anxiety. As identified in the consultation process, this means having a good knowledge base about

palliation and the available resources. An educational resource would prepare the CHN and promote continuity of care.

In this report I discussed who was interviewed and how these individuals were selected. An overview of the practicum project was provided, as well the rationale for the consultation. The data collection method, management, and analysis were also discussed. The objectives were identified and met through the consultation process. The importance and implications of the results of the consultation process were discussed, which strengthens the need for this educational resource in the community.

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Appendix D1

Sample Questions for the Interview

- How long have you been a community health nurse?

- Approximately how many palliative clients do you assess in the home annually?

- What resources do you implement for clients and families palliating at home?

- How do you feel about the adequacy of current reference resources available to clients and families in the community?

- In addition to the Caregiver's Guide Book to end-of life care and the booklet provided by Eastern Health, what other information should be provided to palliative clients and families in the community?

- What has been your experience with the transfer of information to clients and families palliating at home?

- Do you think there is a need for a navigational type guiding tool for end-of life care for families and client's palliating in the community? Discuss

- What aspects do you think should be included in the development of the resource to meet the need of clients and families palliating at home?

Appendix D2

Health Research Ethics Authority (HREA) 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
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. IF NO to both questions, continue to complete the checklist.		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 expectations?		x
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		0	

Appendix D2 (Continued)

Health Research Ethics Authority (HREA) Screening Tool

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 = (Count the # of Yes responses)		4	
SUMMARY See Interpretation in Appendix D3			

Appendix D3

Interpretation of HREA Screening Tool

If the sum of Line A is greater than Line B, the most probable purpose is research. The project should be submitted to an 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.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: HYPERLINK

"<http://www.hrea.ca/Ethics-Review-Required.aspx>" <http://www.hrea.ca/Ethics-Review-Required.aspx>.

Interpretation

Using the HREA interpretation information below, the sum of line A was less than the sum of line B ($0 < 4$), indicating this is not a research project. Indicating there is no need for REB approval.

Appendix E
End-of-Life Practicum Project

Navigating Through End-of-Life with at Home Palliation;

Educational Resource for Clients and Families

Nursing 6661

Memorial University of Newfoundland

Karen M. Leyte (009017435)

Navigating Through End-of-Life with at Home Palliation;
Educational Resource for Clients and Families

Purpose:

The purpose of this educational resource is to assist families who decide to palliate their loved ones at home. This resource will provide information regarding end-of-life preparation, access to community resources and services, pain and symptom management and guidance on end-of-life care. Since the diagnosis of a life-limiting places psychological, physical, and financial stresses on the loved one and the caregiver, this resource is intended to help reduce the stress experienced at this time. Furthermore, this resource will provide guidance for new community health nurses (CHNs) during the home palliation process.

The premise of the resource is based on findings gathered from the literature review and the consultation process. In the literature, caregivers requested a more effective transfer of information for end-of-life care. Furthermore, they requested that the information be provided in an unrushed environment by CHNs and in the form of a printed pamphlet or booklet (Arnaert & Wainwright, 2009; Health Canada, 2006). The printed material needed to be relevant and practical and contain information related physical signs of decline, how to deal with pain control (Osse, Vernooij-Dassen, Schadé & Grol, 2006), how to co-ordinate the care of different professionals and obtain help from agencies (Fujimami et al., 2015). The literature further indicates that families who are well-informed are able to provide care more effectively and experience less anxiety (Health Canada, 2009).

CHNs struggle with the needs of home palliation (Meirelles Sousa, & Dornelles 2015; O'Brien & Jack, 2009). The consultation results identified that the transfer of information pertaining to home palliation is based on their knowledge and comfort level of the CHN with home palliation. This can result in a lack of standard of care received by those palliating at home. In addition, because of the accumulated stress of care giving, caregivers can have difficulty retaining information. This education resource will improve the transfer of knowledge between the CHNs and the clients and caregivers; promote the retention of information by the families and caregivers; improve the quality of care provided through home palliation; and decrease caregiver stress.

Most people diagnosed with a life-limiting illness want to die at home and providing quality palliative care is basis human right (WHO, 2015). Eastern Health offers a palliative end-of-life care (PEOLC) community-based program for those who wish to palliate at home. By providing support through community nursing, grief counsellors, and financial assistance through services and equipment, loved ones can have quality of life at this difficult time. In the development of this useful resource, I worked with the PEOLC coordinator and with CHNs to ensure the information was relevant and accurate. Furthermore, in the resource, I addressed details regarding end-of-life planning, crisis intervention, and what to do at the time of death. These are concerns that were identified by the CHNs, the PEOLC coordinator, and by Dr. Cheryl Hurley (a palliative care physician). Finally, I contacted individuals in the community for accurate information on prior to including it in the resource.

The resource is written primarily at a grade six level, according to the SMOG readability test. However, because some words cannot be simplified without losing their

original meaning, some aspects of the resource are at a grade eight reading level. The educational resource will be given to the client and caregiver by the CHN when there is a diagnosis of a palliative life-limiting illness. It will be left in the home for the client and family to review and also for the nurse to review with the client. The resource is written from a third person narrative and encourages interaction between the nurse and the family unit.

Goals:

- To improve the transfer of information, through implementation of an educational resource surrounding end-of-life issues for caregivers who provide home palliation, and to the loved one diagnosed with a life-limiting illness.
- To help reduce the stress incurred by the caregiver when caring for a loved one palliating at home.

Objectives:

Once implemented, the Educational Resource will:

- Provide a framework to new CHNs to follow when providing care for both the clients and caregivers during home palliation.
- Provide guidance and knowledge to caregivers related to of community resources available through the PEOLC program and how to access available community resources.
- Provide guidance and knowledge to caregivers related to crisis management such as a pain and symptom management.

- Provide guidance and knowledge to caregivers related to importance for end-of-life preparation especially "Do Not Resuscitate" orders, Advance Health Care Directives, Last Wills and Testaments, and funeral planning.
- Prepare caregivers/family members for what to do in the event of a home death.
- Promote and provide a holistic nursing approach to the individual and family during home palliation.
- Promote an open dialogue between the community health nurse and the family/individual pertaining to end-of-life planning.

End-of-Life Planning



Time to Begin...
Time to Begin...

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End-of-Life Program

Being told that you or your family member has a life-limiting illness is not easy. It could be cancer or another end-stage heart, lung, kidney or nerve disease. This is a hard time for everyone, and it can be very stressful.

In the last stage of life, Eastern Health offers palliative care services through its end-of-life community program. These services are offered to you and your family in your home, and are meant to provide support and comfort when caring for a loved one and to improve their quality of life at this time.

There will be many choices you and your family will make at this time, including end-of-life planning. This is a guide to help you and your family through the end-of-life-stage and to let you know what is available to help you at this time.



To be Accepted in the Program:

- A cure has been ruled out
- The loved one is aware of their life-limiting illness and that death is close (within 30 days)

- The loved one wants to be at home
- A family doctor is willing to provide end-of-life care in the home
- A caregiver is willing to help care for the loved one at home (Eastern Health, 2013)

Role of the Community Health Nurse

A community health nurse will visit you in your home over the course of your illness. The nurse will work with you and your family to help meet the needs of both you and your caregiver. Your nurse will work with the palliative care team and/or your family doctor to make sure you are comfortable. The nurse can access services such as home support and put equipment in the home.

Your nurse will provide emotional support to you and your family at this time. Talk to your nurse about what you expect, or if you have any concerns or fears. The nurse will visit, but he or she only gets a snapshot of your life. Here are things to consider discussing with the nurse:

- How much pain am I really having?
- Is there anything I need to talk about with my family?
- Is there anything I need or want to do before I die?
- Where do I want to die?

- Making funeral arrangements - set a time to do so
- What is caregiver stress? And are home supports needed to help?

Set Goals with Your Nurse

1. _____

2. _____

3. _____



Role of the Palliative Care Team



The palliative care unit team is a consult service that is offered to the St. John's metro area, and includes Witless Bay, Conception Bay South, Flat Rock, Torbay, and Holyrood. When diagnosed with a life-limiting illness, a referral is sent to the palliative care unit team. This referral needs to be sent from a doctor or a nurse. To receive this service, you have to agree to the care offered by the palliative care team and be accepted by the palliative care unit.

The palliative care unit is a team of doctors and nurses located at the L.A Miller Center on Forest Road, St. John's. The Miller Center has a 10 bed unit that offers palliative care services and symptom control. The team will arrange for follow-up at the Miller Center outpatient clinic or in your home. This will depend on your health at the time. When you need a home visit, a doctor and a nurse will visit you.

The palliative care team not only deals with end-of-life issues, but are also experts in pain and symptom management. Some people go to the palliative care unit to get better management of their symptoms and then return home. As the end-of-life nears, you may wish to die at home or go to the palliative care unit.

The palliative care unit has a website that offers support and answers questions and concerns about end-of-life care. This site is an excellent resource. It also offers an online discussion forum. You may access this website by going to

www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/Newfoundland/Local+palliative+care+programs_services/Health+Care+Corporation+of+St_John_s_Palliative+Care.aspx

Role of the Family Doctor

You will need a family doctor to follow you at this time. Not all family doctors make home visits, so check with your own family doctor to make sure that he or she will come to your home. Your family doctor will work with the nurse and the palliative care team to help manage your pain and symptoms.

You should be able to reach your family doctor when you need him or her. Some family doctors will give a cell phone number to the family. If you have a crisis or need medical advice after regular clinic hours, your family doctor can help you.



The family doctor should come to the home at the time of death. If the family doctor is unable to come during the day, your nurse can come at this time. For more information, see the section on “what to do at the time of death”.

Role of the Caregiver

It is stressful caring for a loved one dying at home. As the loved one nears the end-of-life, the needs of the loved one will also increase. This means the loved one may need more help with personal care and help with day-to-day tasks.



Caring for your loved one can be rewarding and yet challenging.

Since giving end-of-life care can be tiring, caregivers may experience emotional and physical fatigue. Caregivers may have “caregiver stress”. You may have feelings of guilt, loneliness, anger, frustration and anxiety. Talk to you nurse about how you feel.

As a caregiver, it is important to care for yourself. While difficult, as a caregiver, you need to take a break and accept help from others whenever you can.

The program offers home support and equipment to assist with the care (please see what is offered under the end-of-life program). The nurse will work with you and help you care for your loved one.

Role of the Bereavement Counsellor

Bereavement or grief counselling is offered through the end-of-life program. At the time you become aware that you have a life-limiting illness, a referral is sent to the counsellor.

The counsellor offers support to both you and your family.



At this time you may be grieving for the past, present, and future. Grief is a normal response to a loss, but depression is not a normal response to grief. If you or your family feel depressed, tell your nurse or doctor.

The counsellor will call you and plan a visit in your home. The counsellor can meet with you or

your family together or alone. If you do not want to meet with the counsellor, that is okay, but the service is offered to your family as well. In the meeting, you can talk about any concerns.

The counsellor will be also available to the caregiver after the death of the loved one for grief counselling.

What the End-Of-Life Program Offers

To help you and your family spend your final days at home, the end-of-life program offers support that includes access to equipment, supplies, and services. These supports can make you more comfortable and decrease some of the stress at this time.

Take time to look over the list with your nurse and decide what things could help. What you need may change as time passes. If so, just ask your nurse and what you need will be delivered to your home as soon as possible. This service is free. After the loved one passes or you decide that you do not need the equipment, some of the equipment will need to be returned. The end-of-life program will have the equipment picked up from your home.

The end-of-life program offers equipment, supplies and services at no cost to you or your family.

Equipment

- hospital bed*
- over-bed table*
- walker*
- wheelchair*
- urinals
- bed pans
- commodes*



* Equipment to be returned

Supplies

- soaker pads
- Attends or Pull-ups
- mouth swabs
- lines for injecting medicine under the skin
- Boost or Ensure drinks
- Tena wash
- Unscented one-use washcloths
- compressors and nebulizers to help with breathing



Services

- home oxygen *
- suction by special order for health reasons
- home supports **
- symptom and pain medicine only***
- grief support
- ambulance services only to palliative care unit or to the emergency department****



*home oxygen is covered under the end-of-life program. Discuss oxygen coverage with your nurse. The program will cover the setting up of the oxygen in the home. If you already have oxygen set up in your home prior to acceptance into the program, the monthly payment will be arranged through the end-of-life program.

Please give any home oxygen receipts to your nurse and the receipt will be sent to the end-of life program. Note that it can take up to six weeks for a refund.

** Home supports may be used to assist the family with the care of the loved one. The amount of home support that is offered depends on the needs of the family. Also, if you have insurance, some of the home support is provided by an RN. If you need 24/7 home support, you may need to consider going to palliative care to meet your needs.

*** The end-of-life program will cover 100% of certain medicine for pain and symptoms related to end-of-life care. It does not cover regular medication. Most of these medicines will be for your care at home. It is important to let your nurse know the name of your pharmacy right away. The end-of-life program will contact your pharmacy. When the medications are picked up, there will be no cost.

If you have insurance, the end-of-life program will co-pay what insurance does not cover.

If you have ANY earlier receipts, just give them to your nurse and the receipts will be sent to the end-of-life program. The medications may be covered under the end-of-life program. The receipts must have your name, the name of the medication, and cost listed.

****If you use your ambulance receipt, please give the receipt to your nurse and the receipts will be sent to the end-of-life program.

What is Not Covered under the End-of-Life Program?

While there are many things included under the end-of-life-program, there are a few things that are not covered. Please see list of items that are not included:

- Hair washing troughs
- Side rails
- Wedge pillows



- Vomiting dishes
- Creams or lotions
- Powders
- Bath chairs
- Chair or bath lifts
- Grab bars
- Rides to appointments
- Special mattresses

If you are at risk for falling or need special equipment that is not covered under the program, your nurse can consult physiotherapy or occupational health therapy.

Physiotherapists or occupational health therapists may visit you at your home to assess and help meet the need.

Supports in the Community

There are also volunteer supports in the community that are able to help at this time. It may be worthwhile to check out other local based groups such as the Lion's Club or the local Rotary Club. There is also the Red Cross and privately owned agencies.

The Red Cross

There are also volunteer supports in the community that are able to help at this time. The Red Cross is a donation-based charitable organization that provides services to the community. The donations help with the upkeep and cleaning of the equipment.

The Red Cross provides many services including equipment, transportation services, and meals on wheels.

The Red Cross also offers the following supplies for a period of up to three months:

- Wheelchairs
- Four wheel and two wheel walkers
- Crutches and canes (Quad and single canes)
- Bath seats and transfer benches
- Vera frames - rails for toilet seat
- Raised toilet sets
- Transport chairs - push only wheelchairs
- A few bed rails
- Commodes



The Red Cross offers rides to and from appointments for a small fee in the St. John's and metro area. You can get a book of ten passes for \$40.00 plus tax.



In the Conception Bay South and Seal Cove area, a book of ten passes will cost \$60.00 plus tax. One pass will take you to your appointment and back again.

The Red Cross is located at 17 Major's Path, St. John's. For equipment, ask your community nurse for a referral. A family member can pick up what you need here.

The Nurse Next Door

The Nurse Next Store is not covered under the end-of-life program. This agency offers 24/7 nursing care and has nurses trained in home palliation. Your insurance may cover an RN or you may hire the nurse privately. You may check with your private insurance company related to their services offered at the end-of-life.

End-of-Life Planning

An important part of end-of-life planning includes preparing documents such as a Do Not Resuscitate (DNR) order, advanced health care directives and Wills. In addition, you and your family should consider funeral planning before your illness advances.

DNR

As you choose to spend your last days at home, you and your family need to plan for the actual moment of death.



If you choose to die at home or at the palliative care unit, you should have a "Do Not Resuscitate" or DNR order in your home. Talk to your nurse about a DNR order. Your nurse can get a DNR order from your family doctor.

A DNR order simply states that if you should stop breathing in the home, you do not want to have CPR or any rescue measures. It lets everyone know that your death at home was expected.

Once it is signed by your family doctor and the community health nurse, place the DNR order by the phone, so your family will know where to find it.

When the loved one dies at home, **do not call 911**. If the family does call 911, a DNR will stop the response team from giving rescue measures. Show the DNR to the funeral home personnel when they arrive.

Please see the section on “what to do at the time of death”.

Advanced Health Care Directives

An advanced health care directive is a way for you to share your health wishes for end-of-life care to your family and to others. An advanced health care directive is a legal document.



In this document, you choose a person to carry out your health wishes. This person will be your substitute decision maker and will make decisions on your behalf when you are unable to speak for yourself. You will need the signatures of two witness. These signatures cannot be your substitute decision maker or the spouse of the substitute decision maker (Government of Newfoundland and Labrador; Speak Up, 2016).

Make time to sit down and talk to your loved ones about what you want. When your wishes are written down, it makes difficult health decisions easier on the loved one. This

will help reduce stress related to end-of-life decisions. Ask your nurse for an advanced health care directive.

For more facts on advance health care directives, check out the “Speak-up” website for Newfoundland and Labrador. You may access this website at

<http://advancecareplanning.ca/resource/newfoundland-and-labrador/>

For an online advanced health care directive and information on end-of-life support, please access <http://www.nlpalliativecareassociation.com/links.php>

Preparing a Last Will and Testament

An advanced health care directive is not the same as a Last Will and Testament. A Will is a document that you create with the help of a lawyer that allows you to direct the management and distribution of your property or estate after your death (The Canadian Bar Association, 2016).



If you are not married and are living with your common-law partner, a Will allows you to care for that person after your death. A legal enforceable Will can make sure your

belongings and property will be given to who you wish, and can help prevent or resolve any disputes after your death.

Funeral Planning

Planning a funeral before you die can be a little overwhelming for both you and your family. Yet, it can provide comfort to family members knowing the funeral is what the loved one would want.

Also, by having a pre-planned funeral, it allows the loved one to take care of their family while they are still alive.

Having the funeral arranged in advance can decrease the stress after the passing of the loved one. So, consider what type of funeral you would like, and sit down and talk with your family about it.

Some things to consider are:

- Cremation or burial
- Wake
- Tribute
- Photos



- Hymns/songs
- If you have a church service, who do you want to take part and in what way
- Burial plot

Spiritual Preparation

Spirituality is unique to each person. The spiritual aspect of life and religious faith are not the same thing, but often do go together. Becoming aware of one's death may cause you to look back on life and give meaning to past life events.

Good spiritual health helps people to make sense of what is taking place, and they find comfort at the end-of-life. It has been linked to improved coping and quality of life.



Spirituality is about hope and trust, meaning and purpose, and forgiveness. It is about a belief and faith in yourself and others, or a belief in a higher power. Spiritually allows you to reflect on your values; important end-of-life decisions; love and relationships; and self-expression.

Your spirituality may change throughout your illness. Take time to explore your thoughts and feelings. You may find support and comfort from your local clergy and church family.

(Note: Information taken from various sources-(see Bibliography)

Pain and Symptom Management

The main goal of end-of-life care is to achieve the best quality of life for you and your family when there is no longer a cure for the illness and the illness stops responding to treatments.

As the illness advances, it may be harder to cope with the related pain and symptoms.

Your nurse will work with your family doctor and the palliative care team to help make you comfortable. Do not be afraid to let your health care team know if you are not getting good pain relief.

Physical Changes

As the end-of-life nears, you will notice a change in your loved one's physical health. As the body prepares to die, there is a physical shutting down.



Not all these signs and symptoms will be present or appear in a certain order. The amount of pain and other symptoms that may be experienced during end-of-life is different for everyone. Other than pain, there can be other symptoms that you may have. Here are some common symptoms that one can have as the illness advances (please see Table 1 for symptoms at the end- of life and Table 2 for symptoms that may occur as death becomes closer):

Table 1-Symptoms at the End-of-Life

Sign	Causes	What to do
Unable to move bowels	Medication, lack of food and water, or the disease	Ask the Health care team for medical advice. Possible stool softeners, laxatives, suppositories or enemas. If related to disease, check with PCU or family doctor.
Sore mouth	Lack of nutrients, yeast infections, dry mouth	Mouth care - brush teeth or dentures twice a day. Mouth swabs with water. To remove the film –use 1 tsp baking soda with 2 cups of water. Medication for yeast. Biotene or Moistur spray for dry mouth. A “Pink Lady” for sore mouth causing pain when swallowing. This will numb the area.

Table 1-Symptoms at the End-of-Life (continued)

Sign	Causes	What to do
A loss of bladder and bowel control	Loss of bladder and bowels may occur as the muscles relax.	Protect the bed with soaker pads. Incontinent supplies. Your loved one may need a catheter.
Weight loss	Disease progression; loss of appetite; not eating much; nausea and vomiting	Boost or Ensure if able to manage. Small frequent meals. Do not force food, if not hungry.
Sleeping more	Disease progression, body shutting down	Lots of rest. Pace activities and do not overdo things. Let the loved one sleep. Spend time with them when they are alert.

Note: Information taken from various sources-(see Bibliography)

Table 2: Symptoms as Death Becomes Closer

Symptom	Causes	What to do
Decrease in food and fluids intake	The loved one will have a decrease in a desire to eat or drink. The body is slowing down.	Do not force the loved one to eat or drink. You may need a syringe to give small amounts of fluid. Do not give fluids or food if the loved one coughs when they swallow.
Nausea and vomiting*	Disease, treatments, medications	Small meals Talk to the health care team for medical treatment.

Table 2: Symptoms as Death Becomes Closer (continued)

Sign	Causes	What to do
Coolness	<p>The hand, arms, feet and legs may become cooler as then body prepares to shut down.</p> <p>The skin may also change in color either pale or dusky.</p>	<p>Keep warm with a blanket.</p> <p>Do not use hot water bottles or electric blankets. The loved one may not be able tell of the bottle or electric blanket is too hot and it may cause a burn.</p>
<p>Restlessness*</p> <p>A person may be restless and not in a delirium. However, restlessness may occur before delirium.</p>	<p>The loved one may pull at the sheets or do repeated actions such as grabbing at the air.</p> <p>This is due to decrease oxygen to the brain and a decrease in body functioning.</p>	<p>Stay calm and keep the home quiet and peaceful.</p> <p>If things becomes worse, you may need medication.</p>
Low urine output	<p>The urine output will decrease and become ‘tea’ colored. This is because the loved one is not eating or drinking much and the kidneys are shutting down.</p>	<p>A catheter may be inserted by your nurse.</p>

**Table 2: Symptoms as Death Becomes Closer
(continued)**

Sign	Causes	What to do
Change in breathing patterns	The breathing patterns as death is close. The breathing may be shallow with periods of no breathing of five to thirty seconds and up to a full minute.	Try and make the loved one comfortable. You may use pillows to help prop your loved one up in bed. The hospital bed can be turned up to a semi-sitting position.
Delirium (confused) You may see agitation, distress and restlessness. Also, he/she may see things.*	Side effect of medication; organ shut down; Pain; sepsis; discomfort from bladder or bowel, and decrease oxygen. Disease progression	Consider the cause. Do not try and challenge the individual. Remain calm and talk to the loved one.
Breathlessness *	Disease progression. The loved one may become short of breath and have problems breathing	Semi-sitting position in the bed, relaxation breathing, well ventilated room. Talk to your health care team for medical treatment

**Table 2: Symptoms as Death Becomes Closer
(continued)**

Sign	Causes	What to do
Lung secretions or death rattle	Build-up of mouth and throat secretions and/or chest secretions. This is a strong sign of death within 48 hours	This is more stressful to the family than the loved one. The loved one may not be aware of what is happening and the gag and cough reflexes are often absent. The doctors may or may not order anything to decrease the amount of mucus produced.

Note: Information taken from various sources-(see Bibliography)

*Common crises that can occur during the end-of-life include: pain crisis; uncontrolled nausea and vomiting; restlessness and confusion; and breathlessness



What is a Crisis?

In the final stages of end-of-life, the care becomes more stressful. End-stage care can be hard to manage when symptoms overlap. A crisis can occur when the caregiver cannot meet the needs of their dying loved one.

There may be a quick change in health, or the caregiver and loved one are unable to cope with the symptoms, or the care may become too difficult to manage.

Pain Crisis

As the illness advances, the pain medication may not be the right dose for the pain level. While a loved one may have pain, he or she may not want to take a lot of medication because it makes them sleepy or it has unwanted side effects.

PAIN MEASUREMENT SCALE

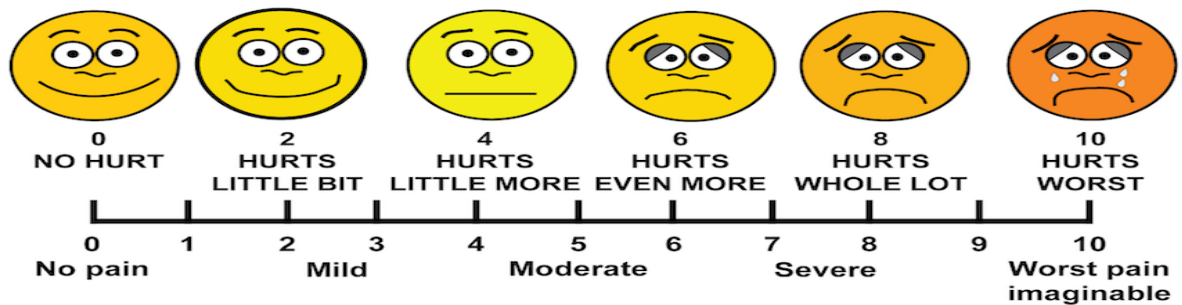


Figure 1: Wong-Baker FACES Pain rating scale. From http://www.wongbakerfaces.org/public_html/wp-content/uploads/2014/07/InstructionsForUse_rv0714.pdf

Because the loved one is not getting good pain control, the pain may worsen and become difficult to get under control. This can lead to a pain crisis. A pain crisis is “an event in which the patient reports pain that is severe, uncontrolled, and causing distress for the patient, family members, or both.” A pain crisis can occur at any time during the course of the disease.

As per the pain measurement scale;

- 0:** there are no symptoms.
- 1-3-**The symptoms are mild
- 4-6-**The symptoms are moderate
- 7-10-** The symptoms are severe.

A pain level should never be an eight or higher. If the pain level is reported at a four or more on the pain measurement scale, let the nurse know. By addressing the pain or symptom early, a crisis may be prevented.

If you cannot take a pill, some medications can be taken as a liquid or a needle given just under the skin. The nurse will teach your caregiver how to give the medication.

If the loved one is anxious or has spiritual distress, the pain can be worse. If a pain crisis occurs, the individual will not be able to get any relief and this is now a medical emergency.

If you are accepted for the palliative care unit, and there is a bed available, you can go to palliative care unit for pain and symptom management. This does not mean that you cannot come back home. Some people go to palliative care for pain control and then go home once the pain is managed. If there is no bed available, or you are not accepted for palliative care, you may have to go to the emergency department.

Uncontrolled Nausea and Vomiting

Uncontrolled nausea and vomiting can be a crisis. Nausea and vomiting also can be made worse by pain, and can lead to dehydration and feelings of panic.

Restlessness and Confusion

Your loved one may become confused and agitated. This is also called delirium. This can place the loved one at risk for falls and self-harm. While unaware, the loved one can also be harmful to others.

Breathlessness

The loved one may have periods of rapid, shallow “panting-like” breathing and become short of breath. It may be impossible to bring comfort to your loved one or to relax them at this time. This may be made worse by increase pain and anxiety.

What to Do When a Crisis Occurs?

During the day, the palliative care team is available from 8:30 a.m. to 4:30 p.m. Your nurse is also available during this time.

Sadly, you cannot predict when a crisis will occur.

However, if you accept care from the palliative care team, your family doctor can call the palliative care unit up until 10:00 p.m.



The community nurse may also be available at this time for crisis management and pronouncement of death, if the death is close (within 48 hours). Since the palliative care unit is open 24/7, if you call the unit, a nurse may be able to help you.

If you have a crisis that cannot be managed, you may have to go to the emergency department for treatment.

If you are accepted for palliative care and decide that you want to die in the palliative care unit, you need to call the nurse navigator at the palliative care unit located at the L.A. Miller Center (8:30am-4:30pm). He or she will let you know if there is a bed vacant at that time. If not, you can put your name on a waiting list. The palliative care unit will send an ambulance to bring you to the unit.

If you are unsure if you want to go to palliative care, you can still put your name on the list. If they call, you can say 'no' and ask to be kept on the list.

Spiritual Changes

As the loved one dies, there will be spiritual changes. The spirit goes through a process of separating from the body, and the people and things around them. Spiritual signs may include: withdrawal; not being social; and seeing and hearing things that aren't really there.

Not Wanting to See Many People

The loved one may want to limit the number of people that they want around them. They may only want a few of their closest friends and family there. These select few should offer their support.

Withdrawal

As death become near, your loved one maybe become sleepier and enter in a coma-like state. The body is preparing for a release and is starting to let go.



In caring for your loved one, let them know who you are and talk in your normal voice. Research states that the hearing is present to the end. Use the power of touch and say whatever you need to say that will help the person let go.

Seeing or Hearing Things

It is not unusual for the loved one to say that they have talked or seen someone who have already passed on. The loved one is letting go, and this eases the changeover from life to death. It is best to offer support for their experience rather than disagree with the loved one.

Giving Permission

When a loved one is ready to die, it is important for the family to let the loved one know that it is okay to pass on. It is normal for the loved one to want to hold on. By giving permission, you are saying that things are alright and when they are ready, they can let go. Saying 'good-bye' is hard. This bring release for both the loved one and the family.

(Note: Information taken from various sources-(see Bibliography)

What to Do at the Time of Death

As a family, you may think you are prepared for the death of your loved one, but when the time actually come, it may be more difficult than expected.



With a DNR order in place in the home, you **do not call 911**. If your loved one dies during the day, you can call your family doctor. The family doctor will come to the home at the time of death and pronounce your loved one's death. If the family doctor is unable to attend during daytime hours, your nurse is able to do so.

Also, you need to call your funeral home. The caretaker will come and take your loved one to the funeral home.

If your loved one dies in the night, it is **not an emergency**. Since the death is a planned home death, it is **best to wait** until morning.

If your family doctor is willing to come to home at night and pronounce the death, then call the funeral home. The funeral home will then come as well.

If you cannot wait until the morning, you can call the hospital. Let the operator know that the death was expected. The ambulance and the police will come at this time. Show the first responders the DNR order. The paramedic will pronounce the death of the loved one. Then, you can call your funeral home.

Any Questions???

Notes

*“And in the end it is not the years in your life that count,
it's the life in your years.”*

Abraham Lincoln



Web Resources

The Government of Newfoundland and Labrador has launched a “Speak up” campaign in 2016 promoting advanced health care directives.

<http://advancecareplanning.ca/resource/newfoundland-and-labrador/>

The Newfoundland and Labrador Palliation Association has a website with links to end-of-life care and support.

<http://www.nlpalliativecareassociation.com/links.php>

The Palliative Care Unit has a website

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/Newfoundland/Local+palliative+care+programs_services/Health+Care+Corporation+of+St_John_s+_Palliative+Care.aspx



Important Contact Numbers

Community health nurse: _____

Palliative care team: _____

Family doctor's office: _____

Family doctor's cell: _____

Bereavement counsellor: **752-4369** _____

Palliative care unit: **777-6555/777-8610** _____

Nurse navigator at PCU: **777-7303** _____

The Red Cross: **758-8400** _____

Community volunteer services: _____

Funeral Home: _____

Pharmacy: _____

Clergy: _____

Hospital: **777-6300** _____

Other numbers: _____



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