

Exploring the Nurse Practitioner Role in Palliative Care in New Brunswick

Lisa Duplessis BN RN is a nurse practitioner student at University of New Brunswick,

Fredericton, NB

Sharon Hamilton RN MN NP is a professor at the University of New Brunswick,

Fredericton, NB

## Abstract

Every individual will die, and people have a right to end-of-life (EOL) care. This natural life progression demands to be supported and managed by proficient, caring health care providers to deliver quality EOL care, both in the hospital and community setting (Heyland et al. 2010). In New Brunswick (NB), barriers at EOL care include a lack of access to primary care providers, limited knowledge or practice in the delivery of such care, and a lack of palliative care services available for dying patients. Nurse Practitioner (NP) practice includes management of all the domains of health by addressing psychological, social and spiritual distress, as well as the relief and management of physical symptoms throughout the illness trajectory. The evidence available clearly supports the NP as an integral provider in palliative care management and one who can bring much expertise to the interprofessional team whether in the institutional, community or primary health care settings. Research exploring how NPs can be integrated as active participants in interdisciplinary palliative care teams and in NB's Extra Mural program is necessary to address gaps in care, accessibility to palliative care and to develop strategies for patients' increased quality of life at EOL.

*Key words:* End-of-life, Palliative Care, Nurse Practitioner, New Brunswick, Barriers

## Introduction

End-of-life (EOL) or palliative care is described by the World Health Organization (WHO) as care of dying patients and their caregivers that enhances quality of life at EOL (2014). It encompasses the management of patients' physical symptoms as well as attending to patients' psychosocial and spiritual well-being and caregiver concerns (World Health Organization 2014). EOL care is not limited to a specific age group, but to any person and family in need. Due to a lack of continuity of care and services available based on geographic location, there is an urgent need for collaboration of palliative health care services to ameliorate EOL experiences and provide a more seamless transition between the hospital and the community (Bull et al. 2012; Kamal et al. 2013; New Brunswick Palliative Care Association 2010). Nurse Practitioner (NP) education and practice is founded on primary health care principles that include a holistic approach for patient management across the lifespan including: physical, emotional, spiritual, and social domains of care, all of which are foundational to EOL care (Nurses Association of New Brunswick 2010). NPs collaborate with patients, their families and the interdisciplinary health care team to provide health promotion and disease management strategies (Nurses Association of New Brunswick 2010). This skill set validates NPs as being well suited to manage patients at EOL (Kaasalainen et al. 2013; Letizia and Jones 2012; Liu et al. 2012; Owens et al. 2012).

It is estimated that there were over 256, 000 deaths in Canada between 2013 and 2014 (Statistics Canada 2014). This number is projected to increase by over 330, 000 deaths by the year 2026 (Quality End-of-Life Care Coalition of Canada 2010). The number of patients requiring end of life care will continue to rise creating an emergent

need to improve access to EOL services. Barriers to care at EOL include: a lack of primary care providers, limited knowledge or practice in the delivery of such care, and a lack of palliative care services available for dying patients (Fowler and Hammer 2012; Letizia and Jones 2012; Kaalsalainen et al. 2013; Owens et al. 2012). Within a rural province, such as New Brunswick, there are additional challenges with palliative care delivery such as residents living in rural areas where services are largely inaccessible, an increasing elderly population and a lack of caregivers within communities (New Brunswick Palliative Care Association 2010). Outside of the barriers associated with the provision of EOL care, residents of New Brunswick also face a lack of primary care providers with approximately 50, 000 residents without a family physician (New Brunswick Medical Society 2014). It is crucial that we address these concerns in a timely manner and develop solutions that will improve access to care including the EOL experiences of residents of New Brunswick.

Every individual will die, and people have a right to EOL care. This natural life progression demands to be supported and managed by proficient, caring health care providers to deliver quality EOL care, both in the hospital and community setting (Canadian Hospice Palliative Care Association 2013; Carstairs 2005; Carstairs and Beaudoin 2000; Heyland et al. 2010; Quality End-of-Life Care Coalition of Canada 2010). NPs have much to offer and may well be the solution to addressing these barriers for patients and families in need.

### Palliative Care

Dame Cicely Saunders social worker, nurse and physician initiated palliative care in the mid-20<sup>th</sup> century, founding the world's first contemporary hospice in 1967 known

as St. Christopher's Hospice (St Christopher's n.d.). During her lifetime, Dame Cicely pioneered palliative care contributing to research, teaching, and publications. Her vision of care for patients and their families included a holistic primary health care model, encompassing physical, emotional, social and spiritual health (St Christopher's n.d.). A principal ideal that Dame Cicely incorporated into her end of life philosophy involved the relief of pain as a whole, which she termed "total pain" (Richmond 2005: 238). Dame Cicely addressed all facets of the dying persons' sources of pain believing it was crucial to alleviate the total pain burden in order for patients to experience a good death.

Dame Cicely Saunders devised a standard of care for palliative patients that included dying with dignity and respect while providing care in a holistic manner that set aside the previous purely medical model of care. Today, palliative or EOL care includes addressing the patient holistically as Dame Cicely envisioned. In addition, it focuses on the experience of family members ensuring that respite, coping, and bereavement support are a part of that care (Canadian Hospice Palliative Care Association 2006).

### Palliative Care in Canada

The Canadian Hospice Palliative Care Association (CHPCA 2013) authored A Model to Guide Hospice Palliative Care aimed at guiding caregivers with the tools to provide quality care for patients and their families at EOL. This national model is Canada's standardized approach to hospice palliative care. The model addresses disease and symptom management, psychological, social, spiritual distress and loss, as well as bereavement (Canadian Hospice Palliative Care Association 2013). The values, guiding principles and foundational concepts described by CHPCA consist of a collaborative team based approach supported by evidence informed research to provide optimal care

for Canadians at EOL (Canadian Hospice Palliative Care Association 2013). Guiding principles of EOL care include that it be: person/family centered, ethical, of high quality, team-based, safe and effective, accessible, adequately resourced, collaborative, advocacy-based, evidence-informed and knowledge-based (Canadian Hospice Palliative Care Association 2013).

Carstairs and Beaudoin's (2000: 3) definition of a "quality death" is defined as death without distress caused by any dimension of life with EOL care provided by educated professionals. The Canadian Institute for Health Information (2010) states that 16% to 30% of dying Canadians currently receive specialized EOL care. This number is not acceptable; palliative care through specialized interdisciplinary care teams should be available to all patients at EOL (Canadian Hospice Palliative Care Association 2006; Quality End-of-Life Care Coalition of Canada 2010). There is an expectation that primary care providers be educated in adopting a palliative approach and be available to patients at EOL (Shadd et al. 2013). Terminal patients may have access to their primary care providers to a degree, but many providers do not have the education, expertise, support or time to optimally manage patients using a palliative approach (Fowler and Hammer 2013; Shadd et al. 2013). A cohort study by Heyland et al. (2010) found that dying patients highlight a lack of communication, a lack of emotional and spiritual support and availability of their primary caregiver at end of life, which supports the premise that further improvement is needed.

#### Palliative Care in the United States

We can learn from palliative care initiatives in the United States (U.S.), which have surpassed Canadian efforts to date. Palliative care services in the U.S. are largely

accessible within the hospital and in the community setting. Therefore, whether EOL care takes place in the hospital or patients' home, a long-term care facility or a hospice or clinic setting, care is readily available (Bull et al. 2012). Primary care providers at EOL include both physicians and NPs (Kennedy 2012). As the primary care provider, the NP is responsible for collaborating with an interdisciplinary palliative care team to create a comprehensive care plan and then revisit and reevaluate the plan as the patient's status changes (Kennedy 2012).

Palliative care models in the United States (U.S.) are moving toward a community centered standard that incorporates both inpatient and outpatient care and home and inpatient hospice (Kamal et al. 2013). The benefit of such a model of care includes a "seamless" approach to patient care, allowing for continuity of care despite the environment in which patients are cared for (Kamal et al. 2013). A community-based model enhances accessibility for those in need and allows for care of the patient and their families throughout the illness trajectory and not solely at EOL (Kamal et al. 2013).

Bull et al. (2012) emphasize that intersectoral collaboration needs to be central to a palliative model of care to optimally provide the comprehensive care that palliative patients require. They describe palliative patients who are recently discharged from the hospital as "falling into an outpatient gap," suggesting an essential need for supports and resources within the community (Bull et al. 2012: 798). Goals of care within the community setting include: medication reconciliation, access to necessary follow-up, pain and symptom management and emotional and spiritual support for the patient and family, as well as loss and bereavement resources (Bull et al. 2012; Kamal et al. 2013). Having this degree of support in the community would enhance all aspects of care, help

to reduce costs to the healthcare system and address the gap in care that patients sometimes face when moving between the hospital and community (Kamal et al. 2013).

A cohort study by Bookbinder et al. (2011) found that an interdisciplinary model of care that included NPs demonstrated a decline in patients' symptoms, increased access to community support services and management of patient crises. It was also noted that when the actual death occurred, advance care directives were followed (Bookbinder et al. 2011). Incorporating NPs in palliative care settings in the U.S. and the seamless community centered approach in EOL care points toward a solution for ameliorating current EOL practices.

#### Nurse Practitioners and Palliative Care

In the Standards of Practice for Primary Health Care Nurse Practitioners issued by the Nurses Association of New Brunswick (NANB 2010), the NP scope of practice includes palliative care management. The holistic lens that is foundational to NP practice is identified by patients and their families as instrumental to obtaining optimal EOL care. NPs are able to address the total pain burden that the patient is experiencing as well as family concerns (Kaasalainen et al. 2013; Liu et al. 2012). Owens et al. (2012: 58) conclude that the advanced education obtained by NPs and the totality of the nursing experience make these professionals "...ideally suited to manage both primary and palliative care needs for people at the end of life." The value of primary care NPs lies not only in their unique skillset, but also in their ability to provide greater accessibility to EOL care (Owens et al. 2012).

The role of the primary provider in EOL care includes sustaining an optimal quality of life in the terminal patient by diminishing suffering (Dunphy et al. 2007; World

Health Organization 2014). Quality of life should be defined by the patient and obtained through collaborative and ongoing discussion with the patient, family and their provider (Dunphy et al. 2007). An integrative review by Krikorian and Limonero (2012) state that individuals faced with life-threatening illness or imminent death may experience suffering in a variety of ways that affects his/her quality of life. Dimensions of suffering identified include: biographical, physical, cultural, societal, familial, psychological, spiritual and time and illness-progression factors (Krikorian and Limonero 2012). These elements of suffering are to be continuously assessed, evaluated and managed throughout the illness trajectory in hopes to relieve or avoid suffering and increase quality of life (Krikorian and Limonero 2012).

NP practice includes management of all domains of health by addressing psychological, social and spiritual distress, as well as the relief and management of physical symptoms throughout the illness trajectory (Dunphy et al. 2007; Nurses Association of New Brunswick 2010). It includes; listening, emotional and spiritual support, education, collaboration and provision of care for both the patient and the family (Dunphy et al. 2007). These aspects of care are addressed in all visits and integrated into the comprehensive care that clients receive. End of life care requires astute attention to these multiple dimensions of care that many health professionals may find difficult to address. The nursing profession takes pride in instilling holistic care practices throughout the curriculum and educates students to address all dimensions of care, developing the skills and expertise necessary to provide this comprehensive care to patients and their families.

Skill in addressing spiritual distress is essential when caring for patients at EOL

(Edwards et al. 2010; Sulmasy 2013). As patients face death, they often experience feelings of fear or trepidation as they encounter their own mortality and questions often arise. Sulmasy (2013) describes the need for practitioners to reflect on their own beliefs and values so that they can comfortably address spirituality and its various meanings to patients in their care. Spirituality involves reflection upon one's meaning and purpose in life and not only religion; although one's personal religious beliefs may be a significant factor in one's perception of the meaning of life. Canadians identify spirituality as an important aspect of EOL care where further support from health care providers is needed (Heyland et al. 2010). Competent spiritual care is taught throughout the undergraduate and graduate nursing curriculum to ensure that this dimension of holistic care is assessed with each patient encounter.

#### Palliative Care in New Brunswick

Currently in New Brunswick, the Provincial Framework for Palliative Care in New Brunswick (2010: 6) states, "Each hospital has some structure for palliative care beds, but not all inpatients have access to palliative care physicians, nurses, or other staff who have been trained in palliative care." There is a need to improve the percentage of palliative patients that are able to access the structured palliative care network in New Brunswick. NPs have the education and expertise to provide EOL care, yet NPs are not given governance to practice in hospitals or outside the primary care setting. This restriction extends into the community where resources are extremely limited. The Extra Mural program in New Brunswick provides EOL care through in home services by registered nurses and other multidisciplinary health care providers in some areas within New Brunswick; but services vary depending on geographic location (Government of

New Brunswick n.d.; Provincial Framework for Palliative Care in New Brunswick 2010). Currently, NPs have not been given authority to practice in Extra Mural, which exacerbates the gap of essential services available to EOL patients. The transition between hospital and community requires coordination to prevent gaps in EOL care (Bull et al. 2012; Carstairs 2005). NPs working within the Extra Mural program could help to bridge the gap through providing primary health care services to patients in their own home as well as address issues that may arise as patients transition from hospital to community settings. It would be beneficial to the public that NPs be incorporated into inpatient hospital care and interdisciplinary palliative care teams as well as in local Extra Mural programs.

There are recommendations in the Provincial Framework for Palliative Care to establish a “provincial approach” in serving the public by “establishing a formal palliative care service in each health zone” (New Brunswick Hospice Palliative Care Association 2010: 7). Integration of services, along with the addition of NP expertise would benefit patients and their families by enhancing their experience during the terminal illness trajectory with comprehensive EOL care regardless of their geographic location. Because dying patients often are followed by their primary care provider and there is a lack of services in the province, there is a need to assess and educate providers in EOL care to ensure that there is interim support for patients and their families as we await the implementation of formal services (Carstairs and Beaudoin, 2000; Carstairs 2005; Cook et al. 2013; Shadd et al. 2013). Addressing the EOL education of healthcare providers is necessary to bridge the gap that exists between the patient and access to appropriate care.

According to the Canadian Health Institute for Health Information (2011) New Brunswick has the highest rate of hospital deaths in comparison to other Atlantic provinces. The New Brunswick Hospice and Palliative Care Association is addressing this issue by supporting the development of hospice organizations that provide dying patients and their family's care and support in their own homes as well as constructing formal, in house facilities (2014). This service is advantageous to those who wish to die at home, rather than in the hospital, which is the preference of most Canadians (Bacon 2008 as cited in Canadian Hospice Palliative Care Association 2014). The Saint John New Brunswick region is addressing the need for enhanced EOL care through the development of Hospice Saint John, where there is a ten-bed facility available to the residents in the community. The city of Fredericton is currently in the process of constructing a hospice facility to meet the need for specialized care in that region. Though beneficial to those living in these areas, there are many other residents of New Brunswick who would profit from hospice services that are accessible to all.

### Conclusion

According to the Blueprint for Action 2010 to 2020 by the Quality End-of-life Care Coalition of Canada, there is an urgent need for hospice palliative care to be accessible to all Canadians (2010). Access to care in the setting preferred by the patient is ideal and contributes to quality of life at EOL (Quality End-of-Life Care Coalition of Canada 2010). Palliative care needs can be accomplished through collaboration of care, funding, and support (Quality End-of-Life Care Coalition of Canada 2010). Although, there is a gap in the literature pertaining to the provision of palliative care in Canada and specifically New Brunswick by NPs, the evidence available clearly supports the NP as an

integral provider in palliative care management and one who can bring much expertise to the interprofessional team whether in the institutional, community or primary health care settings. NPs have education and experience in end of life care, advanced directives and management of symptoms while practicing through a holistic lens that incorporates care directed at all the essential domains related to palliative care management.

Currently, the New Brunswick Extra Mural program does not include positions for NPs. Change is crucial as NPs in Extra Mural would help to bridge the gap between hospital and community settings allowing for enhanced collaborative practice, supporting patients in their transition, providing timely symptom management, being instrumental in avoiding adverse events such as medication errors and ultimately saving healthcare expenditures by avoiding unnecessary emergency visits. The ongoing trend of patients who wish to die in their own homes supports the vision of implementing NP positions in the Extra Mural program and allows communities access to care providers who are able to manage all aspects of patient care at EOL.

#### Recommendations for Further Research

The need for further education in EOL care is an area that must be explored with all NP primary care providers because of their direct involvement in EOL care. Future research regarding NPs confidence and capabilities in providing comprehensive EOL care is necessary to identify if further education in palliative care is needed. NPs involvement in EOL care is not well established, although present literature supports that NP practice positively affects the EOL experience through symptom management and patient/family satisfaction along with decreasing costs by decreasing emergency visits. Research directed at NP outcomes in EOL care would also be of benefit to support

implementation of the role in New Brunswick. Research exploring how NPs can be integrated as active participants in interdisciplinary palliative care teams and models of care and in extra mural programs are necessary to address gaps in care, accessibility to palliative care and increase quality of life in patients at EOL.

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