An Orientation to Hospice Palliative Care for Home Care Nurses

by

Kathleen Johnston
B.Sc. (N), McGill University, 1989

A Project Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF NURSING

In the Faculty of Human and Social Development

University of Victoria

An Orientation to Hospice Palliative Care for Home Care Nurses

By

Kathleen Johnston
B.Sc. (N), McGill University, 1989

Supervisory Committee

Dr. Marjorie McIntyre, Supervisor
(School of Nursing)

Dr. Gweneth Doane, Departmental Member
(School of Nursing)

Dr. Jane Milliken, Outside Member
(School of Nursing)

Supervisory Committee

Dr. Marjorie McIntyre, Supervisor
(School of Nursing)

Dr. Gweneth Doane, Departmental Member
(School of Nursing)

Dr. Jane Milliken, Outside Member
(School of Nursing)

ABSTRACT

This project is a curriculum to orient new home care nurses to hospice palliative care nursing practice. The curriculum is founded on the Supportive Care Model of nursing (Davies & Oberle, 1990) and the hospice palliative care nursing competencies outlined by the Canadian Nursing Association (2007). Experiential Learning and reflection were selected as pedagogical approaches. The curriculum in seven modules and a curriculum blueprint are included as appendices.

Table of Contents

> Part of the inherent difficulties of education in palliative care is that it is not a logical and linear discipline, but is conceptually complex and is characterised by forms of knowledge that are personal and shared, which communicate real meaning through interpretation, and have moral and existential elements. . . . Palliative care education cannot be seen simply in terms of skills and knowledge that we would associate with cognition. Higher order thinking and reflective processes must play a part. (Becker, 2007, p. 379)

I was introduced to the idea of creating an orientation curriculum for Home Care Nurses (HCN) in palliative care nursing practice through my work as a palliative care clinical resource nurse. I was initially attracted to the idea because of its practicality; I struggled to support new nurses in my own role. As a clinical educator, I am familiar with teaching the 'doing' of nursing; implementing a new policy, teaching the skills to operate a new pump or computer software. Many nurses coming to community palliative care nursing practice from acute care settings are also familiar with skills focused education based on empirical nursing knowledge. Nursing practice and palliative care nursing specifically require knowledge that is "subjective, contextual, dialogic, and values driven" (Watson, 1988). Teaching and learning palliative care nursing requires creative pedagogies that may be unfamiliar to nurses and clinical educators alike. My goal is to create an orientation program that addresses the unique knowledge required for community palliative care nursing practice and supports educators and orientees through the use of pedagogies that support critical thinking skills and reflective practice. Using resources and structures supported in my particular work environment, competency development and experiential learning will be foundational theoretical perspectives. As I have progressed through my course work in graduate studies, I recognize the opportunity that exists in this project to integrate my knowledge of palliative care nursing practice with my studies in education.

Background Information

Although nurses in most clinical settings care for patients at end-of-life, hospice palliative care (HPC) nursing is designated as a major nursing specialty in Canada with its own certification examination, competencies, skills, and knowledge base (Canadian Nurses Association, 2008). Patients and their caregivers registered with a HPC program require focused support and interventions beyond those typically provided by non-HPC specialized nurses supplying end-of-life care in many health care settings. Although specialist multidisciplinary HPC teams exist, their purpose is to provide consultation to primary providers, not manage the overall care and support of patients. Therefore, home care nurses, as primary providers, require education in the many dimensions of HPC practice to care for patients effectively. Without this knowledge and skill, nurses restrict their involvement with HPC patients and are limited in their ability to manage common symptoms such as pain effectively (McClement, Care, Dean, & Cheang, 2005).

Most people diagnosed with a life threatening illness prefer to spend their time at home, with the support of family and friends, rather than in a hospital or facility setting (Maida, 2002). This population and their lay caregivers face difficult challenges including coping with physical and functional decline, complex and distressing symptoms, and psychosocial issues such as changing family roles and the experience of grief. HPC services are guided by a particular philosophy of holistic care when disease cure is no longer possible. HPC provides support for the patient and family throughout the duration of their illness including bereavement care, whether the patient is in an acute care hospital, hospice, long term care facility, or their own home. Although the philosophy of care remains consistent, each setting presents unique challenges for nurses providing care. The majority of patients registered with the Fraser Health Authority

(FHA) HPC Program at any one time are located at home. In the 2006/2007 fiscal year, 2550 HPC patients in FHA of the approximately 3600 patients registered with the program during that time period received care from HCN (Barkman, 2008).

Home Care Nursing in FHA is a generalist practice model. HCN typically make visits for wound care, intravenous therapy, chronic disease management, and palliative support in a single work day. New community nurses need to balance their learning needs for supporting high acuity HPC patients with other aspects of nursing practice. HCN, along with family physicians, are the primary care providers for HPC patients at home. As many family physicians no longer make home visits, the HCN may be the only professional care provider who regularly interacts with these patients and their caregivers. “Home care nurses are the healthcare professionals spending the most time in the home, and therefore having the greatest opportunity to affect end-of-life care” (Ferrell & Borneman, 2002, p. 21). In contrast with acute care practice, HCN’s work alone without readily available support from colleagues. A wide variety of knowledge and skills are required. Clinical judgement is necessary to make the multitude of daily decisions that are often unnecessary in acute care practice, from scheduling nursing visits and allocating other resources to assessing caregiver capacity. Thus, HPC community nursing practice requires a unique body of knowledge, critical thinking and relational skills to support patients and caregivers at a particularly vulnerable time of life. The organizational structure of HPC practice in FHA relies on HCN to deliver the majority of professional care. It is essential that new orientees to HCN have the knowledge and supports necessary to give competent, effective patient care.

Part of the role of HPC clinical resource nurses is providing an orientation to new HCN as they learn to practice community HPC. In FHA, ten HPC teams provide support to local communities. Most program initiatives and planning for education occur at an authority wide level. HPC nursing orientation for HCN is currently coordinated at both the local and regional levels. New HC nursing orientees attend two day-long regional interdisciplinary workshops on HPC practice. These generic workshops support nurses and other health professionals working in a variety of settings to care for patients at end-of-life. Topics include (a) the nursing role, (b) common ethical issues, (c) communication, (d) symptom management, (e) HPC resources and (f) psychosocial concerns. Orientation to the specific role of the HCN in HPC is provided at the local level, usually by the clinical resource nurse. Local HPC orientation programs vary from short didactic presentations given as part of a general orientation, to a resource binder containing policy and procedural information, to a two day lecture style session in symptom management and communication skills. The orientation is short, content focused, and dependent on the resources and skills of the local HPC team. Any orientation curriculum developed needs to consider the available resources, as well as the skills and abilities of the facilitators.

Curriculum Considerations

My initial conception of this project was the production of a resource manual that would guide nurses in basic HPC practice as well as introduce them to local resources and FHA policies. Through education-focused course work and an introductory literature search, the concept has evolved into a self-directed curriculum that utilizes structures and resources already developed in the health authority, in conjunction with experiential learning to support the development of critical thinking skills and reflective practice. My original ideas concentrated on providing all the forms, policies and resources novice nurses require for practice. Instead, I focused on how to support these nurses to practice effectively as an outcome, and the scope of the project became quite different.

Because my project is of interest to my practice setting, I wanted to expand this academic process to include supports for educators or facilitators who would be implementing this orientation curriculum. The HPC Program has developed a professional development pathway (Fraser Health Hospice Palliative Care Program, 2008) for acute care based HPC practice. A regional mentorship program has received much support from Professional Practice within the health authority. Minimum educational requirements for HCN have been set out by the HPC program including completion of the previously mentioned two days of group education within the first year of practice. Ensuring the curriculum plan incorporates some of these structures and formats will encourage consistency in the overall orientation process and benefit from previously developed resources in the health authority.

The process of curriculum development also requires answering similar pedagogical and epistemological questions. “[C]urriculum provides the infrastructure for organizing and delivering content and learning experiences, building toward cognitive, affective, and psychomotor outcomes” (Jillings & O’Flynn-Magee, 2007, p. 384). Curriculum can be defined differently depending on the philosophy and context of the author, but usually includes: a set of outcomes or performance objectives; foundations or boundaries; philosophy; design structure; organizing frameworks; educational activities; and evaluation (Dillard, Siktberg, & Laidig, 2005). Each step requires making decisions based on available evidence and relevant nursing theory while considering a philosophical approach to learning and knowledge. Through this project I provide answers to the question of how to best support learning for new community HPC nurses through enacting the curriculum development process.

Literature Review

Narrowing the focus of this project for an effective literature search was challenging. There does exist descriptive literature about educational programs in HPC nursing, orientation programs, and community nursing programs, but much of it is not research based. Orientation programs in general aim to ensure nurses have the skills to fulfill a specific nursing role including an introduction to the particular culture and rules of an organization (Connelly & Hoffart, 1998). Orientation attempts to balance the two tensions of preparing a product (competent nurse) for a health care institution and education and professional development of an individual nurse. Literature describing orientation programs in acute or critical care environments may contain valuable information about the process of developing such a program, but often centres on teaching technical skills which excludes many components of HPC nursing practice. Reflecting on the variety of knowledge forms in HPC nursing and a pragmatic approach to the learning environment has directed the literature search towards experiential learning theory and competency frameworks.

HPC Nursing Knowledge

Before decisions are made about content, structure and methodology of the curriculum, it is important to articulate the complexity and diversity of HPC knowledge that must be integrated into nursing practice. As indicated in the opening quotation to this project, palliative care knowledge extends beyond the scientific understanding of disease processes and pain pathways into the realm of situated, personal and interpersonal knowledge including ethical and spiritual components (Becker, 2007a). Embracing these knowledge domains is also suggested by the Supportive Care Model (Davies & Oberle, 1990) which forms the foundation for the Canadian HPC Nursing Standards of Practice (2002). The model identifies five dimensions of HPC nursing practice including the foundational dimensions of valuing the worth and uniqueness of each individual and preserving the integrity of both the family and nurse. Carper’s (1999) patterns of empirical, aesthetic, personal, and ethical knowing are all embedded in Davies and Oberle’s conceptualization of HPC nursing practice.

Is there consensus on the appropriate content areas for HPC education? Zurmehly’s (2007) study on the role of community health nursing and Davis and Oberle’s (1990) theoretical model of the supportive role of the HPC nurse suggest some of the knowledge necessary for new community HPC nurses to assume their responsibilities. As previously discussed, this includes the need to practice autonomously and a strong foundation in caring for families. The participants in Zurmehly’s study also identify good patient and family teaching skills, acceptance for the autonomy of the patient and family, and proficiency using documentation and community resources. Specific to the HPC role, learning needs include proficiency in controlling pain and other symptoms, knowledge of commonly used medications, how to access HPC resources, working as part of a team, in depth understanding of spirituality, and ability to talk comfortably about end-of-life issues (Davis and Oberle). Education programs evaluated in the literature usually contain content on symptom control, psychosocial care, grief and bereavement, ethical issues, research, goals of end-of-life care, communication techniques, spirituality, HPC resources, culture, cancer treatments, team development, and coordinating care (Hughes, Parker, Payne, Ingleton, & Noble, 2006; Kenney, 2003; McClement et al., 2005; Thulesius, Petersson, Petersson, & Hakansson, 2002). Although no program included information about all of these subjects, the content appears to be consistent in most instances. The literature mentioned in this paragraph reflects the content of the Canadian Hospice Palliative Care Association Nursing

Standards of Practice (2002) and the work begun by the Fraser Health Authority HPC Program to develop a professional development pathway for nurses (2008).

Educators and employers want to know the best way to teach a certain content area to ensure value and effective translation of learning into practice. Most of the studies support palliative care education as effective in changing attitudes, increasing confidence, and increasing participants' knowledge base in HPC practice (Duke & Appleton, 2000; Hughes et al., 2006; Kenney, 2003; McClement et al., 2005; Wessel & Rutledge, 2005). Because these studies do not address the effectiveness of individual methods, it was not possible to state what methodologies are more effective for learning HPC nursing. Bugge and Higginson's (2006) systematic review of palliative care education was unable to find studies providing evidence of factors influencing HPC education. Their review of studies of adult education in informal health care settings supported a multifactoral approach to methodology, information presented in real life contexts, and learning tailored to individual needs. The most commonly identified educational methods found in the literature were: reflection; small group activities; problem based learning; case studies; and experiential learning. Learning approaches were often referred to as learner-centered. Three studies recognized the benefits of a clinical component for learning (Kenny; McClement et al.; Wessel & Rutledge).

Evaluation of HPC education program outcomes was found to be a frequent topic in the literature. In an era of evidence based practice and fiscal responsibility, employers need to know they are getting value for money spent on staff education. That much education focused research is of an evaluative nature speaks to the importance of evaluation in educational practice. Demonstrating the effectiveness of educational efforts on nursing practice is challenging. Rigorous studies supporting direct conclusions that link particular educational offerings to effective nursing practice outcomes require controlled studies and highly specific interventions. This type of research is often not feasible, financially or methodologically, in this setting. None of the studies' authors were able to demonstrate that their education program made a difference to nursing practice except by self report. In addition, each study measured different variables to evaluate their program: anxiety, knowledge of family systems, knowledge of pharmacology and symptom management, and attitudes. This variety makes comparing the effectiveness of each program challenging, emphasizing the need to clearly state the objectives of the education program for evaluative purposes.

Role Transitions

New orientees to HPC community nursing practice are a diverse group. Historically, recent acute care experience was a requirement of the job. Current nursing workforce shortages have compelled employers to hire new nursing graduates to Home Health and an employed student nurse program has been initiated in FHA including HCN. Occasionally, new HCN have a specific interest and experience in palliative care. Each learner will have distinctive learning needs to achieve role competency.

Some unique role characteristics of the nurse in HPC and community nursing are identified in the reviewed literature. Davies and Oberle's (1990) descriptive study of an expert palliative care nurse developed into a model of what the authors describe as the supportive role of the nurse. This role contrasts the traditional therapeutic nursing role practiced in many acute care settings. "The therapeutic role is associated with active medical treatment and aimed at restoration of the patient to health; whereas, the supportive role is that set of behaviours aimed at caring for the patient, supporting independent functioning, and easing pain and discomfort"

(Davies & Oberle, 1990, p.87). As many new nurses come to community practice from acute care settings, this may represent a significant role shift in attitude and knowledge.

This supportive role exists within the distinct environment of community practice where many of the roles fulfilled by the nurse in acute care settings are transmitted to family caregivers. The time required for developing and maintaining relationships with the family as well as the blending of boundaries between the nurse and family was noted in the literature (Zurmehly, 2007). Carr (2004) discusses the impact of the family in clinical decision making for community nurses that she labels "triadic collaborative decision-making" where decisions are made within the nurse-carer-client triad. "The informal carer figures significantly in the home setting and is an integral aspect of the decision-making process" (p. 855). New HC nurses learn to work within a changed balance of power, negotiating the nursing role within the family structure which is unique to each situation. Davis and Oberle (1990) name "preserving own integrity", for example by setting limits and self reflection, as a dimension of the supportive nursing role with families in HPC practice. In community and HPC nursing, individual nurses often work intimately with families over extended time periods and family members can become reliant on the nurse for emotional support. Nurses themselves may begin to rely on families for emotional or social meaning in their lives. Nurses new to both HPC and community practice may be especially vulnerable and will need support as they transition into this role.

The emphasis on autonomous practice was also identified by Zurmehly (2007) as a component of the community nursing role. "The themes that were associated with autonomy included independence, confidence, competence, being alone, and being responsible. Autonomy included the freedom to make decisions based on clinical management and nursing judgement" (p. 165). In the community, HPC make daily decisions about visit frequency, amounts of home support services, and overseeing a complex plan of care within a context of uncertainty. Several evaluative studies of HPC education programs identify goals associated with developing autonomous practice (Hughes et al., 2006; Thulesius et al., 2002; Wessel & Rutledge, 2005). Education is seen as increasing the confidence, knowledge, and critical thinking skills necessary to practice independently and make appropriate clinical decisions.

The role transition to community and HPC nursing involves developing attitudes that enable nurses to support dying patients and their families/caregivers. “[T]he extent to which caregivers have dealt with death influences how well they relate to dying patients” (Wessel & Rutledge, 2005, p. 213). Connecting with patients, authentic use of self, and helping the patient find meaning in their end of life journey are viewed as integral parts of the HPC nursing role (Davies & Oberle, 1990). Davies and Oberle recognize that many domains of the HPC supportive role are attitudinal such as valuing, “an attitude or mind-set that provides a contextual base for all the nurse’s activities” (p. 88). Several studies identify the need for education that changes nurses’ attitudes towards death and dying (Hughes et al., 2006; McClement et al., 2005; Thulesius et al., 2002; Wessel & Rutledge, 2005). All studies were able to demonstrate improvement in attitude through their educational programs which is assumed will translate into improved clinical practice. Wessel and Rutledge (2005) recommend “educational efforts need to include an assessment of participants’ attitudes toward death and attitudes toward caring for the dying” (p. 217).

Pedagogical Approaches

In contrast with traditional methods of teaching that tend to promote passive, rote transmission of empirical nursing knowledge; the more subjective and relational components of HPC nursing require approaches to teaching that promote active learning, understanding of context, reflection, interpretation, and critical thinking (Hartrick Doane, 2002; Young & Maxwell, 2007). During the orientation process, learning opportunities primarily exist within the practice environment of the institution, in this example the community Health organization. With these ideas in mind, I have reviewed literature about active learning concepts including development of critical thinking skills, self directed learning, and reflective practice. Acknowledging the limited resources including time, facilitator support, and literature available to orientees also influences the selected pedagogical approach. Specific propositional knowledge is also required for safe and efficient practice within the healthcare organization. The orientees will have varied preferred learning styles and prior learning experiences. A pragmatic outlook has led me to consider Experiential Learning and competency frameworks as theoretical foundations for this orientation curriculum.

Experiential Learning

Experiential learning is based on a constructivist educational philosophy where learning is seen as an active process of constructing versus acquiring knowledge (Cronin & Connolly, 2007). Benner's (1984) study of novice to expert nurses suggests that nurses' understanding and skill level transforms with years of experience practicing nursing. This learning can exist on both an individual and social level. "Experience is the foundation of and stimulus for learning; learners actively learn, in a holistic way, which is socially and culturally constructed and influenced by the socio-emotional context in which it occurs" (Fowler, 2008). Because nursing is a profession, learners must apply theoretical knowledge to varied and complex practice situations that require creative application of previously held knowledge. Experiential learning theory extends beyond direct transmission of knowledge and skill from experienced to novice practitioner. Learners reflect critically on meaningful experiences, and use critical thinking skills to act in complex clinical situations (Maudsley & Strivens, 2000). Thus, the opportunity exists for new HPC community nurses to learn through practice, but educators need to support reflective and critical thinking skill development for experiential learning to take place.

The concept of reflection on experience resulting in learning originated with Dewey and was further developed by Schon and other Experiential Learning theorists (Fowler, 2008). Reflection is usually triggered when an experience falls outside of our previous experience or differs from learned theories. “Reflective thinking is metacognition or a level of consciousness that exists through executive cognitive control and self-communication about experiences” (Kuiper & Pesut, 2004). Reflection is an active, purposeful activity that can include reflecting on our assumptions, prior understanding and experiences, and emotional reactions. Ruth-Shad’s (2003) review of nursing literature on reflection acknowledges that many researchers have questioned the effectiveness of reflection, however other studies have suggested reflection can be effective. Positive outcomes of reflective practice identified in the literature include integration of theory into practice, acceptance of professional responsibility, enhanced critical thinking, greater self-awareness and empowerment. Reflection is a learned skill that develops over time and requires skilful support from educators to be successful.

Reflection is also significant in critical thinking theory. “Reflective practice unites discussion of critical thinking with experiential learning” (Maudsley & Strivens, 2000). Tanner’s Clinical Judgment Model (2006), created through literature synthesis, illustrates how nurses make clinical decisions through interpretation of contextual information and reflection that occurs both during and after a clinical experience. Tanner’s interpretation of critical decision making in nursing acknowledges the profound impact of contextual elements in clinical practice to nursing actions and the value of tacit and personal knowledge that nurses bring to the decision making process. The crucial need for community nurses to practice autonomously accentuates the need for educators to support development of critical thinking skills for orientees.

Competencies

Competencies are a “complex set of behaviours built on the components of knowledge, skills, attitudes and personal ability” (Carraccio, Wolfsthal, Englander, Ferentz, & Martin, 2002). Some of the benefits of competency based education identified by these authors include its suitability to self directed adult learners, its learner centered focus, and its emphasis on outcomes and application of knowledge. Competencies can be geared towards different levels of experience such as described by Benner’s levels of novice to expert (Becker, 2007b). Competencies are also recognized as a flexible organizational framework for ordering knowledge in curriculum development theory (Iwasiw, Goldenberg, & Andrusyszyn, 2005). Usually, competencies are evaluated using real world observation, comparing performance to norms or preselected theoretical criteria (Ludlow, Gaudine, & Jacobs, 2007).

A competency paradigm is ideal for self-directed adult learners who can assume responsibility for learning (Carraccio et al.). Self directed learning is generally based on adult education theory and refers to learners identifying their own learning needs, setting goals, identifying learning resources and finally implementing and evaluating learning (O’Shea, 2003). Self directed learning as an educational method has been theorized to foster life-long learning, however it assumes that learners are effective at self assessment and external guidance is required for learning to be effective in unfamiliar areas of practice (Greveson & Spencer, 2005). Using a competency framework for nursing orientation activities supports orientees to develop an individualized learning plan with identified goals that is founded on their previous knowledge and experience. Professional learning, particularly within an institution, differs from traditional learning in that there are preset, specific learning outcomes. Competencies support educators to use orientation time efficiently by focussing learning activities towards gaps in knowledge or performance, and assists in the evaluation of learning. For the organization, orientation programs that incorporate self study have been found to use less staff time than traditional educator lead programs (Connelly & Hoffart, 1998).

At first glance, it seems unlikely that competency would be the ideal framework to facilitate learning in HPC. Competencies by their very nature break learning and performance into a series of measurable steps, contrary to the holistic approach desired in HPC practice (Becker, 2007b). Using competencies to measure technical skills in nursing can be quite straight forward; on the other hand, measuring outcomes such as the critical thinking and interpersonal skills necessary for HPC nursing practice is more complex. If we look more closely at a competency based approach to education, however, benefits and applicability for HPC education can be identified. Competency frameworks evolved in part from theories of educational taxonomies (Becker). The original, Bloom's Taxonomy was designed as a framework for categorizing educational objectives in 1956 (Anderson & Krathwohl, 2001). The taxonomies have progressed from the cognitive domain to include affective and psychomotor domains. Lenburg evolved Bloom's Taxonomy into nursing education, defining eight core nursing practice competencies: assessment; communication, critical thinking; human caring and relational skills; management, leadership; teaching; and knowledge integration (Ludlow et al., 2007). Becker (2007a) describes six domains of competence in nursing (and nursing education): (a) knowledge, (b) technical, (c) analytical, (d) ethical and behavioural, (e) affective and (f) interpersonal. In these expanded formats, a competency framework can encompass the objectives for learning the various domains of HPC nursing knowledge. Competencies have potential to help novice nurses understand the requisite components of HPC nursing through clearly articulating the objectives. Developing competencies and indicators that reflect the various domains of HPC nursing practice and knowledge was a challenging component of the curriculum development process.

In Canada and elsewhere, HPC educators have written competencies, standards and criteria for HPC education (Canadian Hospice Palliative Care Association, 2002). The organizing and conceptual framework for the Canadian standards is the Supportive Care Model (Davies & Oberle, 1990). The Canadian Nurses Association (2007) has articulated a list of competencies for certification in HPC nursing through examination. The competencies are categorized under the topics: care of the person and family; pain management; other symptom management; end of life planning; loss, grief and bereavement support; interdisciplinary/collaborative practice; education; and professional issues and advocacy. Our regional HPC program has recently developed a draft of a professional development pathway for acute care HPC nurses based on these competencies (Fraser Health Hospice Palliative Care Program, 2008) and there is program support to standardize this format for all areas of HPC practice currently under discussion. These documents supported the decision for the use of competencies as a framework for progression and evaluation of learning and provide guidance for development of the competency statements.

Curriculum Approach

Examination of the literature within the context of curriculum development provided structure for the methodology. Initially, philosophical approaches to the curriculum are identified and embedded throughout the curriculum content (Iwasiw et al., 2005). I have chosen to identify a theoretical approach to nursing practice (the supportive role of the HPC nurse as described by

Davies and Oberle, 1990) as well as a pedagogical foundation for the curriculum (experiential learning) as described in the literature review. The purpose and goals of the orientation curriculum are outlined in the Curriculum Blueprint (see Appendix A). The seven competencies as outlined in the program goals are taken from the Canadian Nurses Association (2007) list of competencies for HPC nursing certification and have been adapted for beginning level community HPC nursing practice. The outcome indicators indicating competency in each dimension of practice are developed from the Canadian Nurses Association document and the Fraser Health Hospice Palliative Care Program (2008) Professional Development Pathway. Both of these documents have been included as appendices to this proposal.

The curriculum is enacted in seven modules, one for each competency. Completion of the outcome indicators for each competency and creation of a learning plan will enable learners to be self directed in setting goals and focus their orientation activities within a learning environment of clearly established learning outcomes. The modules provide content on HPC nursing practice as described in the literature review, information on regional policies and procedures, and direct learners to readings accessed in library resources that are available in all work sites. Facilitation of learning would be provided by HPC clinical resource nurses and experienced nurse mentors. Learning activities are designed to incorporate experiential learning and promote reflection.

This project is not presented as an academic exercise but as a pragmatic combination of on-the-job learning and educational theory. Although not part of this academic submission, I anticipate there will be consideration of implementing the curriculum in the health region. To assist in this process, suggestions for the implementation and evaluation process are included in the Curriculum Blueprint (Appendix A). Appendixes B through I demonstrate the enactment of my project, the development of a HPC curriculum for HCN.

APPENDIX A

Curriculum Blueprint

An Introduction to Hospice Palliative Care for Home Care Nurses

Program Description

The purpose of this course is to introduce orientees to Home Care Nursing to the multidimensional practice of Hospice Palliative Care (HPC) Nursing within the Fraser Health Home Health environment. Students will develop basic level competencies that enable safe autonomous practice guided by the framework of the supportive role of the HPC nurse as described by Davies and Oberle (1990). The program is designed to be completed within the first three months of employment for full-time employees.

Program Goals

Through completion of the orientation program, orientees will be prepared to meet the following goals:

1. Provide nursing care that values and empowers patients and families living with life threatening illness through the nurse-patient relationship and the process of connecting.
2. Assess pain using a "total pain" perspective and develop a plan to manage pain in collaboration with the interdisciplinary team.
3. Assess common symptoms of advanced disease including dyspnea, nausea, constipation and delirium. Develop a plan to manage symptoms in collaboration with the interdisciplinary team.
4. Assist the patient and family to prepare for death. Support and educate families to care for patients dying at home.
5. Assist patients and families to anticipate and cope with their unique reactions to loss and death.
6. Communicate and collaborate with the interdisciplinary team including the patient and family to define goals and plan care.
7. Collaborate with the person, family and interdisciplinary team to address ethical issues related to End-of-life care.
8. Demonstrate an understanding of the concept of culture and its application to end-of-life nursing practice.
9. Identify own connection to death and dying and how it influences practice.

APPENDIX A

Approaches to Learning Activities

Learning activities are designed from an Experiential Learning theoretical perspective, emphasizing reflection and critical thinking as key foundational components of this approach to learning. Learning experiences are facilitated within a mentor relationship with an experienced peer. Self directed learning is encouraged through self assessment, development of a Personal Learning Plan and the competency and outcome indicators framework.

Learning Activities Using Previously Developed Fraser Health Resources

- Pain Self Learning Module
- Online Pain Module
- HPC Basic Education Day
- HPC Enhanced Education Day

Proposed Learning Activities Related to Areas of Focus

- Identifying components of HPC nursing practice through a chart review
- Write a nursing care plan after a facilitated home visit
- Complete a case study on symptom management
- Reflect on end-of-life care after a Hospice Residence tour
- Participate in collaborative interdisciplinary practice by presenting a patient at interdisciplinary rounds
- Plan a bereavement visit
- Reflect on an experienced ethical dilemma
- Contemplate personal attitudes toward death and dying through journaling.

Suggestions for Implementation

Successful implementation of the curriculum in the health authority depends upon skilled facilitators to guide the learning process. The HPC Clinical Nurse Specialists and Clinical Resource Nurses should identify a core group of experienced mentors available to support orientees. Ideally, an education and support process for mentors would be developed beyond the general mentorship training already in place.

Evaluation and quality improvement should be considered prior to implementation. The competency framework has potential for evaluation of learning. An evaluation tool for both learners and mentors could be designed to collect qualitative data. Some HPC clinical resource nurses have expressed an interest to trial the curriculum in their communities and participating in the evaluation process.

The HPC Education Committee is encouraged to develop a regional orientation day to complement the self-directed modules and provide an opportunity for social learning. A regional program would maximize use of interdisciplinary team resources and should emphasize the unique needs of community HPC nursing such as supporting caregivers/resource allocation.

APPENDIX B

Welcome to Community Hospice Palliative Care Nursing in Fraser Health!

This orientation guidebook is intended to support your journey through orientation. Every new Home Care Nurse comes to orientation with different learning needs. Some nurses using this guide may have practiced HPC community nursing with a different agency and need to learn about Fraser Health specific policies and local community resources. Perhaps you have cared for patients and families in an acute care palliative unit and have never worked in a community setting. Maybe you are a recent graduate feeling overwhelmed with everything you need to learn in your first position. Wherever you are starting from, this guide will help you develop a learning plan to match your needs.

This guidebook is designed to encourage self-directed learning. In each module, you will have the opportunity to assess your learning needs and develop your own learning plan with the support of a mentor. By the end of your orientation, you should feel confident and prepared to practice independently with patients and families with predictable outcomes.

For most nurses working full time, the orientation period will be three months. Depending on your previous experience, workplace requirements, hours worked and other factors, the orientation period can be extended. We suggest establishing a time frame with your supervisor or the HPC CRN before you begin. Continue to review this goal as you move through the orientation period with your mentor or supervisor.

This binder belongs to you and is a ‘work in progress’. Orientation is only the beginning of your journey in HPC nursing! When you complete the orientation, you will develop a learning plan to guide you as you begin independent practice. As you continue learning from experiences with patients and families, peers, HPC specialists, courses, conferences and readings, use this binder to store information and keep a record of your journey.

Enjoy the trip!

Using the Orientation Guidebook

The structure for this guidebook originates with the Canadian Nurse's Association List of Competencies for Hospice Palliative Care Nurses and the Canadian Hospice Palliative Care Association Nursing Standards of Practice. You will hear more about these documents in Module 1. Each orientation module is developed from a particular competency:

Module 1: Care of the Person and Family

Module 2: Pain Management

Module 3: Management of Other Symptoms

Module 4: End of Life Planning/Dying and Death Management

Module 5: Loss, Grief, and Bereavement Support

Module 6: Interdisciplinary Collaborative Practice

Module 7: Professional Issues and Advocacy.

Each Module has a similar structure:

1. **Outcome Indicators Checklist**: Outlines the outcomes that need to be met to complete the module. Achieving these outcomes will indicate that you have met the module competency at the level of a beginning nurse capable of independent practice. You can be creative with the evidence for meeting each competency. Evidence might be a reflection, a discussion with your mentor, compiling a list or completing a reading, chart documentation etc.

2. **Self-Study Activities:** These activities are designed to give you the background information you would need to meet the competency. These activities include readings from standard HPC textbooks that exist in each Home Health office.

3. **Practice Activities:** These activities are designed for you to apply the knowledge from the self-study activities in your work setting. Depending on your experience in the competency, you and your mentor may jointly decide to begin with an observational experience, with a supervised experience or independently.

4. **Learning Plan:** Start to develop your learning plan as you complete your initial outcome inventory in each module. The learning plan will help you focus your time and get the most out of your orientation experience. It also helps your mentor support your learning needs. Your learning plan will be a "work in process" as you move through the orientation and into your new position.

5. **Module Wrap Up:** Taking time out to reflect as you progress through orientation will help you make meaning of your experiences. It is also a part of self-care; taking an emotional 'pulse' of how you are doing.

How to Get the Most out of the Orientation Guidebook

- Work through the modules in the order they appear. Each module builds in some way on learning in previous modules.

- Every Home Health Office has a standard library of HPC resource materials that you will need to complete the learning activities. Before you begin, locate the following resources in your office:

  Ferrell, B.R. & Coyle, N. (2006). *Textbook of palliative nursing.* New York: Oxford University Press.

  Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Baltimore, MD: Health Professions Press.

  Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).* Victoria, B.C.: Victoria Hospice Society.

  Fraser Health Hospice Palliative Care Program (2006). *Symptom Management Guidelines.* The Guidelines are available in hard copy format in your office or available online @ http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliative_Care/Pages/SymptomGuidelines.aspx

- It's helpful to have access to the internet for additional resources. You can use a Fraser Health worksite computer using your Windows username and password.

- Complete the Outcome Indicators Checklist **prior to starting the module** to identify your learning needs. You will **complete the Outcome Inventory again at the end of the module** to evaluate your progress and demonstrate that you have met that particular competency.

- Begin with the independent learning activities at the start of the module focusing on the learning needs you identified in the Outcome Indicators Checklist.

- Write a draft of your learning plan for each module prior to meeting with your mentor to plan the practice experiences. This will help both of you to plan the most effective experience to meet your learning needs.

- Schedule time after your practice experiences to answer questions, reflect on the experience with your mentor and identify further learning needs. Discuss with your mentor/Palliative CRN how to schedule the time required for learning in your day.

- When you and your mentor agree that you have successfully finished the orientation activities, schedule a time to meet with your mentor and supervisor to review your progress with the orientation competencies and finalize your plan for future learning.

Working with a Mentor

As a new community nurse, it is not uncommon to feel isolated at times. Unlike acute care practice, your colleagues are not readily available for support and information. Your mentor will help you to learn common practices and routines that are specific to your work site. He or she is also a resource person and guide during your orientation. Many of the learning activities in this module involve experiences with patients and families that you will carry out with your mentor.

Depending on your community, you may already have a relationship with a mentor from Home Care Nursing orientation activities. In other areas, the HPC Clinical Resource Nurse (CRN) may step into the mentor role from time to time. As you begin your orientation to HPC, spend a few moments connecting with your mentor. The questions below will help you get to know each other and clarify your expectations:

Mentor's Name: ____

Telephone : __________________________ Pager: ______________________

Email: ____

- What are my previous experiences with mentorship/being a mentor?

- What worked well and what was challenging in previous mentoring experiences?

- How do I learn best?

- How will we give each other feedback?

- How frequently will we meet?

- How will we handle urgent/emergency situations?

- If my mentor is not available, what is the back-up plan?

*Adapted from “Mentorship: Planning Together” FH Mentorship Program (2007)

Learning from Experience

Although we learn many important things from books, lectures and theories, much of what we learn in nursing (and life!) comes through our experiences. Patricia Benner’s (1984) famous study of novice to expert nursing knowledge suggests that experience helps nurses to solve clinical problems. During orientation, you will have many opportunities to try out new ideas in practice with the guidance and support of your mentor. Every patient and family’s experience with life-threatening illness will be unique. Taking the time to reflect (on your own and with your mentor) about your experience will help you develop clinical judgement.

Clinical Judgement and Reflection

Tanner (2006) describes clinical judgement as a cycle involving:

- *Noticing*-deciding what information is relevant in a clinical situation based on our knowledge of theory and knowledge of the individual patient
- *Interpreting*-generating ideas or theories about what are the possible actions
- *Responding*- deciding on a course of action or no action
- *Reflecting in action*- adjusting nursing actions because of patient responses
- *Reflecting on action*- reviewing and evaluating the process.

Reflection is key to both learning from experience and developing sound clinical judgement. Read the following short section to learn more about reflection:

⇨ Fraser Health Symptom Guidelines: Psychosocial Care
Read the section on Reflective Practice on Page 4.

HPC Basic and Enhanced Education Days

As part of your orientation, you will attend two full day programs on HPC nursing practice. At these workshops you will have the opportunity to network with nurses from all areas of HPC practice. The workshops provide additional content about the Fraser Health HPC Program, symptom management, HPC nursing practice, communication skills and working with families. The workshops include small group work and case studies.

Check with your Team Leader or HPC CRN to register for these workshops. You can self register by downloading the registration form from the Fraser Health Intranet under Education. Both workshops are offered monthly at different locations in the region.

Personal Learning Plan

Name: ________________________________ **Date:** ____________

This learning plan is a work in progress. Add to it as you work through the modules. You will identify learning needs completing the competency assessments, through personal reflections, feedback from your Mentor and Learning Activities. When you complete your orientation period, update and review the learning plan with your mentor, CRN or Team Leader.

Identified Learning Need	Goal	Plan/Activities	Time Line	Outcome/Evidence	Date

Personal Learning Plan
Page 2

Name: ______________________________ **Date:** ______________

Identified Learning Need	Goal	Plan/Activities	Time Line	Outcome/Evidence	Date

APPENDIX C

Module 1:

Care of the Person and Family

Module Contents:

Care of the Patient and Family: Outcome Indicators Checklist

The Home Care Nurse provides nursing care that values and empowers patients and families living with life threatening illness.

Pre=self-assessment prior to completing module

Post=review with mentor prior to signing off

Key

N=No Experience

S=With Support

C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Describes HPC philosophy and program to patients and families including role of the HCN				
Initiates discussions with patients and families about: -diagnosis/prognosis -goals of care -dying and death				
Demonstrates effective communication skills: -Active Listening -Presence -Empathy -Reflection -Facilitation				
Identifies factors contributing to cultural identity				
Demonstrates acceptance and valuing of beliefs that may differ from your own				
Recognizes personal attitudes, feelings, and values regarding death, culture, spirituality				

Indicator	Pre	Post	Evidence	Date/Initial
Demonstrates the value of self by practicing self care				
Provides teaching to patients and families that respects capacity and readiness concerning: -what to expect as disease progresses -resources and services -treatment benefits and burdens -physical/emotional/spiritual support				
Documents Nursing Assessment using the Data Base and Flow Sheet				
Assesses and documents PPS				
Creates a Plan of Care in collaboration with the person and family				
Documents and revises Care Plan using FH form				
Justifies scheduling of HCN visits using established criteria				
Completes ‘Palliative Clients After Hours Report’ and enters data on Meditech				

*Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

Hospice Palliative Care: A Definition

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

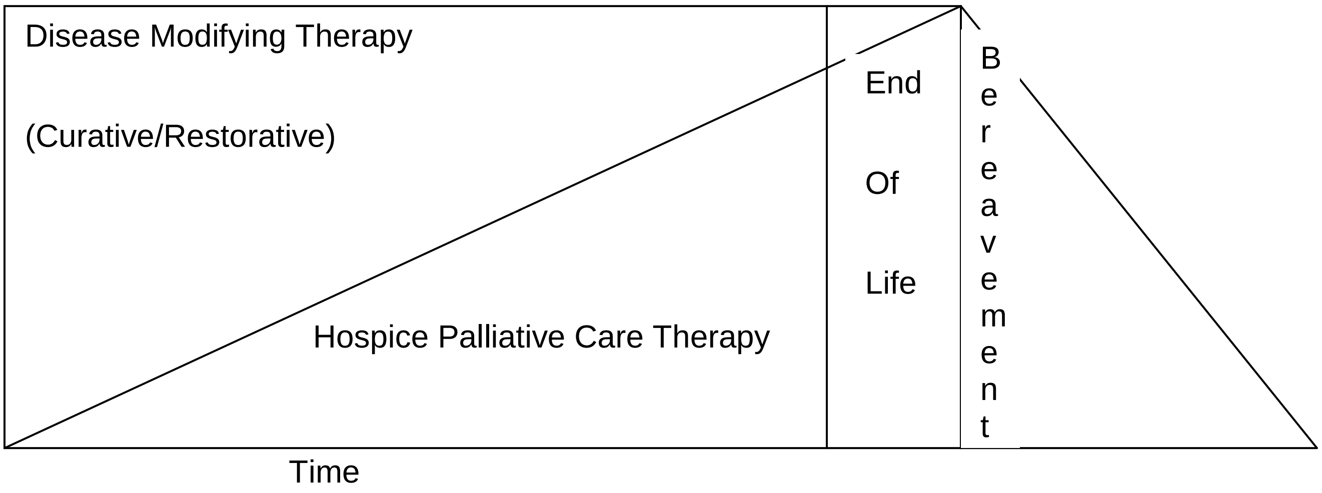
Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.” (2009)

Look carefully at this definition; it is important that we have a clear understanding of palliative care so we can explain it to our patients and their families.

What stands out for you in this definition? Does it change any assumptions about palliative care that you previously had?

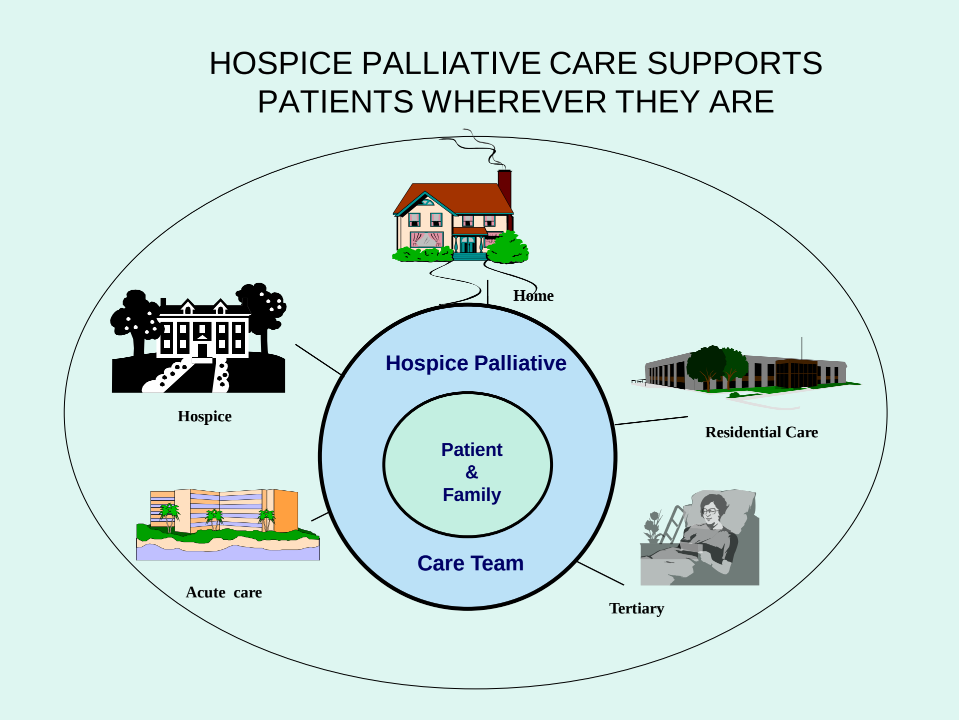
Many people, including health care professionals, misunderstand palliative care to begin after all therapies designed to control diseases or prolong life have stopped.



This model of palliative care from the Canadian Hospice Palliative Care Association (2002b) visually demonstrates that palliative, supportive therapies to manage symptoms and improve quality of life can begin early on in the treatment of most chronic or life threatening illnesses. In the model, the diagonal line between curative and palliative care is represented as a straight line. Of course, in reality the line twists and curves depending on the patients' needs and goals as their illness progresses.

HPC in Fraser Health

Another common misconception about palliative care is that it is a specific unit in a hospital or hospice. In Fraser Health, patients are registered with the HPC Program in their home community. Services follow the patient and family if they move into a different care location such as acute care, residential or hospice care.



In Fraser Health, there is no strict prognostic criteria for registration with the HPC Program. Patients can be registered on the HPC Program and receive HCN services when:

- they have a life threatening illness with an anticipated prognosis of weeks to months (rather than years)
- the **primary** intent of treatment is improved quality of life not **cure** of the disease
- they continue to receive disease modifying therapies
- the patient and/or family agree to the referral.

Every year in Fraser Health, approximately 3600 patients are registered with the HPC program. Most of these patients and families will receive HPC services at home from Home Care Nursing at some point in their illness.

<u>BC NurseLine Palliative Response:</u>

HCN services and most family physicians are only available during the day and early evening. The HPC Program has a relationship with the BC NurseLine to provide overnight telephone support for Fraser Health patients who are registered with the HPC program. On or near the first visit, families are provided with a phone number that is unique to FH HPC patients. Special HPC protocols were designed to support the BC

NurseLine nurses to provide telephone support. For more complex situations, one of the HPC CRN’s provides backup support for families.

HPC services are also provided in:

Hospice Residences

Hospices are located in most communities. They provide care in the final three months of life for patients who can no longer be supported at home or who do not wish to die at home. Care is focused on comfort, support for patient and family, and symptom management. Disease modifying treatments and diagnostic investigations are not available in hospice. The BC No Cardiopulmonary Resuscitation form must be completed prior to admission.

⇨ Read the patient information brochure on Fraser Health Hospice Residences located in the resources section of this module. Identify the kinds of care that can be provided in Hospice, the cost for Hospice care and where your local hospice is located.

Residential Care facilities provide end-of-life care for patients with a prognosis of **longer than** 3 months. The HPC Consult Team in the facility’s community is available to provide consultation support. HPC patients living at home who are considering Residential Care need to be referred to the Long Term Care Case Manager for assessment.

Acute Care admission may be appropriate for patients who require tests, surgery or other treatments. Many HPC community referrals come from Acute Care facilities. HPC Consult Team members are available to see patients in acute care, if needed.

Tertiary Hospice Palliative Care Units (THPCU) are located in Burnaby, Abbotsford and Surrey Hospitals. Patients are admitted to assess and treat:

-Difficult pain syndromes

-Complex physical symptoms

-Complex psychological/spiritual/social issues

-Family/Caregiver distress

-Potential to achieve a higher level of functioning and quality of life

-Complex care planning issues.

The goal for the THPCU’s is to provide specialized, skilled assessment and intervention in a supportive acute care environment. THPCU’s stabilize patients so they may return home or go to a hospice or residential care setting, if home is no longer an option. Patients must be registered with the HPC program but a DNR order is not required. If you are wondering if THPCU might be appropriate for one of your patients, speak with his/her GP or a member of your HPC consult team.

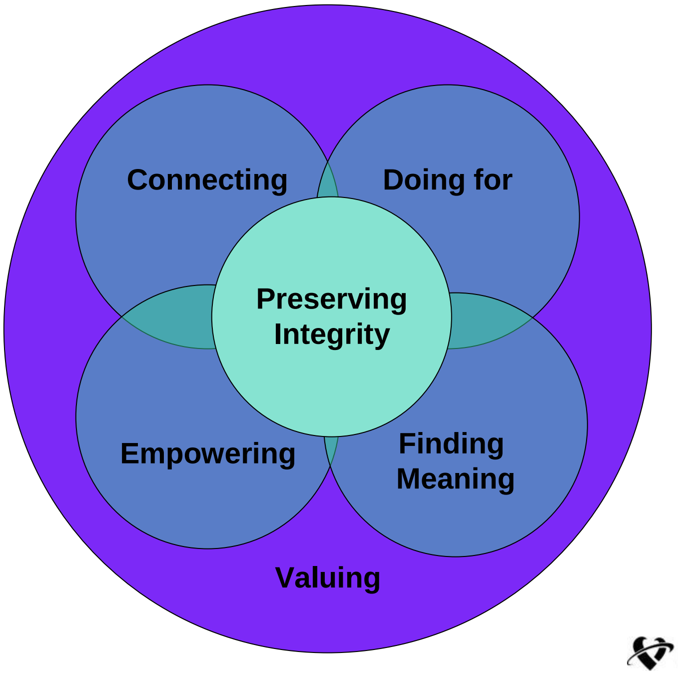
Questions for Reflection...

Why would you suggest to a patient that he or she consider Hospice care instead of a THPCU?

How might you respond to a patient or family who is requesting to die in an acute care environment?

Hospice Palliative Care Nursing

For patients and families living at home, the Home Care Nurse (HCN) is often the most frequent visitor on the care team. “Home care nurses are the healthcare professionals spending the most time in the home, and therefore having the greatest opportunity to affect end-of-life care” (Ferrell & Borneman, 2002, p. 21). HPC nursing practice in Canada is supported by the Hospice Palliative Care Nursing Standards of Practice (2002a). These standards are founded on the Supportive Care Nursing Model developed by Canadian nurses Betty Davies and Kathleen Oberle (Davies & Oberle, 1990).



fraserhealth

[

At this time, take a moment to consider the six dimensions of the Supportive Care Model.

Valuing

"The HPC nurse believes in the intrinsic worth of others, the value of life and that death is a natural process. Valuing is primarily an attitude rather than an action."

Connecting

"The HPC nurse establishes a therapeutic connection with the person and their family through making, sustaining and closing the relationship."

Empowering

"The components of empowering include assessing the family, assessing and supporting the person and family's coping style, assisting with decision making and supporting choices made by the family, assisting the family to deal with ethical dilemmas, allowing the family to vent and defuse frustrations, assisting in healing relationships, and giving information on all aspects of care."

Doing For

"The goal of 'doing for' is to free up the person and family to focus energy in the areas that are most empowering for them."

Finding Meaning

"Finding meaning involves focussing on living and making the best of the situation by offering hope, as well as acknowledging and talking about death."

Preserving Integrity

"For the nurse, this dimension includes the ability to maintain self-worth and self-esteem in order to continue effective functioning."

These quotations and more information about the model and the Standards of Practice can be found at:

www.chpca.net/resource_doc_library/Hospice_Palliative_Care_Nursing_Standards_of_Practice.PDF.

Communication in HPC

Many, if not most, novice HPC nurses have some anxiety about saying the wrong thing or not knowing what to say to a patient or family. This anxiety also happens to experienced HPC practitioners who are anticipating a difficult conversation. It helps to remember communication needs to be more about listening than speaking; giving patients and families an opportunity to tell their story. Forming a connection with patients and families is a process that develops over time but is the backbone of HPC nursing practice.

A second challenge often faced by new HPC nurses is focusing on the ‘doing’ part of nursing-completing a form, changing a dressing, giving information. Nurses can create distance by focusing on physical tasks (Barnard, Hollingum, & Hartfiel, 2006). Often just as important is the ‘being with’ part of nursing. ‘Being with’ could mean listening, accepting difficult emotions, listening to fears, being present and not feeling we have to have all the answers or be able to make things better. Although this sounds simple and straight forward, ‘being with’ patients who are dying requires maintaining an emotional connection that can be very difficult. We need to practice self care to continually establish relationships with people who are dying but at the same time maintain a sense of self and balance in our lives.

Facilitation is a communication skill that helps us assess patients needs, goals of care, and develop a plan of care that is tailored to patient’s needs and wishes (Lawton & Carroll, 2005). Facilitation can involve: following cues; progressing at the patient’s pace; asking open ended questions; affirming; summarizing; reflecting and clarifying. As trust develops, patients will feel able to ask more direct questions.

The following readings provide more in-depth information about communication and psychosocial assessment. You will also find many examples of questions that can help initiate difficult conversations or respond to patient concerns. Complete the optional readings if you identified communication skills as a learning need.

⇨ Fraser Health HPC Symptom Guidelines: Psychosocial Care
Pages 12-15.

Optional:

Ferrell, B.R. & Coyle, N. (2006). *Textbook of palliative nursing.*
Pages 70-73.
Table 4-6 on page 84 on “Questions to Facilitate the Goals and Focus of Care in the Last Phases of Life”.

Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*
Pages 85-90.

Questions for Reflection...

Reflect on an experience you have had with dying, either personally or professionally. Looking back, how did you learn and grow as a nurse? As a person? What was the most difficult or challenging part?

How would you describe the Hospice Palliative Care Program to patient or family member? Trying writing down what you might say to prepare yourself for a real situation.

As you read through the above sections, note any questions that you could see yourself using in a conversation with a patient or family member.

Culture and Diversity

Culture is another concept that extends across all of HPC nursing practice. We typically think of culture in terms of ethnicity. Often we as nurses only consider culture when we perceive it as separate from our own cultural or ethnic experiences. To learn more about considering culture in HPC nursing practice, read the following section from the Psychosocial Guideline:

⇨ Fraser Health Hospice Palliative Care Symptom Guidelines
Psychosocial Care: Understanding Culture on pages 10 and 11.

Reflecting on how culture affects patients' and families' experiences with death and dying and our own assumptions about culture is important in every clinical experience. If we learn to question our own biases and assumptions about culture and approach all families with an outlook of curiosity and respect for diversity, we will have made an important start to deliver culturally competent care.

Interpreters can be reserved in advance for home visits through Fraser Health language services. Contact information is available in the resources section of this module.

Questions for Reflection...

What is my Cultural Background? What factors contribute to my cultural identity? (e.g. religion, education, occupation, language etc).

What preconceived notions do I have about certain groups or cultures?

What do I believe causes good health? Illness?

Spirituality

Although we often think of spiritual care as the realm of a specific person, often a religious leader, spiritual care needs to be a part of day to day care for all HPC practitioners. Spirituality may include religious affiliations but also concerns what gives your life meaning and hope, personal integrity and values.

Questions for Reflection...

Many aspects of the Supportive Care Model (Davies & Oberle, 1990) *involve a spiritual component. At this time, take a second look at the model on page 6. In what way is spirituality reflected in the various dimensions of HPC nursing practice?*

Give an example of an open-ended question you might use to assess spirituality and spiritual needs.

Self Care

> Often, the very things that make hospice palliative care so rewarding make it difficult. Palliative care can be a source of great personal satisfaction and growth, yet it challenges professionals to face their own vulnerability and the fragility of life. (Cairns, Thompson, & Wainwright, 2003)

Read the following information about self care:

⇨ Fraser Health Hospice Palliative Care Symptom Management Guidelines: Psychosocial Care, Page 5 and the top of Page 6.

In the Supportive Care Model discussed earlier (Davies & Oberle, 1990), self care is a component of maintaining the integrity of the nurse. The three components of Preserving Own Integrity include: looking inward to reflect on what gives our lives meaning; valuing self and the work we do; and acknowledging our own reactions.

Palliative Performance Scale (PPS)

PPS measures functional performance status in 10% increments from healthy to death. The PPS is easy to use and non-invasive: you can calculate PPS from the data you collect in your regular nursing assessment. A copy of the PPS should be in each patient chart for easy reference.

As nurses, PPS can support our decisions to provide various services, for example:

-Hospice care is suggested for patients with a PPS of <50%

-Hospital bed rental is usually limited to patients with PPS <40%

-consider Home Support Services for PPS <60%.

PPS is also considered as part of an overall assessment in planning nursing care. For example, if a patient's PPS is changing quickly we want to know what is happening medically and from a psychosocial perspective. For more information about the PPS and psychosocial implications of PPS read:

⇨ Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Pages 26-34.

Question for Reflection....

As you complete your assessment during a nursing visit, you realize that the patient's PPS has declined from 50% to 40%. What are some of the possible implications for the patient, caregiver and care plan from both a physical and a psychosocial perspective?

Scheduling Home Care Nursing Visits

Deciding the frequency of home care nursing visits can be one of the most challenging decisions for new nurses. This is especially true in HPC practice because of the many complex and subtle factors influencing the assessment.

Change is expected for patients with advanced disease so regular visits are necessary even if they sometimes occur as telephone contact. Patients who are close to death at home, changing quickly or have unmanaged symptoms may require BID visits. Factors such as caregiver capacity, family resources, other team members involved, and complexity of the care plan affect decisions about nursing visits.

In the resource section, you will find a matrix with guidelines for scheduling visits. This guideline is to support your decision-making but is open for interpretation.

Making the Connection: Resources for Patients and Families

In this section, you will have the opportunity to look at some of the resources that have been developed by Fraser Heath and the Fraser Health HPC Program to support patients and families.

As we review the various materials, **take the time to locate them in your worksite**. Some Home Health offices have compiled all the resources into a resource binder which may be of assistance to you.

Review each document carefully.

You will need to introduce materials to patients and caregivers at the most appropriate time and explain the relevant content.

Care at Home Package

Intended to be given to each family on the first HPC home visit. Each HPC community has tailored this package to their own specific community needs. This Duo tang or binder contains pockets to store business cards and handouts so patients can keep all their information in one location. Patients can bring their binder or Duo tang to appointments. Inside the Care at Home Package you will find:

1) A Team Approach. Community specific brochure that explains HPC services and provides contact information for the local Hospice Society.
2) Medical and Nursing Contact Numbers. Gives specific hours and contacts for Home Care Nursing and the BC NurseLine palliative care specific phone support service. Make sure patients and caregivers are clear on how to receive 24hour supports. It is especially important to review the contact information as the patient's situation changes.
3) Palliative Support after Regular Home Care Hours. Optional information about contacting the BC NurseLine Palliative Response available in Chinese, Korean and Punjabi.
4) Home Medication List. Encourage patients to maintain this list. Most patients will need some assistance to get it started. Encourage them to have it available if they call for assistance or attend medical appointments.
5) Common Reactions when Coping with Serious Illness. Many of these suggestions also apply to professional caregivers!
6) EI Compassionate Care Benefits (Given out on a PRN basis in some communities). EI Compassionate Care Benefits provide financial support for caregivers to care for gravely ill family members in the last 6 months of their life. The definition of 'family member' is very flexible. There is a 2 week waiting period but the benefit can be shared among various family members. Find out more information online @ http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#proof
7) Making Informed Decisions About CPR (Given out on a PRN basis in some communities). Describes CPR and the benefits and burdens of the treatment.
8) No Cardiopulmonary Resuscitation. This triplicate form is produced by the BC Ministry of Health and is recognized by BC Ambulance as a physicians order authorizing DNR. See more information about this form under Advance Care Planning.

Questions for Reflection...

How would you present the Care at Home Package to a patient and family? Write down an example of what you might say.

What factors in your assessment would influence the way you present the Care at Home Package?

A Caregivers Guide: A Handbook about End-of-Life Care

This book is prepared by the Canadian Hospice Palliative Care Association. It provides medical and nursing information to support family caregivers. You are encouraged to offer it to all families, usually after you have developed a relationship to know how it might be received. Some families will want to read the book cover to cover while other families may decide they are not interested. The book also assumes a fairly high rate of literacy in English. It can be an excellent teaching resource for families if you highlight selected sections that are relevant at a particular time.

BC Palliative Care Benefits Program

This program is provided through the BC Ministry of Health to support persons with a life threatening illness to live at home. It provides financial coverage for medications, basic equipment and medical supplies. A criterion for coverage is a prognosis of 6 months or less. Patients who are receiving benefits for longer than 6 months should be reviewed by the HPC Team to determine if they are still appropriate.

Medications covered by the program include those used for symptom management. Some OTC medications are also covered (e.g. laxatives, ibuprofen) if the patient has a physician prescription. The patient will receive the medications at no charge direct from their community pharmacist. For a complete formulary of medications as well as more information about the program go online @

http://www.health.gov.bc.ca/pharme/outgoing/palliative_physguide.pdf.

Medical supplies are available in your health unit as standard ward stock and are normally delivered to the patient during a HCN visit. The most commonly used supplies tend to be wound care and incontinence products. Ask your HPC CRN or mentor if you are unsure of this procedure in your office.

Basic adaptive equipment can be loaned to patients who do not have other options. Patients who have third party medical coverage (for example Veteran’s Affairs, Extended Health coverage, WCB) need to explore these options first.

There are several forms that apply to this program:

- BC Palliative Benefits Patient Information Brochure. This may be included in the Care at Home package in some communities. It must be given to all patients/families prior to ordering any equipment.
- BC Palliative Care Benefits Program Application Form. This form needs to be signed by both the patient and a physician acknowledging a prognosis of less than 6 months. The completed form is faxed to the number at the top of the form.
- Standard Equipment Rental Order Form. The HPC program contracts equipment rental through medical supply companies. The fax order form

provides the medical supplier and contact numbers for your area. Home Care Nurses can order any equipment on the Standard form. A PT or OT referral may be helpful for more complex situations.

Phone **and** fax the equipment supplier to ensure the order is received.

Place a copy of the equipment rental form on the patients chart and give the original to the HPC Clerk.

When the client dies or is admitted to Hospice or Acute Care and not expected to return home it is very important that the vendor is notified to pick up the equipment. Ask your mentor or HPC CRN what is the procedure to ensure equipment is picked up in your office. There is a standard fax form to facilitate the pick up process.

- <u>Rehab-only Equipment Rental Order Form.</u> As above except the equipment specified on this form can only be ordered after an OT or PT consult. Copies of this form must also go on the patient's chart and to the HPC Clerk.

<u>Red Cross</u>. The Red Cross Society loans equipment for up to three months and may be a good option for simple equipment needs. Locate the Red Cross Equipment order form and list of depot locations in your community.

Nursing Documentation

This section assumes that you have been oriented to the basic structure of the Home Care Nursing patient chart. At this time, briefly review the standard HPC chart forms.

<u>Data Base:</u> This form, standard for all Home Care Nursing patients, is used to record medical and psychosocial history. It is not necessary (and usually not advisable!) to collect all of this information on the first visit. Because most patients see multiple care providers, they appreciate not having to repeat their story to each nurse that enters their home. The information collected and recorded on this form should be sent to receiving institutions when the patient is transferred to improve continuity of care.

<u>Palliative Care Check List:</u> The purpose of this form is to track the patient's palliative care journey. It is a vital communication tool and allows nurses to view the work that has been done with patients and families in one location. Some communities will also record other information on this form, for example if the patient has received "A Caregivers Guide" or dates the patient was discussed at HPC Rounds.

<u>HPC Nursing Care Plan:</u> The Care Plan should provide measurable goals, specific nursing interventions and evaluation criteria. The care plan should be user-friendly so that nurses unfamiliar with the patient and family will understand both the 'big picture' plan as well as what needs to be accomplished during that visit. As the HPC Nursing Care Plan is a blank canvas, it can be intimidating for new nurses. Make a point of reading care plans written by various experienced HPC nurses in your office to give you

some ideas about how the care plan can be used. You will become more proficient designing care plans with experience. For certain patients, other available standard care plans may be helpful, such as Wound Care or PICC Line Maintenance.

HPC Nursing Flow Sheet: The flow sheet records standard items that are usually reviewed at each nursing assessment. Although the Flow Sheet facilitates documentation of common concerns, it can limit nursing care if it is allowed to guide your visit and assessment. It's a sad fact that some patients who have experienced multiple nursing visits can almost recite the flow sheet for us. With experience you will find it easier to complete your assessment based on your facilitated conversation with the patient and family and keep the Flow Sheet as a reminder of common concerns. All new problems or changes should also be documented in the Progress Notes.

After Hours Form: Provides information accessible on Meditech for the BC NurseLine After Hours Program. This information is all that the HPC CRN will have available when answering telephone calls from patients and families overnight. It is especially important to include accurate information about safety concerns in case the CRN is required to make a home visit during the night. In most communities, the HCN enters this information into Meditech directly. In other areas, the HCN fills out a paper copy which is provided to a clerk for data entry. Discuss with your mentor or CRN the process in your community.

Activity 1 Chart Review (2 Hours)

Select a chart to review of a patient who has been on the HPC program for a few weeks and has had several nursing visits. Your mentor can help you select a good chart to review. Please remember patient confidentiality as you complete this activity. As you read through the chart answer the following questions:

1) Where did the original referral come from? What information was included in the referral?

2) Is the patient registered with the BC Palliative Benefits Program? What equipment or supplies have been ordered?

3) What information is available on the chart about the patient's psychosocial assessment? What else would you like to know about that is not available on the chart?

4) Read through the patient's Check List, Care Plan and recent Flow Sheet and progress note entries. Consider what has been happening to the patient's PPS. What do you think would be the priorities for the next nursing visit?

Activity 2 *Patient Visit* (4 Hours x 2)

Complete 2 separate home visits with your mentor.

- Depending on your level of experience and comfort, decide with your mentor if the first visit will be an observation experience only.
- It is preferable to have the visits on separate days to allow time for preparation and reflection.

Prior to each visit:

1. Review and update your Learning Plan. The Learning Plan document can be found at the end of the Overview Section.
2. Review your Learning Plan and expectations for the visit with your Mentor.
3. Thoroughly review the Patient Chart.

After the visit, take time to debrief with your mentor. Complete all documentation from the visit. Reflect on your experience by answering the following questions:

What was unexpected during the visit?

How were the goals of the visit determined? What communication styles were helpful?

How is Culture impacting the experiences of both the patient and family and the Nurse?

How did the Care Plan change as a result of this visit?

What do you expect will happen over the next 2-3 visits for this patient and family?

How was the date of the next follow up visit decided?

Module 1 Wrap Up

As you finish this module, take a few moments to write freely about how you are feeling at this moment. You can write down any thoughts that enter your mind. If you are looking for ideas, you might try thinking about what has gone well and why, what has been challenging, thoughts you have had about death and dying, what you might like to know more about, feelings about your new role etc.

Finally-Reassess your progress with the **Outcome Indicators** at the beginning of Module 1 and update your **Learning Plan!**

Module 1 Resources

Community specific HPC Team Information and Phone Lists

How to Access the FH Symptom Assessment Guidelines Online

Process for Ordering HPC Equipment

Guidelines for Ordering Medical Equipment (TriCities)

Palliative Performance Scale

EI Compassionate Care Benefits Information Sheet

Instructions for Completing After Hours Form

Scheduling HCN Visits for HPC Patients

Hospice Information Brochure

How to Contact an Interpreter in FH

APPENDIX D

Module 2:

Pain Management

Module Contents:

Pain Management: Outcome Indicators Checklist

The Home Care Nurse assesses, initiates and evaluates strategies to manage pain using a "total pain" perspective.

Pre=self-assessment prior to completing module

Post=review with mentor prior to signing off

Key

N=No Experience

S=With Support

C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Identifies the multidimensional factors influencing the person's "total pain" experience.				
Demonstrates knowledge of the physiology of pain: -Transduction -Transmission -Modulation -Perception				
Understands and identifies the various classifications of pain: -Acute vs. Chronic -Malignant vs. Non-malignant -Neuropathic -Nociceptive				
Identifies non-pharmcological strategies for pain management				
Conducts a pain assessment using the Symptom Assessment Acronym				
Collaborates with the person, family and interdisciplinary team to develop a pain management plan				

Indicator	Pre	Post	Evidence	Date/Initial
Demonstrates knowledge of medications commonly used in end-of-life care to treat pain				
Responds to potential side effects of commonly used pain medications				
Accurately converts the dose of one opioid to the equivalent dose of a different opioid				
Accurately converts the dose of one opioid to the equivalent dose of the same opioid when given by a different route of administration				
Identify signs of Opioid Toxicity				
Describes 2 types of breakthrough (BT) pain and how to calculate an appropriate BT analgesic dose				
Collaborates with Person and Family to develop a self-management plan for pain management				
Completes Fraser Health Online Pain Module				

*Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

Pain is a frequent symptom at the end-of-life and a common reason for referral to the HPC Program. Your previous experiences with patients in pain will determine your learning needs and the time required to meet this competency. The experience of chronic malignant or non-malignant pain is generally more complex and challenging than typical incidents of acute pain.

Most of the content you will need to meet this competency is included with the first two learning activities.

You will be introduced to the Symptom Assessment Acronym in Activity 2. A copy of the Symptom Assessment Acronym is included at the end of the module.

Other Suggested Readings:

If you require more information about pain management as you complete your Learning Plan and work through the Outcome Indicators, consider:

Information on “**Total Pain**”

> Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*
> Pages 144-145.

Information on using **Opioids**:

> Fraser Health HPC Symptom Guidelines
> Guideline on Opioid Principles

There are several chapters about pain management in:

> Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).*
> Chapters 4-8.

Activity 1 Self Learning Module

This activity involves completing the Self Learning Module: Basic Pain Management for Generalist Nurses Caring for Palliative Patients which is located at the end of this module.

Read through the “Directions for use of Module” on page 4. Following these instructions will allow you to customize this learning activity to your learning needs.

Activity 2 Online Pain Module

Instructions for accessing and completing this online learning activity are located at the end of this module. Depending on your learning needs, you can bypass some of the content and challenge the final exam. Instructions to print out your certificate of completion are also included.

Activity 3 Complete a Pain Assessment

Prior to beginning this activity, update your learning plan to include your goals for learning pain management and review with your mentor.

With your mentor, identify a patient who has pain as a symptom. Your mentor should accompany you to visit the patient.

Using the Symptom Assessment Acronym, complete and document a thorough pain assessment as a component of a palliative assessment.

With support from your mentor, develop or adjust the pain management care plan.

Answer the following questions:

What type(s) of pain do you think the patient was experiencing? What information from your assessment supports this?

Critique the patient's current medication regime. Consider the route, effectiveness, breakthrough dose, convenience, adjuvants, management of side effects.

What barriers can you identify to effective pain management?

How did you ensure collaboration from the patient/family/interdisciplinary team in the creation of the care plan?

Module 2 Wrap Up

As you finish this module, take a few moments to write freely about how you are feeling at this moment. You can write down any thoughts that enter your mind. If you are looking for ideas, you might try thinking about what has gone well and why, what has been challenging, thoughts you have had about death and dying, what you might like to know more about, feelings about your new role etc.

Congratulations, you have now completed Module 2. Reassess your progress with the **Outcome Indicators** at the beginning of Module 2 and update your **Learning Plan!**

Module 2 Resources

Pain Self Learning Module
Directions for Accessing Online Pain Module
Instructions to Print Online Pain Module Certificate of Completion
Symptom Assessment Acronym
Pain Assessment Tool
Analgesic Equivalency Chart
Using the Fentanyl Patch

APPENDIX E

Module 3:

Management of Other Symptoms

Module Contents:

Management of Other Symptoms: Outcome Indicators Checklist

The Home Care Nurse assesses, develops and initiates a plan to manage common symptoms of advanced disease including dyspnea, constipation, nausea and delirium.

Pre=self-assessment prior to completing module

Post=review with mentor prior to signing off

Key

N=No Experience

S=With Support

C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Conduct a comprehensive symptom assessment using the Symptom Assessment Acronym for -Dyspnea -Constipation -Nausea -Delirium				
Analyzes the symptom assessment to identify the possible causes of -Dyspnea -Constipation -Nausea -Delirium				
Demonstrates understanding of the pharmacological and physiological use of medications in managing: -Dyspnea -Constipation -Nausea -Delirium				
Understands the role of oxygen in dyspnea management				

Indicator	Pre	Post	Evidence	Date/Initial
Collaborates with the person, family and interdisciplinary team to develop a symptom management plan				
Identifies signs and symptoms of common HPC emergencies including: -spinal cord compression -SVC syndrome -opioid toxicity				
Identifies other common symptoms of advanced disease including fatigue, depression, seizures, anorexia and cachexia, psychosocial and spiritual distress, alterations in body image and intimacy				
Implements the FH HPC Bowel Protocol				
Demonstrates understanding of non-pharmacological approaches to manage symptoms -Dyspnea -Constipation -Nausea -Delirium				
Teaches patients and families strategies to manage symptoms using a patient-specific approach				
Completes the HPC Basic Education Day				

*Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

Although dyspnea, nausea, constipation and delirium are only a small sampling of the total symptoms experienced by patients with advanced disease, they are some of the more common and distressing ones. In this model, we will examine the impact of these symptoms including assessment, common causes, and management strategies. Strategies to support patients in the home environment will be emphasized. We will also review a few of the more common complications that can occur for patients with end stage cancer that need to be recognized quickly to prevent life threatening complications.

Basic Steps to Symptom Management in HPC

Similar to pain management, there are basic principles that apply to management of all symptoms in palliative care.

1. Complete a thorough assessment. A thorough assessment is necessary to determine the potential causes of the symptom and management strategies that will be consistent with the patient's goals and values. In Module 2, you had the opportunity to use the Symptom Assessment Acronym to assess pain. This same tool is appropriate for assessing all of the symptoms in this module. A thorough assessment should be instigated whenever the patient identifies a new symptom or there is a change in a previously identified symptom.

2. Try to identify potential causes for the symptom. Often the most effective way to treat the symptom is to eliminate the cause. For example, if nausea is related to constipation, treating the constipation will be a more effective long term strategy than an antiemetic medication. That being said, most patients should still have their symptoms treated while the cause is identified and addressed.

   Depending on the cause, the patient's goals and prognosis, treating the cause may not be appropriate. In this situation, treatments to improve the symptom would be the best option. For example, patients in the last days of life who are experiencing delirium from an infection may choose to be treated with neuroleptic medications to ease their symptoms rather than antibiotics to treat the infection.

3. The care plan needs to be developed collaboratively with the patient, the caregiver and the interdisciplinary team. Asking questions to determine the patient's goals and fears about the symptom will help prioritize treatment strategies. Is the treatment available in the home environment? Do the patient and family have the resources to implement the plan at home? What are the benefits and burdens to the treatment strategy?

The Fraser Health Symptom Guidelines

You have already encountered the Symptom Guidelines in Module 1 including the Psychosocial Care Guideline and learned how to locate the Guidelines online. You will find the guidelines very helpful as you work through Module 3. Each Guideline has a similar structure:

-Definition of Terms

-Assessment

-Diagnosis and potential underlying causes of the symptom

-Education—Tips for educating patients and family members

-Non-pharmacological treatments

-Pharmacological Treatments

Some guidelines include information specifically formulated for patients and family education. Home Care Nurses have been very creative in their use of the Guidelines, for example copying certain sections for the patient's chart as resource materials or sending a specific Guideline to a family physician to collaborate on a treatment plan.

The patient resource book *A Caregivers Guide: A Handbook about End of Life Care* is another helpful teaching aid for symptom management.

Dyspnea

Dyspnea is a common, distressing symptom at end-of-life that is often misunderstood by patients and nurses alike. Dyspnea is symptom in patients in patients with lung cancer (90%), end stage lung disease (95%), CHF (60%), ALS and cancer in general (50%). Dyspnea has been reported in 70% of patients at the very end of life (Ferrell & Coyle, 2006). Dying of 'suffocation' is a real fear for many patients.

Assessment

Dyspnea is a subjective sensation, very much like pain. Traditionally, we have assessed dyspnea by counting respirations or measuring oxygen saturation but dyspnea is not tachypnea or hypoxia. We need to talk to the patient to find out their experience of breathing discomfort to assess dyspnea. Using the Symptom Assessment Acronym helps identify the impact of dyspnea on the patient's quality of life.

Diagnosis

There are numerous causes of dyspnea at end-of-life, some more easily treated than others.

Take a moment to come up with a list of as many causes as you can think of for dyspnea. When you are finished, compare your list with the one in the *HPC Dyspnea Symptom Guideline* on page 3.

Treatment

"Whether or not the underlying cause(s) can be relieved or treated, all patients will benefit from the management of the symptom using education, energy conservation and breath control, airflow and medications" (Dyspnea Symptom Management Guideline, p. 5).

Education

Because dyspnea can be so distressing and anxiety provoking to both patients and caregivers, education needs to be simple, concise and repeated. Patients and families need to know that there is something that can be done to make them more comfortable and have a plan to manage sudden crisis. Writing down a simple, step by step plan for both day to day management and crisis management can be helpful.

⇨ Read: Appendix B: Shortness of Breath. Fraser Health HPC Symptom Management Guideline for Dyspnea. Pages 12-13.

This is a patient/family education handout that is available separately in your office.

In point form, list what you would want to tell a patient about breath control and air flow to manage their dyspnea.

Oxygen in Dyspnea

Research does not support using oxygen to manage dyspnea in non-hypoxic patients. The cost of home oxygen is only covered for people who meet the standard criteria for the Home Oxygen Program. You can see the criteria for the Home Oxygen Program on page 7 of the Dyspnea Symptom Guideline. Note in the criteria that Home Care Nurses can assess if HPC patients qualify for oxygen subsidy using a pulse oximeter.

PleurX Pleural Catheter

PleurX is a small bore tunnelled catheter that is inserted into the pleural space by a thoracic surgeon. Its purpose is to drain malignant pleural effusions that re-accumulate and cause dyspnea. The effusion is drained intermittently (usually 1-3x/week) using a special drainage kit.

The Pluerx catheter is only one component of a comprehensive care plan to manage dyspnea. The catheter drainage procedure is a specialized skill. Talk to your HPC CRN or Team Leader if your patient has a PleurX catheter and you have not been certified in the drainage or dressing change procedure.

Energy Conservation

Energy conservation is best done from a holistic, multidisciplinary team approach.

Goal setting can assist the patient and family to set priorities. Home Supports could help conserve energy used for ADL’s. PT and OT can assist with techniques and adaptive equipment to make tasks easier. If anxiety is a large component of dyspnea, there may be a role for counselling or spiritual care.

Pharmacological Management

⇨ Read: Recommendation 5 and 6 in the Dyspnea Symptom Guideline, pages 5-7.

Opioids are the first line of therapy for dyspnea in advanced disease. Opioids are used to manage dyspnea in a similar fashion to pain management. Patients who suffer from dyspnea even at rest likely need regular or extended release dosing of the opioid. There needs to be a breakthrough dose available. Patients can be taught to use a breakthrough dose if they are anticipating dyspnea through activity. Although benzodiazepines such as Lorazepam are occasionally used on a PRN basis if there is a large anxiety component to the dyspnea, neuroleptics, especially Methotrimeprazine, are being used more frequently.

Questions for Reflection..

What potential barriers can you identify to the implementation of the Symptom Guideline recommendations?

How might culture impact the experience of dyspnea? Remember that culture is more than ethnicity (see Module 1).

Nausea and Vomiting

Nausea and vomiting may be used interchangeably by patients in conversation but they are actually different issues. Nausea is a symptom and a subjective sensation that may or may not lead to the sign of vomiting. Nausea in advanced disease is often multifactoral, however, understanding the cause will lead to a more specific and effective treatment plan. Assessment using the Symptom Assessment Acronym will help identify causes and also give us information about how the symptom is affecting the patient's quality of life. Abdominal assessment is also important in assessing nausea.

As you think about the different causes of nausea in advanced disease, please have the pictorial representation of nausea triggers available, found in the resource section of this module. This diagram is copied from the Nausea Symptom Guideline. It will help to have this diagram open and refer to it as you read.

There is an area in the brainstem that is responsible for triggering vomiting, the Integrated Vomiting Centre (IVC). There are 5 nerve pathways that can activate the IVC.

- Chemoreceptor Trigger Zone in the 4th ventricle of the brain. Medications, chemical imbalances and sepsis use this pathway to cause nausea/emesis. Medications frequently used to inhibit this pathway are Haloperidol, Metoclopramide, Prochlorperazine and Ondansetron. *Note that Ondansetron is suggested for chemotherapy induced nausea. It is used infrequently in HPC because it is very expensive, is not covered by the BC HPC benefits plan, and is very constipating.*

- Vagal stimulation from the GI Tract. This pathway is stimulated from: bowel obstructions; extrinsic pressure from tumours, a swollen liver or ascites; or irritation from blood or medications. Frequently used medications to inhibit this pathway are: Metoclopramide or Domperidone to stimulate motility; dexamethasone to decrease inflammation and pressure from tumours; and octreotide to decrease gastric secretions when obstructions cannot be relieved.

- Increased ICP can result from brain tumours and metastasis to the brain. This is treated with Dexamethasone.
- The Vestibular System in the inner ear triggers vomiting in disequilibrium and opioid use. Commonly used medications in this category are Dimenhydrinate and Scopolamine.
- Cerebral CNS. Stress, anxiety, smells can stimulate vomiting in absence of the other pathways. Often nonpharmacological approaches are most effective.

Education

Patients and families can be taught nonpharmacological methods to improve nausea and vomiting such as:

-minimizing oral intake until vomiting stops

-restricting fluids with meals

-good oral care

-eating bland, cold foods and avoiding sweets

Often patients and families need education about how to take their antiemetic medications. Sometimes patients will try one dose of a new antiemetic and then stop because it “didn’t work”. Encourage patients to try taking medications regularly and using the maximum dosage until the symptom settles.

Ensure that the patient or caregiver understands that a particular medication is being used to treat their nausea. Some medications that are frequently used as antiemetics in HPC, for example Haloperidol, will not be labelled as an antiemetic by a community pharmacy in their patient education handout!

Emphasize the importance of good bowel care and pain management in the control of nausea. Ask if the patient has been able to keep his medications down. The parenteral or rectal route might need to be considered, even in the short term, for patients with significant emesis.

Questions for Reflection...

What antiemetic medications did you use most frequently in your previous nursing experiences? What causes of nausea are targeted by these medications?

How can nausea affect quality of life for both patients and families?

Constipation

Constipation is often one of the most chronic symptoms of advanced disease. Nurses have the opportunity to impact constipation by implementing proactive bowel care and providing timely advice to patients.

For patients with cancer, bowel and pelvic tumours, ascites, spinal cord compression, decreased oral intake, decreased activity level, opioids and other medications and depression can all contribute to constipation (Ferrell & Coyle, 2006). A list of common medication used in HPC that can contribute to constipation is available in the *Bowel Care Symptom Guideline.*

Assessment

Although nurses are encouraged to use the Symptom Assessment Acronym to assess constipation, there are some specific questions and physical assessments that should also be used. Patients should be asked:

-Time of last BM

-Time of last normal BM

-Consistency of last BM

-Usual bowel pattern

-If they are passing flatus and amount

-pain with defecation

-any oozing of liquid stool

Physical Exam:

-examine the abdomen for distension

-auscultate for bowel sounds

Management

⇨ Read HPC Symptom Management Guideline Bowel Protocol which has been included at the end of this module.

Most patients will require proactive and aggressive bowel care because constipation is much easier to prevent than treat. Patients should be started on *regular* laxatives when opioids are initiated. Remember that laxatives are covered by the BC Palliative Care Benefits Program if the patient has a physician prescription. Patients that have not had a BM in 3 days require intervention - see the Bowel Protocol for details.

In general, the most common laxatives used in FH HPC are Sennosides and Lactulose as directed by the Bowel Protocol. Bulk forming laxatives are discouraged as most patients are not able to drink enough fluids for them to be helpful. Stool softeners have not been shown to be effective.

Standard nonpharmacological remedies can be encouraged keeping in mind the abilities and physical condition of the patient.

Education

If constipation is not well managed, some patients will stop taking their opioid medications: good patient education is essential. Teach patients that constipation is a usual but manageable side of effect of opioids and they will likely require regular use of laxatives as long as they are taking the opioid medications. Having patients record their BM's on a calendar along with the amount of laxative taken will help gauge the proper amount of laxative required to maintain bowel function. If a patient becomes constipated and requires a rectal intervention, ensure they understand they need to immediately resume a more aggressive oral bowel routine.

Delirium

Delirium is one of the most difficult symptoms for families to manage at home. Delirium can occur at any time but is especially common as the patient approaches death (terminal restlessness). Nurses have an important role in the early identification and diagnosis of delirium and supporting caregivers to cope with this challenging condition.

To help us understand the family experience and the power of 'being with' as a nursing intervention with delirium, read:

⇨ Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*
Pages 232-236.

Assessment and Potential Causes

Successful treatment of both the symptoms and underlying causes of delirium is more likely early identification. Family caregivers often notice subtle changes in the patient's cognition that can quickly escalate to full blown delirium if not addressed. Using the phrase "potential delirium" instead of "confused" or "disoriented" in discussions with physicians and family members reinforces that this is a treatable medical condition. Review the assessment and potential causes of delirium in HPC by reading:

⇨ HPC Symptom Guideline for Delirium and Restlessness
Pages 3-8.

Management

Delirium management involves attempting to address reversible causes where possible depending on the patient's goals of care. Delirium that occurs near the very end of life is frequently not reversible and the focus of care should be on controlling symptoms and making sure the patient and caregiver are safe.

Families will need a lot of support to care for a loved one with delirium in the home. Education about delirium as a medical condition and providing some helpful communication approaches can help families cope (see bottom of page 8 in the

Symptom Guideline for suggestions). There should always be a plan in place if the delirium escalates and the patient become agitated or aggressive. This is a good time to review goals and discuss options such as increasing home supports, nursing visits and considering hospice as a back- up plan.

All patients, whether the delirium is reversible or not, will benefit from symptom management. Helping the patient sleep at night is especially important and usually requires the use of neuroleptic medications. Methotrimeprazine can be sedating and is often used at HS to help induce sleep. Benzodiazepines can worsen delirium, especially in the elderly, and should not be the first line of drug treatment.

Depending on the patient's goals, rehydration and correcting electrolyte imbalances may be considered, for example in opioid toxicity. Admission to THPCU may be arranged or occasionally hydration in the home with **hypodermoclysis** is considered. Hypodermoclysis involved infusing medications or fluids subcutaneously. This procedure requires physician orders and the equipment is a standard IV set up. More information about this procedure can be found in the Nursing Policy and Procedure Manual.

Don't forget to check for common sources of discomfort that may be contributing to delirium and restlessness such as constipation, pain, urinary retention or even poor mouth care.

Potential Emergencies in Advanced Cancer

Certain types of cancer put patients at risk for complications that can be life threatening if not treated urgently. Home Care Nurses need to be aware of these potential complications to ensure patients receive timely intervention.

For each of the following, define the condition, identify common signs and symptoms and describe the usual treatments.

Opioid Induced Neurotoxicity

See the HPC Symptom Management Guideline Opioid Principles on page 11.

What is it?

Which patients are most at risk for opioid induced neurotoxicity?

What are the common signs and symptoms?

What is the usual treatment?

Superior Vena Cava Obstruction

Read: Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).* page 260.

What is it?

Which types of cancer have the highest risk for SVC Obstruction?

What are the common signs and symptoms?

What is the usual treatment?

Spinal Cord Compression

See the *HPC Symptom Guideline* for Spinal Cord Compression.

What is it?

Which types of cancer have the highest risk for Spinal Cord Compression?

What are the common signs and symptoms?

What is the usual treatment?

Activity 1 Case Study

The following case reviews some of the symptom management concepts covered in Module 3.

You are making an extra visit today to see Frank, a 68 year old man with lung cancer. Yesterday you received a phone message from his GP's office that Frank had missed his appointment because he wasn't feeling well. The GP requested a nursing assessment.

This is the 3rd time you have visited Frank since he was referred by his GP a month ago. Frank was diagnosed with non small cell lung cancer 2 months ago with metastatic disease to the mediastinum and ribs. He was treated with radiation which was completed one month ago. He has a history of type 2 diabetes, COPD on the Home Oxygen Program for 1 year, and coronary artery disease.

Frank is divorced and has been retired from his work at a pulp mill for several years. He lives alone in a small condo. There is a half flight of stairs from the main entrance to his unit and Frank is able to park the scooter in the hallway to charge the battery. His daughter Lisa lives close by with her 10 year old son. Lisa works during the day but has been visiting her father several times a week and helping him with his laundry and grocery shopping.

When another nurse visited Frank last week he was feeling a bit more short of breath than usual and had started taking ibuprofen regularly for rib pain. He was independent with his ADL's and had been out to eat lunch at a nearby restaurant on his scooter. His PPS was 70%. The nurse had advised Frank to see his GP. His nursing visits are scheduled weekly.

Today, when Frank answers the door, he appears in his robe and is unshaven. There are several drinks by his Lazy Boy chair. He tells you he feels "lousy". After he saw his doctor last week he was started on MEslon 30 mg BID for his rib pain which is now improved to the point where he is sleeping through the night but still hurts if he has been coughing a lot. When you ask Frank what is bothering him the most today he says "I can't eat anything, I feel so sick". He hadn't had a bowel movement for several days so Lisa bought him some stewed prunes yesterday but he hasn't felt able to eat them yet. To further assess his nausea, you use the Symptom Assessment Acronym.

O=started 3 days ago

P=nothing helps, he feels this way all the time

Q=feels 'queasy' and bloated. Sometimes he is sweaty.

R=just in his belly

S=is relieved he hasn't been vomiting

T=tried taking Rolaids but doesn't think they have helped

U=Thinks problem is from constipation, hasn't had a good BM in 5 days

V=wants to eat better so he can keep his strength up

1) *What other questions would you like to ask Frank? What else would you like to assess?*

2) *What do you think might be contributing to Frank's nausea?*

3) *What would you do to address Frank's constipation during your visit today?*

4) *Write instructions for Frank on how to manage his bowels after your interventions today based on the FH HPC Bowel Protocol.*

5) *As the only medication Frank has ordered for symptom management is the MEslon, you decide to call his physician. Write a list of topics you would like to discuss with his physician. What do you expect he will order?*

Luckily, you were able to get Frank's bowels working and his nausea settled. It is one month later and Frank has been doing fairly well. However, for the past 3 days he is feeling increasingly short of breath. He has been too SOB to walk down the stairs to his scooter or take a shower. He tried turning his oxygen up from 2l to 4l/min but that hasn't helped. He has not thrown up but hasn't felt like eating anything. He is trying to drink the Boost that Lisa brought over yesterday. Last night he woke up feeling acutely short of breath and very panicky. "If this is how it's going to be, I'm ready to go now" he tells you. "I don't want to put Lisa through this."

You ask Frank what he is most worried about and he says "my breathing, I'm scared I'm going to suffocate to death". You decide to begin by completing an assessment of his dyspnea.

O=Has been SOB for past 2-3 years which has gradually been getting worse.
Started to feel SOB all the time 3 days ago.

P=It gets worse when he walks or coughs.

Q=feels like chest tightness, can't get enough air in

R=it's making him cough, increased brown sputum

S=4/10 in his chair but 10/10 sometimes when he has to use the washroom

T=turned up his oxygen, increased his Ventolin inhaler to q2h

U=I think the cancer is getting bigger, there's nothing that can be done

V= 'I want to be able to look after myself in my own place'

Frank has a congested sounding cough with thick brown sputum. When you auscultate his chest, you can hear crackles on inspiration in the left lung.

6) *List some potential causes of Frank's sudden increased dyspnea.*

7) *Although Frank is refusing to go to the hospital, you convince him to agree to be assessed by his GP who has ordered a chest x-ray, increased Frank's SR and BT doses of Morphine and ordered a PRN dose of Lorazepam S/L. Write a plan to teach Frank what he needs to know to manage his dyspnea.*

8) *What other discussions should be started with Frank at this time?*

<u>Answer Key:</u>

1) Assess abdomen, rectal check, listen to bowel sounds. Get more information about Frank's regular bowel pattern and his recent BM's. What information was he given by his GP when opioids were initiated?

2) Frank is likely correct that his nausea is related to his constipation. Initiation of opioids could also be contributing.

3) Frank should have a rectal intervention as he has had no BM for 5 days. Type of enema would depend on the results of the rectal check. Confirm Frank is registered with BC HPC Benefits Program. Ask GP to phone in a Rx for laxatives to community pharmacy.

4) Start regular sennosides as per bowel protocol. Emphasize need to take laxatives daily, that it will take some adjustment to find the correct amount of medication to maintain regular BM, and to take a laxative today even if he had BM from enema. Also cover non-pharmacological interventions.

5) GP - sennosides +/- lactulose

   Antiemetic, likely Metoclopramide 10mg AC meals and HS regularly until nausea settles and oral intake resumes and then may decrease to prn. ?BT dose for his analgesia

6) Pneumonia, SVC obstruction, tumour, pulmonary embolism, pleural effusion, radiation damage, COPD exacerbation, CHF, anxiety

7) See Shortness of Breath patient information in the HPC Symptom Management Guideline for Dyspnea page 12 + 13

8) Frank has given clues that he may be ready to talk about his death. He has also indicated his goals of remaining at home and not being a burden to Lisa. This is a good opportunity about how palliative care might support his goals. He might also benefit from home supports or adaptive equipment at this time.

Activity 2 Working with your Mentor

After you complete the case study, review your progress with the Outcome Indicators and develop your learning plan with your mentor. Work with your mentor to find learning opportunities to develop your skills in symptom management and meet the orientation competencies. The activities could include patient assessments, chart reviews, writing care plans, participating in HPC clinical rounds or further reading.

Module 3 Wrap Up

To finish this module, look around your office for reading about palliative care or end-of-life. Most HPC programs will have a book of poems or short stories. Find one that appeals to you. You might want to make a copy for your resource section.

Congratulations, you have now completed Module 3. Reassess your progress with the **Outcome Indicators** at the beginning of Module 3 and update your **Learning Plan!**

Module 3 Resources

HPC Bowel Protocol

Appendix A Nausea and Vomiting Symptom Guideline

APPENDIX F

Module 4:

End of Life Planning/Dying and Death Management

Module 4 Contents:

End of Life Planning/Dying and Death Management: Outcome Indicators Checklist

The Home Care Nurse assists the patient and family to prepare for death, supports and educates the family to care for patients dying at home.

Pre=self-assessment prior to completing module

Post=review with mentor prior to signing off

Key

N=No Experience

S=With Support

C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Recognizes the physical signs and symptoms associated with dying and teaches families				
Supports the family during the dying process and after death has occurred.				
Supports cultural and religious practices around end-of-life of individual patients/families				
Teaches family members about symptom management to promote comfort as death approaches				
Implements the FH Palliative Drug Kit process				
Assists families to determine the appropriate setting for death				
Initiates ACP conversations including DNR				
Assist patients and families who wish to plan for and access Hospice Residences				
Facilitates arrangements for the pronouncement of death including the Joint Protocol for Expected Home Death				

Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

Most patients and primary caregivers, when asked, report that they would prefer to die at home in the presence of loved ones, yet in Canada 60% of deaths occur in hospitals (Canadian Hospice Palliative Care Association, 2008). Many patients and caregivers assume that all deaths occur in acute care because they have not experienced a home or hospice death. In Fraser Health, the rate of Home Death for patients registered on the HPC program is usually between 15-30%, depending on the community and its resources. Since 2001, Fraser Health has created approximately 100 Hospice Residence beds in communities across the health region. Hospice is now an option for end-of-life for patients who are unable or who do not wish to die at home.

Helping patients plan and prepare for death is a significant part of the role of HPC nursing. Many people have never experienced death before and are unsure and anxious about what to expect. Nursing a patient and family through the experience of a home death can be intense and overwhelming at times. The HCN must anticipate and help the family prepare for expected changes as the patient approaches death. Unexpected changes in the plan of care can happen suddenly that necessitate good communication, flexibility and a team approach to care.

Questions for Reflection...
Have you ever considered what you would want if you were dying? If you visualize the end of your life, where are you? Who is there with you? What would be important?

Imagine you are in the final stages of lung cancer. You are feeling short of breath all the time and pain in your back is keeping you from sleeping at night. You are having difficulty getting up to the commode and are worried what will happen when you are no longer able to get out of bed. What might be most important to you? What would be important to your loved ones?

Developing a Plan for End-of-Life

Discussions about wishes for end-of-life happen over time and wishes may change as more is known about the illness and the realities of providing care. Changes in the patient’s status, caregiver distress or cues that the patient wants to discuss death can initiate conversations about goals of care. Planning for end–of-life can include:

-financial planning, making a will
-planning final arrangements such as a funeral
-cultural or religious rituals
-planning for preferred location of death
-making decisions about medical interventions including ACP and DNR
-learning to manage common symptoms
-saying goodbye to loved ones
-learning what to do when death occurs.

Read: Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*
Pages 177-181: Developing a Death Plan.

Information is included in the resource section to assist families with planning funerals and personal financial and legal matters.

Hospice Residences

Before you begin this section, have a copy of the **Hospice Residence Admission Package** available. You may also want to read through the Hospice Residence Brochure if you have not already done so.

Patients are eligible for hospice in that last three months of life with a PPS of less that 50%. On average, hospice admissions are generally much shorter, less than 3 weeks. Families are always welcome at hospice as long as it is not disruptive to other patients or compromising the patient's care. Tours can be arranged at the hospice residences through the phone numbers listed in the Hospice Residence Brochure.

Some patients and families plan to die in hospice. It is helpful to have discussions about how they will know when they are ready to go to hospice, what will be the signal that it is time to go. Other patients will want to have a home death but will go to hospice if they feel unable to manage at home.

The HPC CNS or CRN must approve all patients to be waitlisted for Hospice Residence. Patients with a non-cancer diagnosis must also be approved by the HPC physician.

A flow sheet depicting the Hospice Admission process is available in the resource section.

Part 1-Initial Registration for Future Needs

Admission to Hospice residence is a two part process. All patients with a prognosis of less than 3 months can have Part 1 completed for future needs. Even patients who are hoping for a home death should be encouraged to have the initial hospice waitlist completed as a backup plan. Prior to completing Part 1, the following needs to be discussed with the patient and family:

- Hospice philosophy of care
- A physician signed DNR order would be required prior to admission
- The per diem fee (currently about $30/day). Families who have concerns about affording the per diem fee should be referred to the HPC SW
- Choosing a first and second choice of location and the first available bed policy
- Provide patient and family with the Admission Data Base to complete.

Contact the patient's physician by phone or fax to inform him/her of the patient's wish to be waitlisted for hospice residence. Ask the physician if they will provide care at the hospice of the patient's choice or if they would like to transfer care to the Hospice physician. If not already completed, a discussion about DNR should also occur.

Fax the completed Part 1 along with the medical history to the Hospice Bed Access Coordinator along with a medical history. The DNR physician’s order and BC Benefits Application (if required) must also be faxed to Access when completed.

Part 2-Regular Admission

Part 2 is completed when the patient is ready to take the next available bed.

- Contact the CNS/CRN to inform them the patient is ready for admission
- Contact the patient’s physician by telephone to discuss the admission and determine that the patient is medically appropriate for hospice (i.e. there are no medical issues that need to be resolved, diagnostic tests required etc).
- If the family physician will be caring for the patient at hospice, inform them that they will be faxed admission documents and that a hospice RN will be contacting them for admission orders
- If the family physician will not be caring for the patient at hospice, inform them that you will call them shortly to provide the phone number of the Hospice physician so they can call and give a report.
- Phone the Hospice Access Coordinator at the phone number on the Part 2 form. You will be required to provide information about the patient’s care needs as described on the Part 2 form.
- You will be contacted by a nurse or care coordinator at the Hospice residence where the patient is to be admitted to give report. Obtain the phone number of the Hospice physician for the GP.
- If the GP is not caring for the patient at hospice, call them with the contact information for the hospice physician to give report
- Contact the family to inform them of the admission. Family is to bring the Preadmission Data Base to hospice.
- Fax all pertinent information from the patient’s chart to the hospice residence including the MAR, ACP documents, Data Base and recent visit notes.

Many communities use a transparent yellow page protector to keep all the hospice forms together on the patient chart.

Death at Home

A home death is often portrayed as a “good death” in the media and in HPC. In the reflection at the beginning of this module, many of us probably envisioned our own deaths occurring at home. In reality, most patients and families have little experience with death and dying and will require expert guidance to make the journey.

⇨ Read: Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).* Pages 596-597.

Planning in advance is particularly important for community patients. Access to physicians for new orders and to pharmacies to obtain medications may be limited to certain hours. Potential symptoms or sudden changes to the plan of care must be anticipated so that appropriate medications and resources are available after regular business hours. Educating family caregivers about what to expect and how to cope with changes that usually occur at the end of life will help them prepare for death.

Signs of Impending Death

Read: Recognizing and Responding to Predeath Changes page 227-232.Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*

Decreasing oral intake can be one of the most distressing symptoms for loved ones who may worry that the patient is starving. Although it may have been helpful to maximize nutrition earlier on in the disease process, imposing food and fluids as patients approach death can worsen symptoms and will not prolong life. Helping families understand that declining interest in food is part of the metabolic changes that occur as death approaches and helping them find alternate ways of expressing care is often all that is needed. Caregivers can be taught the importance of good mouth care using saliva substitutes to promote comfort.

The final stages of dying can take hours, days or even weeks. For families maintaining a vigil, this can be exhausting. Encourage caregivers to take a break and make use of home support services during this time. The dying person may no longer be able to communicate verbally which can be lonely and upsetting for family. Other patients may be confused and restless. To learn more about interventions that can help caregivers cope, read:

Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.*
Pages 215-222.

Most communities have developed resources for families to teach the normal signs of approaching death and what to do after a person dies at home. Locate these resources in your office.

Symptom Management at End-of-Life

Managing symptoms at end-of-life can be challenging when patients cannot communicate verbally, swallowing oral medications can become impaired, and the patient’s condition can change quickly. Thinking ahead to plan for symptoms that might arise increases the chances of a successful home death.

Fraser Health HPC Palliative Care Drug Kit Package

Please have a copy of the HPC Palliative Care Kit Package available as you review the following information.

When a home death is planned, having a Palliative Care Kit (commonly known as a drug box) in the home should be considered in the last days of life. The kits may also be helpful if the patient has unstable symptoms. If there are any concerns about safety or substance abuse in the home or with any caregivers, please speak with a member of the HPC consultation team before obtaining a kit. Patients **must** be registered for BC Palliative Care Benefits before they can obtain a kit.

The medications in the kits are meant to be used as a temporary measure until a regular prescription can be obtained. The kits must be ordered by the physician and medications cannot be dispensed from the kit without a physician's order. Each community will have a specific pharmacy(s) that supplies the kits. There are supplies in the kit for subcutaneous injections. These supplies are for backup use only and must be restocked from Home Health Unit Supplies. In most communities, the combination for the lock is 911. **Do not give the lock combination to anyone except the family physician.**

Read through the Palliative Care Kit Package to find out:

- How would you get a physician's order for a kit?
- Where is the pharmacy where you can obtain a kit in your community?
- How do I sign out medications from the kit?
- How does the kit get to the patient's home?
- What do I do if I run out of a medication in the kit?

Exercise:

Using the "Dosing Suggestions for Health Professionals" form found in the drug kit, write a list of medications you would expect to see ordered for a patient planning to die at home to manage the most common end of life symptoms. If you are having difficulty, read:

> *"Medications in the Home for Comfort" Page 626.* Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).*

Using S/C Medications in the Home

As the patient’s condition deteriorates, anticipating the need for s/c medications in advance is important to obtain prescriptions, supplies and teach family members to provide the injections. Most caregivers can be taught to give s/c medications using a needleless access device and pre-loaded syringes prepared by the Home Care Nurse.

The Medication Preload Record in the Palliative Care Kit Package is an optional chart form than can help track the amount of medication available in the home for the patient and caregiver.

As swallowing becomes more difficult, discussions can be held with the patient, family and physician about eliminating unnecessary medications that are not promoting comfort.

At the Time of Death

Occasionally, the HCN is present at the actual time of death. More frequently, the family is alone with the patient. Helping the family plan for the time of death helps family members feel prepared. Discussion could include what cultural or religious rituals would be important at the time of death, people who would want to come and see the body or be available for support.

Joint Protocol for Home Death

A copy of this protocol is available in the resources section of this module. If families chose to make prearrangements with their preferred funeral provider, they can waive the need for pronouncement of death by completing this form. The caregiver would wait for one hour after the patient stops breathing and then call the funeral provider as arranged. Even if this form is completed, families should be aware that they can still request pronouncement of death or phone the HCN office or BC NurseLine for support.

Pronouncement of Death

Patients who do not complete the Joint Protocol for Home Death need to wait to have death pronounced by a physician or Home Care Nurse prior to having the body removed by the funeral home. If the patient dies during the night, the family will often need to wait until morning for pronouncement and they need to be prepared for this.

See the Home Care Nursing Standard, included in the resource section for more information on pronouncing death.

Activity 1 Tour of a Hospice Residence

Individually, or with other orienting nurses, arrange a tour of your local Hospice Residence. Ask your HPC CRN for the contact information of the Care Coordinator or other appropriate Hospice team member to arrange the tour.

During your tour, reflect on the following:

1) Imagine you are a patient or family member being admitted to the hospice residence. What do you think you would notice?

2) How is culture observed and incorporated into care at hospice?

3) How are alternative therapies integrated with medically focused care at hospice?

Write a few sentences about your experience at hospice.

Activity 2 Planning Ahead

On a Thursday afternoon, you make a home visit to your patient Charles Joe and his wife Esther. Charles has pancreatic cancer and would like to die at home. Since you last saw the couple three days ago, Charles PPS has declined from 40-30%. He is drowsy but oriented. Esther tells you he was too tired to get out of bed yesterday and has only had a small amount of juice so far today. He was able to take his pain medications today with a bit of jam. The DNR form is signed and in the home. Esther worried about Charles falling if he needs to use the washroom.

What resources would you like to have in place?

What would be your priority during this visit?

What educational resources would you consider using in your discussions with Charles and Esther?

What do you expect will be the nursing care plan for the next few visits?

Module 4 Wrap Up

Read the narrative by Eileen O’Donnell as she describes the death of her mother on pages 271-273 of *Transitions in dying & bereavement* by Cairns, Thompson, & Wainwright.

As you finish this module, take a few moments to write freely about how you are feeling at this moment. You can write down any thoughts that enter your mind. If you are looking for ideas, you might try writing your own narrative about a death you have experienced.

Congratulations, you have now completed Module 4. Reassess your progress with the **Outcome Indicators** at the beginning of Module 4 and update your **Learning Plan.**

Resources

Hospice Admission Flowsheet

Joint Protocol for Home Death

When I Die: Information about Funerals for Families (TriCities)

Information Your Family Should Know About Funerals

APPENDIX G

Module 5:

Loss, Grief and Bereavement Support

Module 5 Contents:

Loss, Grief and Bereavement Support: Outcome Indicators Checklist

The Home Care Nurse assists families to anticipate and cope with their unique reactions to loss and death.

Pre=self-assessment prior to completing module

Post=review with mentor prior to signing off

Key

N=No Experience

S=With Support

C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Demonstrates understanding of the concepts of loss, grief, anticipatory grief and bereavement				
Personally reflects on my own experiences of loss and grief				
Assists patients and families to locate information and resources on grief and bereavement				
Makes referrals to the Hospice Society for ongoing bereavement support where appropriate				
Identifies individuals at risk for complicated grief				
Provides bereavement support through a home bereavement visit				
Identify strategies to help me cope with cumulative loss				

*Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

In this module we will be considering grief and loss, both while living with advanced illness and after a death. Most of us will have experienced a significant loss in our life whether from loss of a loved one, divorce, job loss or other major loss. This loss may be quite recent. The readings and exercises in this module may lead to unexpected feelings of distress or sadness. You may need to take a break to work through your feelings. Members of your HPC team are experienced in supporting people going through grief and loss. You are encouraged to seek out a HPC team member, your mentor or other support person if you are feeling upset or distressed.

In this module you will learn about:

- The grief process and different types of grief
- Nursing assessment of grief
- Risks for complicated grieving
- Resources available for bereavement support
- Dealing with cumulative losses as a HPC nurse

Grief and Loss

The experiences of grief and loss exist often begin with the diagnosis of an incurable illness and continue into the bereavement period. Grief can be defined as the emotional response to a significant loss, whether experienced or anticipated (Ferrell & Coyle, 2006). Various types of grief have been described.

Anticipatory Grief is an unconscious process of preparing for changes in status or roles that will occur after death.

Complicated Grief is marked by the presence of symptoms such as intrusive thoughts of the deceased, yearning and/or searching for the deceased and excessive loneliness since the death, experienced daily or to a marked degree, for at least 6 months, causing clinically significant impairment in social, occupational or other areas of functioning (Fraser Health HPC Symptom Guidelines: Psychosocial Care).

Disenfranchised Grief is may be experienced with a loss that cannot be socially acknowledged or publically mourned.

Cumulative Grief is the occurrence of multiple deaths, either at the same time or in serial fashion. This often occurs in HPC nursing practice, and may lead to bereavement overload or what has been called cumulative grief. Cumulative grief is the caregiver’s emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died. (Fraser Health HPC Symptom: Psychosocial Care).

Bereavement occurs when someone experiences the death of a significant other.

Mourning involves the social customs and cultural practices that accompany bereavement. Cultural rituals pertaining to death and bereavement provide meaning to the experience and acknowledgement of the loss (Ferrell & Coyle, 2006).

Grief is a normal response to loss and does not usually require professional intervention. That being said, we can be more beneficial as nurses if we understand what is the usual process of uncomplicated grieving and some nursing interventions that can support patients.

⇨ Read: Fraser Health Hospice Palliative Care Symptom Guidelines Psychosocial Care: Understanding Grief and Loss and Factors Contributing to Complicated Grief on pages 8+9.

Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Section on “Grief Reactions” pages 292-296 and “Ten Things to Know about Grief” on page 351.

Activity 1: Personal Loss Exercise

Choose a loss from your personal experience. Pick one that was significant yet one that you will feel comfortable thinking about and discussing with others.

Part 1

Remember your reactions to this loss when it happened and during the adjustment period afterwards. Write down your reactions using the following prompts:

- My Behaviours

- My Feelings

- My Thoughts

- My Physical Reactions

- My Spiritual Responses

Part 2

Again, focus for a few moments on your loss and recall the reactions of those people around you at that time.

Optional: If there are other orientees at your worksite, share your ideas about ways to be helpful and the pitfalls to avoid.

What was helpful?

What was not helpful?

What did you need that you may or may not have received?

This exercise is taken from:

Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Baltimore, MD: Health Professions Press. Page 318.

Bereavement Supports

In most communities in Fraser Health bereavement support is provided by the Hospice Societies. Services vary by community from information mail-outs to support groups and counselling.

If your community mails out bereavement information to the contact person for all deceased patients registered on the HPC program, locate the package in your office and read through the information. Also locate any other information available about bereavement supports in your community and find out what specific programs are available through your local Hospice Society.

If the patient and family had a relationship with a hospice volunteer prior to death, this relationship may continue for a while after death to provide some bereavement support.

Home Care Nursing Bereavement Visits

Home Care Nurses customarily make a single bereavement visit to the family of the deceased patient. The precise timing of the visit can be flexible but generally should be after the flurry of the funeral arrangements and initial financial or legal matters are settled. Initially following death there may be a period of shock and numbness in which the bereaved family member absorbs the reality of the death. Waiting for the realities of life to resume can reveal a more realistic reaction to the loss and information about the person's support systems.

The purposes of the bereavement visit will vary but could include:

- 'breaking the connection' of the nurse-family relationship
- Enabling the family to tell stories about the deceased and the experience of the death and after death rituals
- Provide information about what is normal in the grief process at this time and what they can expect in the weeks and months to come.
- Assess for signs of potential complicated grief
- Provide information about community bereavement resources that may be appropriate

If you are concerned that there is a potential for complicated grief as described in the Psychosocial Guidelines, you may want to refer the family to your community Hospice Society for grief counselling if it is available. Locate the referral form for this resource in your office.

Activity 2 The Bereavement Visit

Plan an imaginary bereavement visit to a family you have met since you began your work as a HPC nurse. Based on your understanding of the process of grieving, write 4 questions you might ask this family member to help you understand their experience. Include a question that would help you understand the impact of culture on their grief and bereavement.

Based on your knowledge of this family, are there any factors that would concern you about potential for complicated grief?

Congratulations, you have now completed Module 3. Reassess your progress with the **Outcome Indicators** at the beginning of Module 3 and update your **Learning Plan!**

Module 5 Wrap Up

As caregivers and nurses, we need to take the time to grieve the loss of our patients. As a Home Care Nurse, you may be closely involved with a particular patient and family over a number of months. What opportunities exist in your community or work environment for mourning and grieving? How could you make space in your world to acknowledge grief and loss?

Resources

Local Hospice Society Resources

List of Internet resources

APPENDIX H

Module 6:

Interdisciplinary/Collaborative Practice

Module Contents:

Interdisciplinary/Collaborative Practice: Outcome Indicators Checklist

The Home Care Nurse communicates and collaborates with the interdisciplinary team including the patient and family to define goals and plan care.

Pre=self-assessment prior to completing module Post=review with mentor prior to signing off

Key

N=No Experience S=With Support C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Works in partnership with the patient's primary care team including the family physician				
Identifies members of the interdisciplinary team				
Makes appropriate referrals to interdisciplinary team members				
Communicates effectively the needs of the person and family to the interdisciplinary team in HPC Community Rounds				
Understands how to access support from HPC team members outside regular business hours				
Facilitates and coordinates a smooth transition between community and hospice/acute care settings				
Initiates and Coordinates Home Support Services				

*Indicators adapted from CNA "The Hospice Palliative Care Nursing Exam List of Competencies" (2007) and FH "Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

“Good supportive palliative care is delivered by interdisciplinary teams. The Hospice Palliative Care model is designed on the premise of providing interprofessional care in order to approach each client in a holistic manner and provide “whole person” care. Each member of a team will have a range of overlapping roles, some medical and some non-medical, each focused on a specific state of patient needs. Even if a particular patient or family may choose to not have a specific discipline involved, it can be helpful to include them in the discussion of providing care to patients. Each discipline has their own approach to working with patients and families which can be helpful in gaining a holistic perspective on the patient and their situation in context” (Fraser Health Hospice Palliative Care Program Psychosocial Guidelines, p. 13).

In Module 6 you will explore:

- the various roles of the interdisciplinary team members
- the role of the HCN within the multidisciplinary team
- the characteristics of an effective team and how to avoid common pitfalls
- FH processes to facilitate team communication.

The HPC Team in the Community

The Patient and Family

The patient and family are at once part of the care team and the focus of care. As a Home Care Nurse, skill in supporting family caregivers is essential. In HPC, the concept of family extends beyond the traditional nuclear family to include any relative or person considered a support by the patient. A few of the ways nurses can enable patient and family participation in their care are:

- Encouraging them to tell their personal story
- Respecting preferences and values and incorporating them into the care plan
- Communicating openly and honestly
- Offering straightforward information about what is happening now and what to expect in the future
- Teaching family caregivers to be involved in all aspects of care as they are able
- Coordinating resources to support the patient and caregivers such as equipment and home supports
- Bringing the patient and family perspective to the rest of the care team
- Facilitating communication between agencies especially when the patient is transferred.

A suggested reading to learn more about the perspective of family caregivers is provided in the resources section of this module. *As you read this article, try making a list of factors that support versus factors deter family caregiving.*

Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19, 27-35.

To learn more about nursing interventions to support families in supportive care, you can read Chapter 28 in the *Textbook of Palliative Nursing*:

Davies, B. (2006). Supporting families in palliative care. In Ferrell, B.L. & Coyle, N. (Eds.), *Textbook of palliative nursing* (pp. 545-560).

Family Physician

For most patients at home, the family doctor will be the primary physician. Maintaining a collaborative team relationship with the family physician takes patience and effort. Some suggestions to improve communication are:

- Communicate regularly, even if it is just to provide an update on the patient's condition or the care plan.
- Assist patients/caregivers to write a list of concerns for the physician to bring to their appointment
- Find out how the physician arranges for medical coverage for his/her patients when they are out of the office and after hours
- If the physician does not have previous experience with the HPC program, each community has a Physician Information Package that could be mailed out. Ask your HPC Program Clerk for more information.
- Most communities use pre-printed faxes that are sent to the primary physician to collect and communicate information. An example may be included in the resources section of this module.
- Provide the physician with the URL for the Fraser Health Symptom Management Guidelines http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliativeCare/Pages/SymptomGuidelines.aspx
- Consider using the SBAR if you are phoning the physician to discuss a new symptom or change in the patient's condition. This Guideline is included in the Resources Section of this module. The Guideline was developed for Hospice but can easily be adapted for HCN use.
- Provide the physician with contact information for the HPC physician if they would like to discuss medical management of their patient.
- Discuss all potential referrals for the HPC Physician with the patient's primary physician prior to making the referral.

Palliative Care Physician

Each community HPC program has at least one HPC MD who is available to see community patients in the home on a consultant basis. Most HPC MD consultations are related to symptom management issues. Other reasons to consult the HPC MD are assistance with goals of care, support for the primary physician, or assessment for

Hospice Residence. If you think your patient would benefit from a consultation, first discuss the referral with the patient’s primary physician.

In most communities, the HPC MD is available at rounds for a more informal consultation with HCN and other team members.

There is a HPC MD On-Call physician in Fraser Health available for telephone advice for physician to physician referrals only. If a Home Care Nurse needs to contact the HPC MD outside of regular business hours, this is generally done through the HPC CNS unless prior arrangements have been made.

<u>HPC Social Worker/Counsellor</u>

Although nurses provide much of the psychosocial support in HPC practice, certain patients and families require specialized supports from the HPC SW or Counsellor. The HPC SW or Counsellor is also available to confer with other team members about the plan of care or your personal challenges in working with HPC patients.

Read:

⇨ FH HPC Symptom Management Guidelines: Psychosocial Support
Recommendation 4 Indicators for Specialized Consultation on Page 18.
Appendix D on Page 28

<u>HPC Clinical Resource Nurse (CRN)</u>

The CRN is your first line resource for day to day clinical support. Clinical support issues could include:

- Clinical questions
- Care planning
- Facilitating transfers to acute care
- Difficult pain or other symptom management
- Trouble-shooting for patients whose condition is changing quickly
- Facilitating consultations with other HPC team members
- Unusual clinical practices
- Education needs

Most CRN’s are available to make joint home visits to assist with assessments and care plans.

<u>Clinical Nurse Specialist (CNS)</u>

The CNS provides leadership and clinical support on your community HPC team. The CNS can also support you with any clinical issues if the CRN is not available. Other aspects of the CNS role include:

- Liaison with other care providers
- Clinical support in Hospice Residences and Residential Care Facilities
- Development of educational resources
- Advancing HPC nursing practice through policy development and other initiatives

On evenings and weekends, the CNS on-call is available to assist with decision making around all areas of HPC nursing practice. See the Information sheet in the resource section for more information.

Home Support

Most Home Support Agencies provide specific training in end-of-life care for their staff and the regular CHW's often develop close relationships with patients and families. Using a communication log book in the home and maintaining regular communication with the Home Support Supervisor in your area will promote a team approach to care. The home support care plan should clearly communicate the goals of care and plan for end of life, especially if there is a possibility the CHW will be present at the time of death. The Home Support Agency should also be aware if there is a DNR order in the home.

As a Home Care Nurse, you have the responsibility of managing the Home Support Hours for patients in the End-Of-Life care group (patients registered with the HPC Program in their last 6 months of life). Making decisions about the Home Support Care Plan requires consideration of many factors such as the patient's level of functioning, social support system, symptom management issues, patient and caregiver strengths and the involvement of other team members. In general, Home Support Hours are capped at 120 hours per month (average 4 hours daily) and are only authorized for personal care or caregiver respite. In special circumstances, additional hours or a more flexible care plan can be authorized by your manager.

Please see the resources section of this module for more information about creating a Home Support Care Plan.

Hospice Volunteers

Each community Hospice Society trains and coordinates volunteers who provide support and companionship to patients and families living with life threatening illness and bereavement support after the death. Volunteers may be able to provide companionship respite but are not able to perform personal care tasks.

Many Hospice Societies have volunteer and bereavement coordinators who attend community HPC rounds and are available to discuss referrals for a volunteer. The referral process for a volunteer varies in each community. Ask your mentor or CNS about the referral process in your community.

HPC Pharmacist

The HPC pharmacist is available to HCN for consultation on medication recommendations and concerns, information about obtaining medications or the HPC medication kit.

HPC Program Clerk

The program clerk helps maintain communication within the HPC team including collecting statistics and tracking resources such as the HPC equipment rentals.

Physiotherapy and Occupational Therapy

Depending on the needs of the patient, the Home Health PT or OT may play an integral part in the care team. Make sure to have a verbal discussion of any referrals with the rehab professional involved prior to making any formal Internal Referrals. Sometimes all that is required is a verbal consultation or advice. The rehab professional can also advise you on the most appropriate discipline for the referral. Use the standard Internal Referral process in your community.

Spiritual Care Provider

Most communities do not have a specifically dedicated spiritual care provider for patients living at home. Spiritual care is available in all Hospice Residences and Acute Care Hospitals. Some patients and families may have their own spiritual care provider through a particular religious community or cultural group. If there are spiritual care issues and the patient or family do not have their own spiritual care provider, discuss the situation with a member of your HPC team to determine which member of the team could best provide support.

Activity 1 Making a Referral

Identify the most appropriate team member(s) to address the following issues from the team:

1) Order the HPC medication kit ____
2) Discuss a DNR order ____
3) Assist with a Life Review activity______________________________________
4) Discuss Guardianship of minor children_________________________________
5) Convert from one opioid to another because of toxic side effects _____________
6) Provide bereavement follow up____
7) Arrange for admission to the THPCU___________________________________
8) Support patients to address feelings of guilt _____________________________
9) Arrange specialized medical equipment _________________________________
10) Educate family caregiver about what to expect as death approaches __________

As you consider these activities, it quickly becomes clear that more than one team member might be involved. Some activities may require collaboration between different team members, such as Hospice admission.

Answers to Activity One:

1) Usually the family physician. On rare occasions this can be ordered by the HPC MD if they are closely involved with the patient/family.
2) Although the DNR needs to be signed by a physician, most team members should feel comfortable discussing resuscitation with the patient or family.
3) Hospice Volunteers and SW/Counsellors are usually the most involved in formal life review activities but all team members could participate.
4) Family members, spiritual care, volunteers, nurses can provide emotional support. SW/Counsellor referral should be considered.
5) Depending on complexity, nursing and primary physician. HPC MD and Pharmacist consultation for more complex situations.
6) Most bereavement support is through the Hospice Society. Also HCN can assess for complicated grief, SW/counsellors for complex situations.

7) Frequently the HCN requests a referral from the family physician to the HPC MD. Can also be facilitated through the CNS/CRN.
8) SW/Counsellor, spiritual care, hospice volunteer
9) Rehab professional, CNS
10) Most commonly HCN but also SW/Counsellor, CHW, MD, hospice volunteers

Activity 2 Participate in HPC Community Rounds

With the assistance of your mentor, prepare to present and discuss a patient in HPC community rounds. Consider using the SBAR tool to prepare for the discussion. Which team members would you like to consult? How will you update the care plan and communicate any changes to the rest of the care team? What is your role in bringing the patient and family perspective to the team?

Activity 3 Make a Joint Visit with a HPC Team Member

Conduct a joint home visit with a member of the HPC team such as the CRN, SW, or HPC MD as appropriate for the needs of your patient. You will want to arrange the visit in collaboration with your mentor or the CRN. After your visit, reflect on the following questions:

-In what ways does the HCN role overlap with the role of the other team member?

-How does effective communication occur within the team?

-How does the perspective of the other discipline enhance care and your own understanding of the patient’s care needs?

Module 7 Wrap Up

As you complete Module 7, take a moment to reflect on your own experiences working within an interdisciplinary team. Write a short paragraph about your experiences. What were the benefits and challenges working in a team? What did you do to contribute to or inhibit team functioning?

Congratulations, you have now completed Module 6. Reassess your progress with the **Outcome Indicators** at the beginning of Module 6 and update your **Learning Plan!**

Module 7 Resource List

Physician Checklist

CNS On-Call Information

SBAR Tool

Home Support Guidelines

Guidelines for Range of Home Support Hours

Reading: Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19, 27-35.

APPENDIX I

Module 7:

Professional Issues and Advocacy

Module Contents:

Professional Issues and Advocacy: Outcome Indicators Checklist

The Home Care Nurse collaborates with the person, family and interdisciplinary team to address ethical issues related to end-of-life care.

Pre=self-assessment prior to completing module Post=review with mentor prior to signing off

Key

N=No Experience S=With Support C=Competent for Independent Practice

Indicator	Pre	Post	Evidence	Date/Initial
Indentify common ethical issues in end-of-life care: -Code Status -Euthanasia -Futility -Palliative Sedation -Principle of Double Effect -Truth Telling -Nutrition and Hydration				
Support informed choices by patients and families regarding end-of-life treatments				
Identify my own values and beliefs about common ethical issues in end-of-life care				
Assist the person and family to identify and address common legal issues: -Advanced Directives -POA -Substitute Decision Maker				
Evaluate own learning needs and create a Learning Plan				
Complete the HPC Enhanced Education Day				

*Indicators adapted from CNA “The Hospice Palliative Care Nursing Exam List of Competencies” (2007) and FH “Hospice Palliative Care Professional Development Pathway for THPCU Nurses (2008).

Ethics in HPC Nursing Practice

“Findings of numerous studies that address ethical nursing practice provide clear evidence that end-of-life care and end-of-life decision making raise some of the most ethically troubling situations for nurses” (Storch, 2004, p. 263).

Ethics in HPC nursing is often about the day to day dilemmas that originate in our relationships with patients and families. Patients and families come to the palliative care program with unique values and beliefs about illness, spirituality, death and dying and our medical system founded in their cultural identity. Each member of the care team brings their own set of values and beliefs. Add in the communication challenges discussed in Module 1 as well as the emotion and anxiety triggered by serious illness. Many factors in modern western society also contribute ethical dilemmas such as:

-advanced in medical technology that allow us to delay death
-increased pressure on caregivers related to early hospital discharges, expanded role of women in the workforce and other cultural changes
-pressure on health care resources from financial constraints and an aging population.

It’s not surprising that nurses often find themselves confronted by ethical dilemmas.

Nurses have an important role on the care team in addressing ethical concerns. Nurses can identify ethical dilemmas to the care team, bring the family perspective to the discussion and advocate for patient and family participation in the decision making process.

When ethical dilemmas are not able to be resolved in a way that enables nurses to practice according to their own moral values, moral distress can occur. Ensuring that we identify ethical dilemmas and participate in the discussion and resolution process will help resolve moral distress.

Addressing ethical dilemmas is best done from the perspective of the interdisciplinary team. Ethical dilemmas are a primary reason for consultation with HPC Consult Team either at Community HPC Rounds or on an individual basis.

Thinking about Ethics

At this time you may want to refresh your understanding of common ethical principles and frameworks used in ethics discussions. Here are some suggestions for resources:

The CRNBC Code of Ethics can be accessed online @
http://www.crnbc.ca/downloads/128.pdf

The HPC Nursing Standards of Practice can be accessed online @
http://www.chpca.net/resource_doc_library/Hospice_Palliative_Care_Nursing_Standards_of_Practice.PDF

A quick review of basic bioethical principles is in the *Textbook of Palliative Nursing* by Ferrell & Coyle in a chart on page 1043.

Fraser Health Ethics Services provides education and consultation services, see the FH Intranet.

As part of your orientation, you will attend the FH HPC Enhanced Education Day which includes information about using an ethics model to support decision making.

Common Ethical Dilemmas

Resuscitation

Discussing resuscitation is an opportunity to clarify goals of care and end-of-life plans as well as the benefits and burdens of CPR. Because a physician's DNR order is required for admission to Hospice Residence and to direct ambulance and other health care professional practice in the community, the discussion often moves away from the patient's goals and understanding of their condition and the meaning of DNR to the patient and family.

It is important to explore with the patient and family their understanding of CPR, what they hope to achieve from CPR, what are their expectations of what would happen after resuscitation, what spiritual/cultural factors are influencing their decision, etc. Often patients will overestimate the success of CPR based on media representation or they may fear that agreeing to a DNR order would mean discontinuation of other life-prolonging treatments. Occasionally patients and families may not agree to signing the Provincial DNR form but will accept a physician's decision that the intervention will not be offered. Discussions about resuscitation often occur over time and patient's wishes for this intervention change as their disease progresses.

Futility

⇨ For more information on futility read the section "Futility and Withdrawal of Treatment" in *Textbook of Palliative Nursing* by Ferrell & Coyle on pages 1040-1041 and the Case Study on page 1042.

Euthanasia

Euthanasia or assisted suicide is not legal in BC at this time and most patients who make requests for this intervention realize it is not possible. Most nurses will still struggle with this type of request and it should be discussed with the care team.

⇨ For more information read "When a Patient Asks to Die" in *Transitions in Dying and Bereavement* by Cairns, Thompson & Wainwright on pages 182-183.

Palliative Sedation

Palliative sedation involves giving sedating medications such as Midazolam to a patient with intractable symptoms at the end of life. This intervention is used infrequently and requires extensive involvement of the HPC team including the HPC physician.

⇨ Read more about palliative sedation in *Transitions in Dying and Bereavement* by Cairns, Thompson & Wainwright on pates 238 and 239.

What ethical principles are involved in the decision for palliative sedation?

What is the principle of Double Effect? How is it enacted in palliative sedation?

Truth Telling

Most nurses will have been involved in situations where the family requests medical information be withheld from a capable adult. These requests may stem from cultural practices where discussing death and dying may be inappropriate, different patterns of decision making in families, or fear of destroying hope.

Most HPC offices have a copy of the Pallium LEAP Curriculum. If available, watch a scenario on the DVD *Clinical Communication in HPC* titled "Engaging Culture". Ask the HPC CRN for support with this activity.

How does the physician in the DVD respect the values and beliefs of the family while maintaining her own ethical principles?

Nutrition and Hydration at the End-of-Life

It is uncommon for artificial hydration or nutrition to be provided in the home setting for patients with life threatening illness. Occasionally fluids may be provided on a temporary basis to relieve uncomfortable symptoms related to dehydration such as delirium or hypercalcemia.

Most patients do not experience hunger or thirst in the last days of life and there can be uncomfortable side effects of over-hydration. This can be a distressing time for family members as providing food and nutrition has a high cultural value. There may be concerns that the patient is suffering, starving or dying of thirst.

Nursing interventions can include education, assessing the meaning of food and nutrition to the family and advocating for the family needs and shared decision making to the rest of the care team.

Common Legal Issues

Advance Care Planning

Advance Care Planning (ACP) is a process of talking about values and goals for future health care choices. Sometimes these conversations are recorded in a document called an Advanced Directive. Some of these conversations might be about who would make health care decisions for the patient if they were too ill to speak for themselves or would they want life sustaining therapies in the event of a terminal illness. There are several documents in Fraser Health to support the ACP process:

- Greensleeve. Transparent green page protector placed in the front of the chart to hold ACP documents.

- Community Greensleeve. Green plastic document protector with magnets on the back. Holds important ACP documents on the fridge in patients' homes where they can be easily located by BC Ambulance.

- Patient Information Pamphlets. Concerning ACP and resuscitation. Also available in Chinese and Punjabi.

- 'My Voice'. Example of an Advanced Directive. Documents patients' expressed wishes for future care. Ask a HPC team member if there is an ACP facilitator in your Home Health office.

- No Cardiopulmonary Resuscitation. After completion, the original white copy should be given to the patient to be kept in the community greensleeve. Often a photocopy or the yellow copy can be kept at the back of the Care at Home package. Sometimes the No CPR form is completed at the GP's office or in acute care and there are only photocopies of the original available for the chart.

Advanced Directives

An Advanced Directive is a written document that outlines a person's wishes for medical interventions if he/she was not capable of making medical decisions. Fraser Health promotes an Advanced Directive called "My Voice" and more information is available on the Intranet under Advance Care Planning. Some people refer to an Advance Directive as a living will. The care team is obligated to follow any known advance directive that exists even though it may conflict with the wishes of the family.

Substitute Decision Makers

If a person is not capable of making medical decisions, a Temporary Substitute Decision Maker (TSDM) is selected. Anyone can be nominated as the TSDM by the patient in an Advanced Directed or Representation Agreement. If a specific individual has not been selected by the patient, there is a legal order of relatives that could assume the TSDM role. A list has been included in the Resources section of this manual.

It is important to discuss Advance Care Planning wishes with patients as early as possible in their illness. Most HPC Consult Teams have ACP facilitators who would be able to assist with completing ACP documents. If you are interested in learning more about ACP or becoming and ACP Facilitator, more information is available on the FH Intranet.

Power of Attorney

A POA allows a family member or friend to manage your financial affairs if you are not capable. A POA does not apply to health or personal care decision, a common misconception. More information about POA can be found online at http://www.publiclegaled.bc.ca/snapfiles/Publications/A%20Death%20In%20Your%20Family.pdf

Activity 1 Ethics in Action

Choose an ethical dilemma from your orientation experience or from prior nursing practice in end-of-life care.

1) Write a short paragraph describing the experience. Why do consider the experience an ethical dilemma? What ethical principles were relevant to the situation? How was culture relevant?

2) Identify some of the values and beliefs of the patient and family. How did these values or beliefs affect their behaviour and approach to the situation?

3) What were your own beliefs about the ethical dilemma? How did your beliefs affect your behaviour or nursing practice?

4) How did the dilemma get resolved? By whom? What was your role as the nurse?

Module 7 Wrap Up

By now, you are likely completing your orientation to HPC nursing practice. Congratulations on all your hard work. Take a few moments to reflect on your experiences and update your learning plan.

1) Review the Outcome Indicators for each module with your Mentor or CRN
2) Using the Learning Plan that you developed during the orientation, update your learning goals and plan learning activities for your first year of practice.
3) Schedule a time to meet with the HPC CRN or Team Leader to review the completion of the orientation competencies and your new learning plan.

References

Anderson, L. W., & Krathwohl, D. R. (2001). In Airasian P. W., Cruikshank K. A., Mayer R. E., Pintrich P. R., Raths J. and Wittrock M. C. (Eds.), *A taxonomy for learning, teaching, and assessing*. New York: Addison Wesley Longman, Inc.

Barkman, P. (2008). *Hospice palliative care program statistics 2007/08*. Surrey, BC: Fraser Health Authority.

Barnard, A., Hollingum, C., & Hartfiel, B. (2006). Going on a journey: Understanding palliative care nursing. *International Journal of Palliative Nursing, 12*(1), 6-12.

Becker, R. (2007a). The development of core competencies for palliative care educators. *International Journal of Palliative Nursing, 13*(8), 377-383.

Becker, R. (2007b). The use of competencies in palliative care education. In L. Foyle, & J. Hostad (Eds.), *Innovations in cancer and palliative care education* (pp. 13-23). Oxford: Radcliffe Press.

Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Menlo Park, California: Addison-Wesley.

Bugge, E., & Higginson, I. J. (2006). Palliative care and the need for education-do we know what makes a difference? A limited systematic review. *Health Education Journal, 65*(2), 101-125.

Cairns, C., Thompson, M. & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care.* Baltimore, MD: Health Professions Press.

Canadian Hospice Palliative Care Association (2008). *Fact sheet: Hospice palliative care in Canada.* Retrieved 10/3, 2008, from http://www.chpca.net/events/nhpc_week/2008/Fact_Sheet_HPC_in_Canada_20 08.pdf

Canadian Hospice Palliative Care Association. (2002a). *Hospice palliative care nursing standards of practice.* Retrieved 10/3, 2008, from http://www.chpca.net/resource_doc_library/Hospice_Palliative_Care_Nursing_Standards_of_Practice.PDF

Canadian Hospice Palliative Care Association. (2002b). *A model to guide hospice palliative care*. Retrieved 5/26, 2009, from http://www.chpca.net/resource_doc_library/model_to_guide_hpc/II.pdf

Canadian Nurses Association. (2007). *Hospice palliative care nursing certification*. Retrieved 03/08, 2009, from http://www.cna-aiic.ca/cna/documents/pdf/publications/CERT_Hospice_Palliative_Care_e.pdf

Canadian Nurses Association. (2008). *The origins of nursing specialty certification in Canada*. Retrieved 07/25, 2008, from http://www.cna-aiic.ca/CNA/nursing/certification/about/history/default_e.aspx

Carper, B. A. (1999). Fundamental patterns of knowing in nursing. In E. C. Polifroni, & M. Welch (Eds.), *Perspectives on philosophy of science in nursin*g (pp. 12-19). Philadelphia: Lippincott.

Carr, S. M. (2004). A framework for understanding clinical reasoning in community nursing. *Journal of Clinical Nursing, 1*3, 850-857.

Carraccio, C., Wolfsthal, S. D., Englander, R., Ferentz, K., & Martin, C. (2002). Shifting paradigms: From Flexner to competencies. *Academic Medicine, 77*(5), 361-367.

Connelly, L. M., & Hoffart, N. (1998). A research-based model of nursing orientation. *Journal of Nursing Staff Development, 1*4(1), 31-39.

Cronin, M., & Connolly, C. (2007). Exploring the use of experiential learning workshops and reflective practice within professional practice development for post-graduate health promotion students. *Health Education Journal, 6*6(3), 286-303.

Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. *Oncology Nursing Forum, 1*7(1), 87-94.

Dillard, N., Siktberg, L., & Laidig, J. (2005). Curriculum development: An overview. In D. M. Billings, & J. A. Halstead (Eds.), *Teaching in nursing: A guide for facult*y (second edition ed., pp. 87-107). St. Louis, MO: Elsevier Saunders.

Downing, G.M. & Wainwright, W. (2006). *Medical Care of the Dying (4th ed.).* Victoria, B.C.: Victoria Hospice Society.

Duke, S., & Appleton, J. (2000). The use of reflection in a palliative care programme: A quantitative study of the development of reflective skills over an academic year. *Journal of Advanced Nursing, 3*2(6), 1557-1568.

Ferrell, B. R., & Borneman, T. (2002). Community implementation of home care palliative care education. *Cancer Practice, 1*0(1), 20-27.

Ferrell, B.R. & Coyle, N. (2006). *Textbook of palliative nursing.* New York: Oxford University Press.

Fowler, J. (2008). Experiential learning and its facilitation. *Nurse Education Today, 2*8, 427-433.

Fraser Health Hospice Palliative Care Program (2006). *Symptom Guidelines.* Retrieved 5/26, 2009, from http://www.fraserhealth.ca/Services/HomeandCommunityCare/HospicePalliativeCare/Pages/SymptomGuidelines.aspx

Fraser Health Hospice Palliative Care Program (2008, July). *Hospice palliative care professional development pathway for THPCU nurses.* Unpublished internal document.

Fraser Health Professional Practice and Integration (2007). *Mentorship: Planning together.* Unpublished manuscript.

Greveson, G.C. & Spencer, J.A. (2005). Self directed learning-the importance of concepts and contexts. *Medical Education,* (39) 348-349.

Hartrick Doane, G. (2002). Beyond behavioural skills to human-involved processes: Relational nursing practice and interpretive pedagogy. *Journal of Nursing Education*, *41*(9), 400-404.

Hughes, P. M., Parker, C., Payne, S., Ingleton, M. C., & Noble, B. (2006). Evaluating an education programme in general palliative care for community nurses. *International Journal of Palliative Nursing*, *12*(3), 123-131.

Iwasiw, C., Goldenberg, D., & Andrusyszyn, M. (2005). *Curriculum development in nursing education*. Sudbury, MA: Jones and Bartlett.

Jillings, C. & O'Flynn-Magee, K. (2007). Knowledge and knowing made manifest: Curriculum process in student-centered learning. In L. E. Young, & B. L. Paterson (Eds.), *Teaching nursing: Developing a student-centered learning environment* (pp. 383-402). Philadelphia: Lippincott, Williams & Wilkins.

Kenney, L. J. (2003). An evaluation-based model for palliative care education: Making a difference to practice. *International Journal of Palliative Nursing*, 9(5), 189-194.

Kuiper, R. A., & Pesut, D. J. (2004). Promoting cognitive and metacognitive reflective reasoning skills in nursing practice: Self-regulated learning theory. *Journal of Advanced Nursing, 4*5(4), 381-391.

Lawton, S., & Carroll, D. (2005). Communication skills and district nurses: Examples in palliative care. *British Journal of Community Nursing, 1*0(3), 134-137.

Ludlow, V., Gaudine, A., & Jacobs, M. (2007). The design of a hemodialysis nursing orientation program. *The Canadian Association of Nephrology Nurses and Technologists Journal, 1*7(2), 44-47.

Maida, V. (2002). Factors that promote success in home palliative care: A study of a large suburban palliative care practice. *Journal of Palliative Care, 1*8(4), 282-286.

Maudsley, G., & Strivens, J. (2000). Promoting professional knowledge, experiential learning and critical thinking for medical students. *Medical Education, 3*4, 535-544.

McClement, S. E., Care, D., Dean, R., & Cheang, M. (2005). Evaluation of education in palliative care: Determining the effects on nurses' knowledge and attitudes. *Journal of Palliative Care, 2*1(1), 44-48.

O'Shea, E. (2003). Self directed learning in nurse education: a review of the literature. *Journal of Advanced Nursing*, 43(1), 62-70.

Pallium Project (2006). *Learning essential approaches to palliative and end of life care (LEAP).* Edmonton, AB: The Pallium Project.

Reese, D.J. & Sontag, M. (2001). Successful interprofessional collaboration on the hospice team. *Health & Social Work,* 26(3), 167-174.

Ruth-Sahd, L. A. (2003). Reflective practice: A critical analysis of data-based studies and implications for nursing education. *Journal of Nursing Education, 4*2(11), 488-497.

Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care,* 19(1), 27-35.

Storch, J. L. (2004). End-of-life decision-making. In J. L. Storch, P. A. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 262-284). Toronto, ON: Pearson Education Canada.

Tanner, C. A. (2006). Thinking like a nurse: A research-based model of clinical judgment in nursing. *Journal of Nursing Education, 4*5(6), 204-211.

Thulesius, H., Petersson, C., Petersson, K., & Hakansson, A. (2002). Learner-centred education in end-of-life care improved well being in home care staff: A prospective controlled study. *Palliative Medicine, 1*6, 347-354.

Watson, J. (1988). Human caring as moral context for nursing education. *Nursing & Health Care,* 9(8), 422-425.

Wessel, E. M., & Rutledge, D. N. (2005). Home care and hospice nurses' attitudes toward death and caring for the dying: Effects of palliative care education. *Journal of Hospice and Palliative Nursing*, 7(4), 212-218.

World Health Organization. (2009). *WHO definition of palliative care*. Retrieved 5/29, 2009, from http://www.who.int/cancer/palliative/definition/en/

Young, L. E., & Maxwell, B. (2007). Student-centered teaching in nursing: From rote to active learning. In L. E. Young, & B. L. Paterson (Eds.), *Teaching nursing: Developing a student-centered learning environmen*t (pp. 3-25). Philadelphia: Lippincott, Williams & Wilkins.

Zurmehly, J. (2007). A qualitative case study review of role transition in community nursing. *Nursing Forum, 4*2(4), 162-170.