

A Palliative Care Certificate Program: A Nursing Education Model for Developed and Developing Countries

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Introduction

The provision of effective palliative care requires evidence-based education of nurses and other health care professionals, and teamwork both in urban and rural settings. Two recent palliative care needs assessments of nurses found that the majority of respondents expressed the desire to learn more about palliative care [1,2]. Few respondents noted formal staff certification training in hospice and palliative nursing. When asked, "What specifically would you like to learn?" common responses included such topics as pain and symptom management including the use of complementary alternative modalities (CAM) and medications, general education about palliative care including models of palliative care, death and dying, end-of-life care, and psychosocial issues and end-of-life communication. Web-based instruction was identified as a valuable educational tool as it is remotely available, eliminates travel for participants, and can provide more varied stimulation than traditional lecture-based instruction. Additionally, web-based networking and learning has the potential to improve palliative care in rural settings. This paper describes a nursing education model for palliative care that addresses nurses' educational needs and can be accessed remotely.

Background

Dr. Regina M. Fink (RMF), an Associate Professor at the University of Colorado, College of Nursing (UCCON) and School of Medicine, teaches in a Palliative Care Certificate Program (PCCP) at the UCCON, with two esteemed palliative care nursing experts/colleagues, Drs. Paula Nelson-Marten (PNM) and Nancy English (NE). Both were instrumental in developing one of the first PCCPs for nurses in the United States. Their story about how their program developed is important to share with others who may be contemplating developing such a program in their setting or country. This paper, based on interviews with Drs. Nelson-Marten and English, delineates how the PCCP was developed, who it serves, and the areas of coursework focus. In addition, Dr. Fink had the good fortune to meet Ms. Amal Jafari (AJ), a palliative care nurse in Saudi Arabia at the 2013 Middle East Cancer Consortium Palliative Care meeting in Muscat Oman. Ms. Jafari had a strong desire to update her palliative care knowledge and subsequently enrolled in the PCCP at the University of Colorado in 2014. She has answered questions about her experiences taking the two courses offered and how this program has influenced the care of patients in her country.

Interview with Drs. Paula Nelson-Marten and Nancy English

RMF: How and when did you both develop an interest in palliative care?

PNM: My oncology focus, as an advanced practice nurse, piqued my interest in chronic illness, supportive care, and end-of-life care. My doctoral work in nursing (PhD in research and theory development with a cognate area of moral philosophy) led to my interest in bioethics. The SUPPORT study, published in 1995, revealed that end-of-life care was not being done well in U.S. Hospitals [3]. These findings furthered the development of palliative care as a specialty and confirmed my own interest in the field, caring for individuals with chronic illness who may also be seriously ill. In the late 1990s, I was invited to participate in a palliative care preceptorship program offered at Northwestern Memorial Hospital/Medical Center in Chicago (the unit was then directed by Dr. Charles von Gunten, a physician and palliative care pioneer). I learned a great deal about palliative care through this experience. Since that time, much of my palliative care work has focused on practice, teaching, curricular development, and having three NCI/NIH grants. Two of the grants (funding between 1994-1997 and 1997-2000) were part of collaboration with Dr. Paul Seligman, a medical oncologist and hospice physician at the University of Colorado, School of Medicine, and Regina Fink, oncology clinical nurse specialist and research scientist at the University of Colorado Hospital where we focused on the development of an Interdisciplinary course integrated into the curriculum of both the School of Medicine and College of Nursing. The course, Issues in Terminal Illness and Palliative Care, was made available to nursing, medical, dental, and pharmacy students, and was also opened to health care professionals working for local hospices [4]. Our second grant continued this work and also focused on quality of life for palliative care patients [5]. My own NCI/NIH grant (2001-2004) facilitated the development of the PCCP in Nursing (2005-present) that is discussed in this article. The PCCP has been a sustaining product of the 2001-2004 NCI/NIH grant.

NE: I first became interested in palliative care when I had a personal experience with death and dying. Death changes things; I learned this personally when my mother died. My career focus transitioned from my role as Clinical Nurse Specialist in Gerontology to Clinical Nurse Specialist in Palliative Care. Much of my work experiences have focused on palliative/hospice home care and pediatric palliative care.

RMF: What gave you the idea and impetus to start a PCCP at the UCCON?

NE: After working as a hospice nurse for several years for a local Denver hospice, I realized that quality of life, symptom management strategies, and an interdisciplinary team (IDT) focus was something every nurse needed to know, not just hospice nurses. Patients' and their families' lives were definitely improved when symptoms were well managed; they could participate in life as well as prepare to die. I could see that the nurse, functioning as part of the IDT, was key to improving a patient's quality of life. A few of my colleagues believed the same; we became educator ambassadors for palliative care. Our first step was to understand what acute and home care nurses actually knew about palliative care and symptom management. A needs assessment highlighted that most nurses we interviewed were unfamiliar with the concept of "palliative" care and could not even say or spell the word. At this point we felt we had to get the UCCON involved. There, we met Dr. Paula Nelson-Marten, who shared a similar vision.

PNM: In 1998, our original team composed of Nancy, me, and a group of interested area hospice nurses, a researcher and pain content expert, a statistician, and learning expert, began working on a grant proposal. A national search revealed only four programs in the U.S. that were dedicated to teaching palliative care nursing. These programs included a 1) Nurse Preceptorship Program, at the Medical College of Wisconsin [6]; 2) The HOPE program (home care outreach program for palliative care education) through the City of Hope Medical Center [7]; 3) beginning graduate program in palliative care nursing for nurse practitioner students at New York University (Personal communication with Dr. Deborah Sherman, 11/1997) [8]; and 4) the graduate nursing program at Ursuline College in Cleveland, Ohio [9]. The grant team also found that there was no formal palliative care education offered in the state of Colorado. Since nurses are the largest group of health care professionals to respond to the needs of families and patients with a serious chronic or terminal illness, it was important that educational opportunities existed to develop these skills for Colorado nurses. As Colorado is a predominantly rural state with 53 of 64 counties designated as rural, the grant team believed that education should be taken "on the road" to rural settings. The lack of educational programs for nurses gave the proposed grant project importance in light of the need to develop a "model curriculum" in palliative care that could be taught to nurses in different settings both in Colorado and nationally.

RMF: Tell the readers about your grant funding

PNM: After conducting surveys to establish a need for such a program in both urban and rural Colorado and finding a perceived need on the part of both nurses and institutions for an educational program, our NCI-funded grant, Palliative Care Nursing beyond Hospice: A Nursing Education Model (R25-CA83857, 2001-2004), began in 2001, with the goal of integrating principles and practice of palliative nursing care into urban settings, including acute and long-term care. A secondary goal was to assess palliative care educational needs among nurses working in rural settings and to plan and implement educational offerings for the rural nurse.

There were two components to the "model curriculum" that were developed through the grant; 1) Continuing Education Sessions (for agencies, urban and rural, with CEU's) and 2) a Theory tract (for individual nurses who desired a longer educational program). Two courses were developed for this theory tract, Courses A and B. This is

how the PCCP came into existence; our first class of palliative care theory students began in 2002.

RMF: What was your rationale for writing this grant and proposing this Palliative Care Certificate Program?

PNM: The need for this type of educational program to be developed was substantiated by the 1995 SUPPORT Study [3]. The Institute of Medicine Report, *Approaching Death: Improving Care at the End of Life*, a response to the SUPPORT Study, was comprehensive and listed seven recommendations to improve end of life care [10]. Recommendation # [4] related to the education of health care professional students regarding end-of-life care; "Educators and other health care professionals should initiate changes in undergraduate, graduate and continuing education to ensure that practitioners have relative attitudes, knowledge and skills to care well for dying patients" [10].

RMF: Which nurses did you aim to serve?

NE: We were hopeful that any nurse interested in learning more about palliative care would want to enroll. This included nurses who worked in the acute care setting, home care agencies, or long term care, in both urban and rural settings in Colorado and beyond.

RMF: How long has the PCCP been in existence? How has it been sustained?

NE: The two courses comprising the PCCP have been taught yearly for the last 13 years, from 2002-2015. Nurses have enrolled for the courses through the Professional Development Program at the UCCON using this website [11]. http://www.ucdenver.edu/academics/colleges/nursing/programs-admissions/CE_PD/Pages/palliative-care-certificate.aspx

RMF: Approximately how many nurses have completed the certificate program? Where do they reside?

NE: Twelve to fifteen nurses have enrolled in the PCCP each year; thus, approximately 150 nurses have completed the coursework. The majority of nurses are from Colorado. However, most every state in the U.S. has been represented. We even had international nurses enrol with three nurses from Bermuda and one from Saudi Arabia participating in the program.

RMF: What kinds of nurses enrol?

NE: Many of our classes include both Bachelor's prepared nurses and advance practice RNs (nurse practitioners, nurse educators, clinical nurse specialists, and researchers) who wish to improve their knowledge of palliative care and integrate palliative care into their practice settings. Nurses who are interested in palliative care and have taken our courses are from the inpatient acute care areas (oncology, cardiac, ICU), outpatient clinics (e.g., oncology, heart failure, neurodegenerative/neurological), hospice, home care, long term care, paediatric and adult, and faculty from Colleges of Nursing. In recent years the majority of our students are already APNs. Many works in palliative care and seek extra preparation to take the Advanced Certification Examination in Hospice and Palliative Nursing offered through the Hospice and Palliative Nursing Association (HPNA). In our current course, 14 of 15 students are either APNs, are currently students enrolled in an advanced nursing practice program, or have

another type of nursing master's degree; one student is BSN prepared and has been hired to work in palliative care beginning in 2016.

RMF: Your current certificate program encompasses two courses. Tell the reader what they entail.

PNM and NE: The first of two courses in the Professional Development PCCP at UCCON is Advanced Concepts in Palliative Care. This introductory course focuses on palliative care specialty knowledge and skills for the APN. Course content includes: palliative care assessment, advance care planning, advocacy, care of the patient approaching death, a communication skills review, a focus on ethical

issues, palliative care in diverse populations and settings, and examining current best evidence. Working on a systems thinking project is one of the class assignments. Students work in teams to choose a topic they wish to learn more about, e.g. a special population or particular setting for palliative care. Students are asked to develop a PICO (Population, Intervention, Comparison, Outcomes) question and a search strategy to find [3,4] current (within the last 3-5 years) research articles to review and critique. Results are shared with the class and include a plan for how one would incorporate palliative care into practice with this population/setting. Examples of systems thinking project topics are included in Table 1.

Question	PICO (Population, Intervention, Comparison, Outcomes)
Does palliative care reduce readmissions for chronically ill adult patients?	P: Adults with complex chronic illness I: Palliative Care APN providing palliative care management after discharge C: Standard care: Follow up with PCP after discharge, no palliative care management O: Reduction of hospital readmissions
Does music therapy decrease pain and anxiety, increase patient and parent satisfaction, and improve quality of life in pediatric palliative care patients?	P: Pediatric palliative care patients (0-16 years) I: Music therapy C: Standard care. O: Decrease pain and anxiety, increase patient/parent Satisfaction, and improve quality of life.
Does the Respiratory Distress Observation Scale accurately identify breathlessness/dyspnea in the cognitively impaired adult?	P: Cognitively impaired adults with dyspnea/breathlessness I: Respiratory Distress Observation Scale for the measurement of dyspnea/breathlessness C: Behavioral scale used to measure dyspnea/breathlessness O: Establishment of a valid and reliable measurement tool to assess dyspnea in the cognitively impaired adult
In advanced heart failure patients with LVADs, how does a palliative care consult as compared to usual care impact patient management?	P: Advanced heart failure adult patients with an LVAD I: Palliative care consultation C: Usual care O: Improve quality of life, decrease in symptoms, improve patient satisfaction
Does early advanced care planning for outpatient dementia patients improve quality of end-of-life care and decrease incidence of aggressive end-of-life interventions?	P: Dementia Patients in Outpatient Setting I: Early advanced care planning (ACP) C: Usual care O: Improve quality of end-of-life care and decrease aggressive interventions at the end of life.
Does having conversations earlier about a heart failure patient's prognosis and advance care planning improve end of life planning and outcomes?	P: Outpatient End Stage Heart Failure (Functional Class NYHA 3) I: Early Conversation of prognosis and advance care planning C: Usual Care O: Improve knowledge about prognosis and completion rate of Advance Directive.
Does the initiation of palliative care education improve nurse's palliative care knowledge, aid in the development of a palliative care champions team, and early integration of palliative care?	P: Nurses who care for patients diagnosed with chronic or life-limiting illness I: Initiation of palliative care education program C: No education O: Improve palliative care knowledge, aid in the development of a palliative care champions' team, and early integration of palliative care services.
Do patients with cancer pain experience improved pain management and decreased pain intensity if cared for by palliative care team?	P: Adult patient with cancer pain I: Palliative care consultation for pain management C: No referral to palliative care team O: Improved pain management, decreased pain intensity.
Does a palliative care consult impact the incidence of feeding tube placement on hospitalized advanced dementia patients?	P: Hospitalized advanced dementia patients I: Palliative care consult to discuss goals of care regarding nutrition

	C: Standard care O: Decreased incidence of routine feeding tube placement
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Table 1: Systems thinking project PICO examples.

The second class, Complex Symptom Management in Palliative Care, is an advanced theory course focusing on assessment and management of the multiple symptoms palliative care patients may experience. Symptom management includes physical, psychosocial, and spiritual interventions. Ethical consideration concerning moral

agency, autonomy, difficult decisions; evidence-based palliative care practices; and the role for the APN is explored. Each week students review a symptom or symptom cluster through case study analysis and discussion. A list of symptoms discussed is included in Table 2.

Week	Topic
1	Course Introduction and Symptom Assessment
2	Withdrawing, Withholding, and Ethical issues
3	Pain Assessment
4	Pain Management (Pharmacological and Nonpharmacological Approaches)
5	Nausea and Vomiting
6	Complex Gastrointestinal Symptoms (Anorexia, Cachexia)
7	Anxiety and Depression
8	Fatigue
9	Sleep and Insomnia
10	Dyspnoea
11	Acute Confusional States (Delirium)
12	Symptom Potpourri: Constipation, Malignant Bowel Obstruction, Diarrhoea, Skin Issues, and Malignant Wounds
13	Palliative Sedation
14	Integration Case Study: Final Assignment Case Study Analysis – Heart Failure or Cancer Case

Table 2: Complex symptom management in palliative care – Weekly topics.

RMF: Are these courses in person or online?

NE: The Complex Symptom Management in Palliative Care course has predominantly been online. We utilized multiple methods for teaching the Advanced Concepts Course. During the first three years of the certificate program, a 3 credit in person full semester (Saturday) course was offered. In 2005, a week-long intensive in person on campus class occurred. Then in summer 2009, a hybrid course was developed with students in class for one full week followed by 4 weeks of online coursework. During the summer of 2015, the Advanced Concepts Course was facilitated in a completely online format with 8 weeks of coursework.

RMF: How often are the courses updated? Are these course aligned with the HPNA competencies?

NE: Courses are updated and revised every year, based on new evidence. As technology has improved various formats for discussions have been incorporated into the two courses. Online journal clubs and zoom discussions are just a couple of examples of new ways to engage the students. The 2013 National Consensus Project for Quality Palliative Care Clinical Practice Guidelines have been incorporated into our courses [12]. The HPNA has multiple monographs on various

symptoms and newly developed competencies that form a basis for our courses [13].

Interview with Ms. Amal Jafari

RMF: Tell us about your current role in palliative care in Saudi Arabia?

AJ: As a palliative care nurse specialist, I assist with the diagnosis, treatment, and management of acute and chronic health conditions for cancer patients at the Ministry of National Guard and Health Affairs and Princess Noorah Oncology Center, King Abdulaziz Medical City in Jeddah. My role is multidimensional. Not only am I involved with developing a patient’s plan for palliative care, I also educate nurses, students, and other health care professionals about palliative care and ensure we have adequate educational resources. I collaborate with colleagues to standardize policies, procedures, guidelines, and practice related to palliative and end-of-life care. I increase the awareness about palliative care services in my country by participating in conference and educational activities.

In my work setting, I receive referrals from physicians and other colleagues to see cancer patients in need of palliative care. When

visiting with patients and their family members, conducting a comprehensive palliative care assessment and discussing goals of care with the patient and family is so important. I always incorporate compassion, sensitivity, and respect for cultural and religious differences into my daily practice. I discuss my patient's and family's needs with my physician colleagues to provide the best possible care. My overall goal is to actively participate in developing and maintaining an effective palliative care interprofessional team approach to end-of-life care for patients and their families. Arranging anticipatory grief counselling and bereavement support for family members is another program I coordinate.

RMF: What made you consider enrolling in the palliative care certification course?

AJ: During my work over the past nine years in palliative care nursing, I was exposed to palliative care practices in Saudi Arabia and collaborated with a palliative care physician who completed a palliative care fellowship and training in Canada. After attending the MECC Palliative Care conference, I realized I had a lot more to learn. Therefore, I enrolled in the PCCP to update my knowledge and use this new information in practice.

RMF: What information did you learn from both classes that you are now using in practice?

AJ: I learned many things from participating in the PCCP. I am interested in critically reviewing and appraising research related to palliative care practice in my institution and to teach others to do this. After I participated in the PCCP, I have become one of the most useful resources to other health care providers in my institution related to palliative care. We established and opened a palliative care unit and I assisted with this change. Some other key things I have used in my practice include:

Use the NURSE [14] technique when communicating difficult issues with patients/families.

Involve the ethics committee for ethical dilemmas in end-of-life care issues.

Change symptom management practices based on evidence.

Increase awareness about the benefit of non-pharmacological interventions to control physical symptoms.

See the whole picture for the patients and their families and to practice patient-centered care.

Respect patient and family autonomy and to practice palliative care within ethical and religion principles.

RMF: What was your experience like coming to the U.S. for the in person class?

AJ: It was one of the most beneficial and self-development experiences I have had in my life. I traveled alone and met international experts in palliative care, shared knowledge about my practice, learned from others' experiences, and developed a professional network with other colleagues and experts in the field. There was a sense of respect for cultural diversity and different religious backgrounds.

RMF: How was the online symptom management class? Any challenges you faced?

AJ: It was a bit difficult for me in the beginning as I was also working. There was a significant time difference (from Saudi Arabia to Colorado) to participate in online discussions and work with fellow students on projects. I had never reviewed, critiqued, and discussed articles for symptom management in palliative care with senior nurses and experts in palliative nursing. Discussing medications and prescribing practices in the case studies was also a challenge for me as I am not qualified to practice as an APN in my country. However, it was very useful and beneficial to me to have access to up-to-date evidence-based practice in symptom management for other palliative patients (COPD, heart failure, HIV, and Geriatric) besides cancer patients.

RMF: How have you changed palliative care in your country? What are your future goals?

AJ: I have increased the awareness about palliative care services in my country by participating in educational programs. My goal is to uplift the standard of palliative care practice in my Kingdom. I would like to ensure that non-oncology patients in the hospital and community also receive access to palliative care services. I would like to encourage our palliative care team to participate in research projects to improve the quality of care and practice in palliative care.

Summary

The 2014 IOM Report, *Dying in America*, focuses more on palliative care as being a care continuum from when one is first diagnosed with a chronic or serious life-ending, illness through the end-of-life [15]. It alludes to all of the many changes that have occurred since the first IOM Report, *Approaching Death: Care at the End of Life* [10]. The one constant is the continuing need to educate both health care students and professionals in both chronic and end-of-life care practice from a "whole person" perspective. Herein is the current challenge for all health care professionals, both educators and practitioners: we must all continue to learn and practice all concepts related to palliative care. The science of palliative care is changing daily and it is our responsibility to keep up with the most current evidence and enfold it into our teaching and practice.

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