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# Palliative Care for Chronic Illness – A Different Paradigm for the Advance Practice Nurse in the Nursing Home

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CEDARVILLE UNIVERSITY

SCHOOL OF NURSING

June 27, 2013

WE HEREBY RECOMMEND THAT THE PROJECT PREPARED BY

Melissa Ann Towler

PALLIATIVE CARE FOR CHRONIC ILLNESS– A DIFFERENT PARADIGM FOR  
THE ADVANCE PRACTICE NURSE IN THE NURSING HOME

BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE  
DEGREE OF MASTER OF SCIENCE IN NURSING

2013

Cedarville University

## Abstract

Today, 51% of all Nursing Home (NH) residents are 85 years old and above, 6 years older than the life expectancy for both men and women in the United States (US). Most NH facilities provide care using a medical model of care focused on cure and acute illness, yet many older adults experience dying as a gradual process from chronic disease and/or serious illness. In the US, the need to consider innovative approaches to gradual death and chronic illness is necessary. For those who are actively dying, hospice provides a framework of care focusing on pain relief and comfort. However, neither the current medical model of “cure” nor hospice are adequate to provide care to those of advanced age who are nearing the end of life, but for whom death is not imminent. In contrast, *concurrent palliative care* (PC), as opposed to *palliative care synonymous with hospice* (hospice), does provide a framework of comfort, caring, and quality for older adults with chronic disease or serious illness. The purpose of this project is to introduce an evidence-based recommendation for concurrent palliative care (PC) to be used by the Advanced Practice Nurse in the nursing home.

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## Chapter 1

### INTRODUCTION

*And there is a time for every event under heaven-A time to give birth and a time to die.*

*Ecclesiastes 3:1-2(NASB)*

There is one thing of which we can be certain; death will come to all of us. If we are a Christian, we know that our non-material essence continues on for eternity in spite of the death of our body. Therefore, for the purpose of this project, death will be defined as the end of life here on earth. The New Webster's Expanded Dictionary (1992) defines *end* as the extreme point; the last part; final state; completion; death; close of life" (p.108), and *life* as "vitality; present state of existence; time from birth to death" (p.198). The medical community defines end-of-life (EOL) as referring to a final period (hours, days, weeks, or months) in a person's life during which it is medically obvious that death is imminent or a terminal moribund state cannot be prevented (The Free Medical Dictionary, 2013). Therefore, the EOL is the conclusion of the living state, resulting in death.

In past centuries there was an acceptance of death. Ancient peoples believed in the art of dying (Nuland, 1995). The only possible solution to dying was to let it happen. Once certain symptoms made their appearance the only choice was to die. Many died at peace with God. For those people who experienced suffering, there was resignation, prayer and family to ease the final hours (Nuland, 1995; Cameron and Houldin, 2012).

A half century ago, a new era in medicine began (Nuland, 1995). Modern healers began to try to reduce the suffering associated with death, making death tranquil and kind; but, another change came at the turn of the 21<sup>st</sup> century. Healers began to view

death as more avoidable, and huge amounts of resources were put into the art of saving lives and not of the art of dying (Cameron & Houdlin, 2012). We became advanced at rescue; when rescue failed, we were unprepared for the human experience of death (Nuland, 1995). The advanced medicine of antibiotics, improved nutrition, and developments in public health and safety led to extended life expectancy (Ham et al, 2007). In 2010, the average life expectancy was 78.7 years compared to 47.3 years in 1900 and 68.2 years in 1950 (CDC, 2011). Today, because of increased life expectancy, many times our bodies die gradually from chronic disease and serious illness (Nuland, 1995; Ham et al, 2007). To illustrate, in 2007 the leading causes of death were all chronic in nature: heart disease, cancer, stroke and lower respiratory disease (Meier, Lam and Carlson, 2010).

Western Medicine operates under the philosophy of disease cure and management, which has changed the death experience to a medicalization of death (Cameron & Houdlin, 2012). Death at home has transitioned to death in an institution. One in five deaths in the United States occurs in a nursing home (NH) facility, (CDC, 2008). By 2030, an estimated 3 million people will live in NHs and almost 50% of U.S. adults will die there (Meier, Lam & Carlson, 2010). However, data collected from the 2004 National Nursing Home Survey indicated that only a portion of NH residents received EOL care in the form of palliative, EOL, or hospice care (CDC, 2008).

In recent years, end-of-life care initiatives have become more wide spread. The CDC lists numerous research projects, national and states organizations, and multidisciplinary organizations that have developed, and provided education about appropriate EOL care (CDC, 2012). However, according to Jerant et al, (2004) “studies

have shown that many older persons nearing the end of their life experience unnecessary suffering caused by uncontrolled symptoms” (p. 54). Furthermore, access to palliative care has been found to be dependent on where one lives, with urban areas more likely to have hospital based palliative care units available than rural areas (Santamour, 2008).

During the spring of 2013, I spent 150 clinical hours with a Certified Nurse Practitioner (CNP) who was available for the care of 2000 residents that lived in a number of senior housing settings located in rural southern Ohio. This organization employed a Gerontologist and a CNP who saw patients in an office setting, independent homes, assisted living facilities, two independent apartment complexes and two nursing homes.

The majority of people we cared for were over the age of 65, and some were over 100 years of age. I observed multidimensional suffering among many of the older adults living in the nursing home. The following examples illustrate this point. A blind 87 year old woman who was actively dying in the rehabilitation unit experienced unnecessary suffering without her family at her side, and died six hours after we saw her. Patients in their 90s who no longer had functional or cognitive ability yet they were continued on 25 different medications for numerous comorbidities. Patients with dementia who were put on PRN pain medications; and one patient who was delirious from inadequate pain control after a hip replacement. While the majority of patients had advanced directives on their charts, some did not, even if their diagnosis was end-stage disease. I saw one patient with end stage heart failure, who remained a full code. Despite multiple hospital admissions with progressive clinical deterioration, her code status remained unchanged. At no time (that I saw) was she counseled about her EOL options of care.



In summary, these NH facilities provided care using a cure/acute medically focused model of care. For those residents who are actively dying, hospice care provides a framework of care focusing on pain relief and comfort. Neither the current medical model nor hospice is adequate to provide care to those of advanced age who were nearing the end of life, but for whom death was not imminent. In contrast, palliative care concurrent with curative care (concurrent PC), does provide a framework of comfort, caring, and quality for older adults. The purpose of this project is to introduce an evidence-based recommendation for concurrent palliative care to be used by the Advanced Practice Nurse in a nursing home.

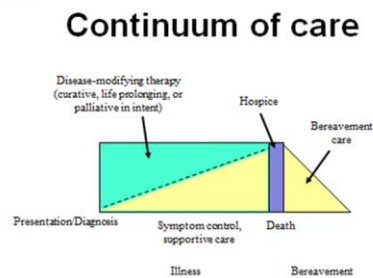
## Chapter 2

### PALLIATIVE CARE

Pastrana et al. (2008) attempted to define the term palliative care in their discourse analysis. They found a lack of agreement on the meaning of the terms used to describe palliative care by palliative care experts. However, they did identify relief and prevention of suffering and improvement of quality of life to be the main goals of palliative care.

Jerant et al. (2004) agreed with this definition of palliative care, adding that PC of older adults should be viewed as care primarily intended to relieve the burden of physical and emotional suffering that accompanies the illnesses associated with aging. They stated that as a framework, palliative care associated only with hospice, is very limited and even flawed. Jerant et al (2004) proposed that PC for the older adult should not be viewed as synonymous with hospice or end-of life care. The authors contrast the conceptual framework of PC for the older adult (concurrent PC) with palliative care associated with hospice (hospice). Concurrent PC for the older adult should be viewed as care of chronic illness using different increments of curative and palliative therapy simultaneously, depending on the needs of the patient (Figure 1).

Figure 1



The following table illustrates the difference between hospice and concurrent PC according to Jerant et al, 2004.

**Table 1. Hospice and Concurrent PC Comparison Chart**

Hospice	Concurrent PC
A terminal event- Deferred until the patient is unequivocally dying.	A longitudinal process- The major focus of care throughout the aging process.
Defined with-in a disease-focused framework-treatment dependent on disease with identifiable cause and specific signs and symptoms.	Defined with-in an illness framework-treatment goals are to heal illness that is defined as the patient's personal experience of the physical or psychological disturbance.
Decision about focus of care not negotiated between patient, family members and provider.	Negotiated agreement between patient, family and provider-determines balance between palliative and curative treatment.
Treatment choices are dependent upon those given by the physician-physician biases and preferences explicit.	Choices are based on the illness trajectory-and treatment intent-physician biases and preferences hidden and implicit.

A parallel system-occurs outside of the usual care process, delivered by specialists-fragmented care.	An integrated primary care focus-Integral part of daily clinical practice-
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### **Ethical Considerations**

Chronic disease is, by definition, not curable; it must be managed according to patient wishes after they are informed of the reality of their condition. Because the medical model has cure as a guiding principle, providing care solely using the medical model of *cure* puts the APN into a difficult position. Instead of *cure*, aging must be realistically seen as a process of gradual decline, but with *optimum health* and *quality of life* used as guiding principles. Concurrent PC is in alignment with the core values that guide APN practice. The APN core values include: 1) advocating for patients, 2) respecting patient and family values and informed choices, and 3) viewing individuals holistically within their environments, communities, and cultural traditions (Hamric, Spross and Hanson, 2009). The goal of concurrent PC is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies (NCP, 2009). The APN core values align with the concurrent PC principle therefore; it is the ethical responsibility of the APN to practice according to core values of the profession.

## Chapter 3

### METHODOLOGY

I used the *Iowa Model of Evidence-Based Practice* to guide the current project. The Iowa Model was developed by Titler et al (2001) of the University of Iowa Hospitals and Clinics. The Iowa model includes: 1) selection of a topic, 2) evidence retrieval, 3) grading the evidence, 4) protocol development, and 5) evaluation. For this project I used steps 1-4 as evaluation was outside the scope of this project.

#### **Example research using the Iowa Model**

In 2011, Myrick developed an Evidence-Based project to improve patient follow-up care after fragility fractures using the Iowa Model. The literature review revealed quality research calling for a bone density scan within 3 months with a referral for osteoporosis. The evidence-based (EB) initiative was implemented with follow-up results indicating 100% of patients received adequate follow-up after fragility fracture.

In 2010, Bergstrom utilized the Iowa Model of EBP to develop a skin care protocol for patients receiving radiation therapy. Although 85%-95% of patients who receive radiation therapy developed skin damage there was no protocol for treatment of this side effect. A protocol was developed by an interdisciplinary team and members of the team helped to disseminate the algorithm. Bergstrom reported that the skin care protocol improved quality care by providing a guideline for nurses to direct the prevention and management of skin damage secondary to radiation therapy (2010).

#### **Steps of the Iowa Model**

##### **Selection of a topic**

While working in a NH, I realized that the key players (APN, MD, RN) did not have an understanding of how to implement concurrent PC into practice. Most care was given under the medical model and the hospice model leaving palliative needs of the chronically ill unmet. I wanted to find evidence to support concurrent PC as a model for the APN in the care of the chronically and seriously ill.

### **Evidence Retrieval**

For this project I searched the following data bases: CINAHL; MEDLINE; Cochrane Central Register of Controlled Trials; Psychology and Behavioral Sciences Collection, and Google Scholar for terms such as Nurse Practitioner and Palliative Care; Nurse Practitioner communication of palliative care; provider communication of advance directives-disease trajectory; disease trajectory in chronic illness; disease trajectory in chronic illness and palliative care between 2001 and 2013. Only articles pertaining to the following criteria were reviewed:

- Palliative care not synonymous with hospice
- Guidelines for care of persons with chronic disease
- Nurse Practitioner focused palliative care guidelines
- Advance Directives/Advance Care planning
- End of life care

### **Grading Evidence**

I chose Melnyk's Hierarchy of Evidence for grading the information I retrieved (Melnyk, 2004). This system is as follows from strongest (I) to weakest (VII):

- I Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs
- II Evidence from at least one well-designed RCT
- III Evidence from well-designed controlled trials without randomization
- IV Evidence from well-designed case-control and cohort studies
- V Evidence from systematic reviews of descriptive and qualitative studies
- VI Evidence from a single descriptive or qualitative study
- VII Evidence from the opinion of authorities and/or reports

Evidence retrieval occurred during April, May, and June 2013. The total number of articles reviewed was 30. We chose to exclude all articles before 2008 because The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care was current through 2007. Four additional articles were reviewed and incorporated into the recommendations that were dates 2008 or later.

### **Protocol development**

The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (CPGQPC), Second Edition, 2009 provides formulated and labeled palliative care practices. The guidelines represent a *consensus opinion* of the major palliative care organizations: The Academy of Hospice and Palliative Medicine (AAHPM); The Center to Advance Palliative Care (CAPC); The Hospice and Palliative Nurses Association (HPNA); National Center of Hospice and Palliative Care Organization (NHPCO); special interest groups, and palliative care leaders in the United States; and a meta-analysis of relevant literature from 2004-2008. The NCP clinical

practice guidelines provide Eight Domains of Quality Palliative Care each containing domain specific practices; exemplary models of the domain, and references that are domain specific. The Eight Domains are stated as “aspects of care” and include: 1) Structure and Processes; 2) Physical; 3) Psychological and Psychiatric; 4) Social; 5) Spiritual, Religious and Existential; 6) Cultural; 7) Imminently Dying Patient; 8) Ethical and Legal. Because of the quality of the research used to develop the CPGQPC, and the comprehensive nature of the document, this guideline was used as the primary document to guide the development of the recommendations found in chapter 4 of this document.

The following is a summary of twenty-four research articles that cover topics associated with concurrent palliative care, but were excluded from the recommendations for the following reasons: 1) they were not nursing home specific; 2) they were not Advance Practice Nurse specific; and 3) although they informed the concept of concurrent PC, they were not specific to this project.

PC in the home. In 2012 Kyle and others described a randomized control pilot study they were in the process of conducting entitled Promoting Effective Advanced Care for Elders (PEACE). The purpose of PEACE was to test the effectiveness of PC in the home setting. In-home interdisciplinary care combined with palliative approaches to symptom management, optimizing function, and addressing polypharmacy were the key PC interventions in this study. The authors stated that the results will provide evidence-based application of PC in the home setting (Allen, Hazelett, Radwany, Ertle, Fosnight & Moore, 2012). The results of this study have not yet been reported.

PC in Assisted Living. In 2004 a non-blinded, prospective comparison trial of a model of PC was conducted in an Assisted Living setting. These authors concluded that



the preliminary findings showed the need for a paradigm shift to PC and gave a promising framework to build upon (Jerant, Azari, Nesbitt and Myers, 2004).

How to research PC outcomes. Two articles were reviewed that discussed ways to research and evaluate palliative care outcomes. In 2011, Higgins and Booth introduced what they called the “randomized fast-track trial” as an alternative to the randomized control trial (RCT) method of evaluating PC services and interventions (pg. 741). They cited many examples of failed trials and few successes leading them to question if RCT are appropriate for PC research. Failures were associated with ethical concerns. In the “fast-track” design no one is denied intervention; and there are two periods where each group has the opportunity to receive standard care and intervention. In 2004, Walshe, Caress, Chew-Graham, & Todd discussed a case study strategy as a way to research PC. The authors believe the case study strategy can contribute to knowledge in a way that is sensitive to the complex, context-dependent and multiprofessional nature of palliative care.

Barriers to EOL care. Some authors have reported that dying nursing home residents suffer from unmet needs because of underutilization of hospice care. (Hoffman and Tarzian, 2005) These same authors suggested barriers to quality EOL care include 1) government policies and practices rooted in questionable assumptions, and 2) a lack financial incentive for the use of hospice. Hoffman and Tarzian (2005) recommended a shift in focus from rehabilitation to palliation (Hoffman and Tarzian, 2005). A third barrier to EOL care has been identified as poor communication between the physician and the patient/family (Farquhar, Barclay, Grande, Emery and Crawford, 2005).

Support for the Implementation of PC. The Affordable Care Act of 2010 requires the Centers for Medicare and Medicaid Services (CMS) implement a 3-year demonstration project that provides aggressive treatment concurrent with palliative care. The authors call the combination of PC and aggressive treatment *palliative/hospice*. In the article they cite the Guidelines for Quality Palliative Care (NCP, 2009) and support PC as a response to the demands of health care reform (Sherman and Cheon, 2012). In 2005, Gullick commented that the National Consensus Project needs to rethink their definition of PC. She argued that defining PC as care given concurrently with life-prolonging care perpetuates a false dichotomy. According to her, PC is not a “compliment” to curative care and that PC should provide the structure to treating chronic illness. She does not have a solution but agrees that the NCP has the opportunity to promote PC as gold standard (Gullick, 2005). Other authors have offered support for the implementation of PC, but also believe PC specialist teams should be formed and trained (Littrivis and Smith, 2011).

In 2006, Lo and Woo recommended that PC be applied to all health care settings and all medical specialties. They described how PC interfaces with geriatric medicine and point out that most people will need PC at some point on their journey of life and illness. These authors specifically discussed psychosocial support, symptom management, quality of life, quality of dying, and advanced care planning (Lo & Woo, 2006).

Disease specific application of PC. The Director of the Center for Advancement of Palliative Care (CAPC) Dr. Diane Meier co-authored an article giving suggestions and best-practice approaches to the practices of PC. She and her colleague presented a case

study of a patient with dementia and heart failure, and how they implemented concurrent PC practices (Morrison and Meier, 2004). The American Heart Association (AHA) has offered support of PC in the treatment of heart disease. The AHA has published in-depth information regarding how to transition someone from non-hospice palliative care to hospice and provides best-practice guidelines for symptom management (AHA, 2013). In 2005, Curtis, Engelberg, and Wenrich, provide a review of research regarding EOL care specific to patients with COPD. These authors primarily focused on the barriers to communication during palliative care, and recommended further research to develop and test interventions to improve communication.

Recommendations about specific aspects of PC. In 2008, a systematic review was published that identified strong to moderate evidence to support interventions used when death is imminent (Lorenz et al.). Although these authors made recommendations regarding EOL care for patients, many of the interventions could be used earlier in the disease trajectory. The authors identified the need for more quantitative research (Lorenz et al, 2008).

Advanced directives. A qualitative study recorded the views of health care professionals on advanced directives (AD) in the United Kingdom (UK). Although the wording of ADs in the UK are different from the US, participants viewed ADs as 1) good for protection of the individual from losing control of EOL issues; 2) protection from family who want to keep their loved ones alive at any cost; and 3) were in agreement that the use of an AD is limited because one cannot adequately predict the future health problems (Thompson, Barbour and Schwartz, 2003). Prommer, (2010) suggested using a values-based history to enhance communication during preparation of Advanced Care

Planning. He further provided examples of value-based discussions that helped to identify patient's values at the EOL (Prommer, 2010).

Communication. The SUPPORT study was a 2 year prospective observational study that looked at shortcomings in EOL care of the seriously ill inpatient (Connors et al., 1995). This descriptive study was followed by a 2 year controlled clinical trial using improved physician communication regarding end-of life as an intervention.

Unfortunately the intervention failed to improve EOL care and was seen as an inadequate method to change established practices (Connors et al., 1995). In 2011, the results of an inductive qualitative study were reported that identified three different models of care and identified the different nurse communication styles used in each model (Wittenberg-Lyles, Goldsmith, Ragan, 2011). These authors supported the PC model of care and suggested that the identified communication styles be used to inform communication curriculum for nurses (Wittenberg, Lyles et al., 2011). Wilkinson, Perry, Blanchard, and Linsell, (2008), conducted a RCT to evaluate the effectiveness of a 3-day communication skills course in changing nurse communication skills with cancer/palliative care patients. The results of the trial showed improved confidence and communication skill along with patient satisfaction in the nurse's communication skills. Patient anxiety was not affected by the intervention.

Patient perspective: Nursing Home. Semi-structured interviews were conducted to report the needs of nursing home residents in Germany. The researchers found that residents of the nursing homes were most concerned about being recognized as individual people with their own life story and preferences. Equally as important to the residents

was social connectedness and everyday choice (Strohbuecker, Eisenmann, Galushko, Montag and Voltz, 2011).

Psychotherapy. Hall, Goddard, Speck and Higginson, (2012) conducted a qualitative study regarding patient views on a form of palliative psychotherapy called dignity therapy. The researchers found the therapy to be beneficial to a small population of nursing home patients and recommend careful consideration before offering it as usual care.

## Chapter 4

### RESULTS

The goal of concurrent PC is to prevent and relieve suffering and to support optimum quality of life for patients and their families without regard to stage of disease process or need for other therapies. Palliative care can be given along with life-prolonging treatment and is typically provided by a team of interdisciplinary professionals. Palliative care is care given throughout the trajectory of chronic disease which expands the medical model (NCP, 2009). It includes treatments that enhance life, optimize function, encourage personal growth and assist with decision making, and advocates the use of hospice when death is imminent. It does not promote one service over another but rather it is a combining of services (medical model; palliative care; and hospice) that creates a patient-centered environment where the needs of the patient are assessed and fully considered (NCP, 2009).

At present, there are many barriers to PC in the NH. Most notably, reimbursement rates drive care; a reality “impeded by perverse incentives” (Meier, Lam & Carlson, 2010 pg. 138). Quality is measured by the absence of decline which is not a reality in chronic disease and death. Life-prolonging interventions will continue to bring higher reimbursement than palliative interventions (Meier, Lam & Carlson, 2010). However, even in *this* environment the APN can practice concurrent PC. Because APNs focus on whole person care, coupled with the ability to diagnose, prescribe medications, and order treatments, he/she is positioned to take the lead in concurrent PC. Once the APN learns the NH environment, the APN can integrate PC principles and the recommended practices of this paper into the everyday care of NH residents. Therefore,

the following recommendations can be used as a starting framework from which the APN can grow in PC knowledge and practice. As PC research grows, there will be evidence-based practices available to help with disease specific approaches adding to effective care for chronic and serious illness. Current best-practice information is found in Appendix 1.

### Recommendations

#### **Recommendation I**

Patient plan of care should take into consideration the chronicity of the disease process and changes in physical health over time. These should include: patient goals for personal health; patient and family preferences; benefits and burdens of treatment options.

*Domain 1: Level II, VI, VII*

Practical guidance for Recommendation I. The APN should be responsible to educate the patient and family on the nature of chronic disease because it aligns with APN core values (Hamric, Spross and Hanson, 2009). Chronic disease is by definition, not curable; it must be managed according to patient wishes after they are informed of the reality of their condition. The chronic disease trajectory should be used to inform the concept of concurrent PC so that the patient and family can make informed decisions.

The use of The Medical Orders for Life Sustaining Treatments (MOLST) or The Physicians Order for Life Sustaining Treatments (POLST) form is encouraged to document patient wishes concerning end-of-life interventions (Meier, Lam & Carlson, 2010). Both forms are order set that specify patient wishes for life-sustaining treatments, feeding tubes, antibiotics, and transfers to hospitals. This order set can follow the patient between health care systems to ensure continuity of care. It is legal in some states but it

is being used in some instances without state law (Kyle, Hazelett, Radwany, Ertle, Fosnight & Moore, 2010) (not graded, study not completed).

## **Recommendation II**

Pain assessment and management should be safe and timely. Pain level should be acceptable to the patient and family if patient is unable to report pain level.

*Domain 2: Level V-VII*

Practical guidance for Recommendation II. For adequate management of pain the APN must utilize pain assessment tools such Edmonton Functional Assessment Tool (EFAT) (Hughes, L.D., 2012). The EFAT quantifies pain on the 0 (no Pain)-10(worst pain) scale, and assesses quality of patient sleep, nausea and appetite.

<http://www.palliative.org/newpc/professionals/tools/efat.html> Hughes (2012) also

recommends that The WHO (1996) pain ladder can be used for pharmacological pain relief approaches.

<http://www.geriatricpain.org/Content/Management/Interventions/Documents/WHO%20ladder.pdf>

## **Recommendation III**

The APN should complete a comprehensive assessment of caregiving needs; capacities of functional, cognitive and coping strategies; and give comprehensive patient education on personal disease management.

*Domain 3: Level V-VII*

## **Recommendation IV**



The APN should assess the need for referrals. Appropriate referrals are made as needed in the following areas: social work: NH required documentation, caregiver assistance, equipment, advance care planning; therapy; psychological.

*Domain 4: Level V-VII*

Practical guidance for Recommendations III, & IV. Current literature does not provide any comprehensive palliative care assessment tools for the APN in the nursing home. Therefore, the APN should thoroughly understand the NH environment so that she can understand what information is already being gathered. Currently, there are Medicare and Medicaid quality initiatives that require the NH to perform a comprehensive assessment of each resident upon admission and periodically thereafter. The NH quality measures come from the Minimum Data Set (MDS) which collects patient's physical/clinical conditions and abilities as well as their preferences (CAPC, 2008). A soon to be released MDS 3.0 (Meier, Lam and Carlson, 2010), should help with the development of care plans matched to resident and family goals. The MDS 3.0 will elicit information directly from residents regarding their preferences, including "Overall Goal" while in the NH. The Measures will include pain and symptom distress and goals of care discussions with residents and caregivers. However, many indications for palliative care such as weight loss and functional decline, will still be considered by CMS as evidence of poor quality care. Nevertheless, the NH assessment should be used for information gathering to complete the recommended assessments. Understanding NH policy and practices will also give the APN practical information regarding interdisciplinary staff and existing ways that care is coordinated.

**Recommendation V**

The APN should complete a comprehensive spiritual/religious assessment using an established assessment tool such as FICA, and make a referral to a religious organization or leader as needed.

*Domain V: Level V-VII*

Practical guidance for Recommendation V. The quantitative and qualitative research of Borneman, Ferrell, and Puchalski (2010) indicates the Faith, Importance and Influence, Community and Address Spiritual History Tool (FICA) is a feasible tool for clinical assessment of spirituality. Biblically speaking, man is made of body, soul and spirit (I Thessalonians 5:23). The spirit (Hebrew translation pneuma) is the non-material essence of man that can respond to God (Hayford, 1995). Caring for the human spirit is as important as caring for the physical part of man. As a Christian, I provide spiritual care for my patients by loving them as Christ has loved me. This love manifests itself by being non-judgmental, by accepting people regardless of their income level, by active listening and by prayer. God has reminded me of this scripture as I care for those with chronic and serious illness.

*Though I speak with the tongues of men and angels, but have not love, I have become sounding brass or a clanging cymbal. And though I have the gift of prophecy, and understand all mysteries and all knowledge, and though I have all faith, so that I could remove mountains, but have not love, I am nothing. I*

*Corinthians 13: 1-2 (New King James Bible)*

**Recommendation VI**

The APN should communicate with patients and families in a culturally appropriate way; which allows for patient preferences regarding disclosure, truth telling, and decision making.

*Domain 6: Level V-VII*

Practical guidance for Recommendation VI. The National Institutes of Health has cultural specific end-of-life information found at [www.nih.gov](http://www.nih.gov).

### **Recommendation VII**

The APN should make a referral to Hospice for the imminently dying patient.

*Domain 7: Level IV-VII*

Practical guidance for Recommendation VII. Hospice is a Medicare Part A benefit available when death is estimated to be within six months. The NH will likely have a contract with one or more hospice agencies. The agency can provide Medicare Hospice guidelines for eligibility and consultation. Further information is found at [www.cms.gov](http://www.cms.gov).

### **Recommendation VIII**

The APN should be knowledgeable about and follow all state and federal statutes and regulations in the following areas: medical decision making; advance care planning and directives; roles and responsibilities of surrogate decision-makers; prescribing of opioids and other controlled substances; pronouncing death; requests for autopsy and organ transplant; and documentation in the medical records.

*Domain 8: Level IV-VII*

Practical guidance for Recommendation VIII. The APN should assess her need for further education regarding this recommendation. The National Institute for Health ([www.nih.gov](http://www.nih.gov)) has factual information concerning all elements of this recommendation.

Furthermore, the Board of Nursing in the APN's state of practice has regulations concerning prescribing opioids and other controlled substances and death announcement rules.

## Chapter 5

### SUMMARY

In the presence of chronic illness, an individual's health follows a trajectory of gradual decline. Patients must be informed honestly about the reality of the chronic disease process. As a health care provider, the APN is responsible for providing this honest, humane model of care. As of 2013, there are many examples of nursing home care models where palliative care is not integrated into traditional medical care. The recommendations of this paper provide a framework for this integration. In the absence of a palliative care program the APN can use these recommendations as concurrent PC interventions.

Chronic illness cannot be cured. However, when PC is given concurrently with life prolonging care, patients' health can be optimized when compared to utilizing either model exclusively. Optimum health with the concurrent PC model includes 1) care that is patient/family centered, 2) symptom control, and 3) improved quality of life.

### Model Case

The following is a model case that utilizes principles from all eight recommendations in the care of an elderly nursing home resident.

*A 70-year-old woman is admitted to the rehabilitation unit of a long-term care facility after a 5-day stay in the hospital for acute exacerbation of chronic obstructive pulmonary disease (COPD). Patients with COPD experience acute exacerbations of their disease, which may produce respiratory failure and a possible need for either ventilatory support or acceptance of death. Further discussion of chronic illness and the usual trajectory for COPD is discussed with*

*patient/family by the Nurse Practitioner. Nursing Home Assessment tools are integrated with APN assessment of pain, spiritual, cultural, legal and other referral needs. Concurrent palliative plan of care is developed and initiated with the ongoing and regular clinical process of patient-appropriate assessment, diagnosis, planning, interventions, monitoring, and follow-up (National Consensus Project (NCP), 2009). Self-care management of COPD is taught to patient/family. Goals of her treatment will be to prevent and relieve suffering; support optimal quality of life for patient/family; help with decision making; and provide for personal growth. Hospice will adjunct care when death is imminent.*

The key players are the Nurse Practitioner, staff of NH and the patient and family. A team approach to care is given with the patients' needs and wishes at the center of importance. Curative treatments are concurrently given with palliative treatments. Every effort is made to honor patient needs and wishes after she is culturally informed of her chronic disease trajectory.

### Conclusion

Palliative care is a widely recognized approach to the care of the chronically and seriously ill. "Globally, palliative care is seen as an imperative as 56 million people die each year with associated physical and emotional suffering" (Sherman & Cheon, 2012 pg.156). In the US, over the last 10 years, palliative care has been the fastest growing trend in health care (Sherman & Cheon, 2012). Those who pay for health care are also taking notice of the trend. Currently, The Affordable Care Act of 2010 mandates Medicare and Medicaid (CMS) to research the effectiveness of PC, because of a projected cut in Medicare spending. The NCP Guidelines for Quality Palliative Care will

likely become a “gold standard” of care, and some already view it as a human right (Sherman and Cheon, 2012; Gullick, 2005). The APN has the opportunity and responsibility to follow the model in practice and to participate in the larger discussion through participation in policy, research and practice of PC. The Clinical Practice Guidelines for Quality Palliative Care, Second Edition were used as the framework developing the recommendations found in this guideline for a concurrent palliative care approach in the nursing home (NCP, 2009).

Concepts once formulated and labeled, tend to shape and guide what we see, and they provide order to observations and experience that enhance understanding of situations and events (Meleis, 2012, pg. 371).

For the APN, concurrent palliative care is a concept that should shape and guide what is seen and should be utilized in every encounter with a patient, families, and co-workers.

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## **Appendix 1**

### **The National Consensus Project Guidelines for Quality Palliative Care.**

[www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)

### **The Center for Advancement of Palliative Care (CAPC)**

[www.capc.org](http://www.capc.org)

Web site provides palliative care resources and information about training

### **The National Board for Certification of Hospice and Palliative Nurses**

[www.nbchpn.org](http://www.nbchpn.org)

Offers Advance Practice Palliative Care Certification

### **End-of Life/Palliative Educational Consortium (ELNEC)**

[www.eperc.mcw.edu](http://www.eperc.mcw.edu)

### **The American Geriatric Society**

[www.ags.org](http://www.ags.org).

