ASSESSING AND COMMUNICATING HOSPICE REFERRAL NEED:
A PROPOSED WEB-BASED EDUCATIONAL MODULE FOR NURSES CARING FOR
TERMINAL ONCOLOGY PATIENTS

by

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A Thesis Submitted to the Honors College

In Partial Fulfillment of the Bachelors Degree
With Honors in
Nursing
THE UNIVERSITY OF ARIZONA
May 2011

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Last updated: Nov 15, 2009
TABLE OF CONTENTS

LIST OF ILLUSTRATIONS ........................................................................................................4
ABSTRACT .................................................................................................................................5

CHAPTER 1: INTRODUCTION .................................................................................................6
The Case of the Pancreatic Cancer Patient ...............................................................................6
Patient Autonomy ....................................................................................................................8
Purpose ..................................................................................................................................9
Theoretical Framework and Evidence-based Practice ............................................................10

CHAPTER 2: THE WHAT, WHEN, WHY, WHO, AND HOW OF END-OF-LIFE CARE
DECISIONS ...............................................................................................................................12
What is Hospice Care? .............................................................................................................12
The Who’s Who of Hospice Care Decision Making ...............................................................13
When is a Hospice Referral Considered Late? .....................................................................15
Why are Late Hospice Referrals Problematic? .....................................................................17
How Can the Quality of End-of-Life Care be Improved? .......................................................19

CHAPTER 3: ENACTING CHANGE ........................................................................................21
Introduction to the Palliative Care Resource Nurse and ELNEC ........................................21

CHAPTER 4: A WEB-BASED LEARNING MODULE FOR PCRNs .....................................26
Web-based Learning and Teaching ......................................................................................26
Creating an Interactive Web-based Module ..........................................................................27
Module Content ....................................................................................................................28
    How to Identify a Patient in Need ...................................................................................28
    How to Communicate Patient Needs to Physicians .........................................................29

CHAPTER 5: OBTAINABLE GOALS AND FUTURE PREDICTIONS ..................................32

APPENDIX A ..........................................................................................................................34
APPENDIX B ..........................................................................................................................36
APPENDIX C ..........................................................................................................................38
APPENDIX D: ADDITIONAL RESOURCES ......................................................................40

REFERENCES .........................................................................................................................43
LIST OF ILLUSTRATIONS

FIGURE 1. Practice Guidelines in Oncology – v.1.2009 ................................................................. 8
FIGURE 2. End-of-Life Decision Making .................................................................................................. 9
FIGURE 3. CHAT Communication Tool .................................................................................................. 31
ABSTRACT

The decision to transition to a palliative care focused plan of care instead of pursuing futile curative options is highly complex, and when made without the use of full interdisciplinary collaboration, can often result in decreased patient quality of life (QOL). The goal of this paper is to explore the causes and implications of a late hospice referral. The results of this paper are intended to improve the continuity of care at the end-of-life (EOL) by proposing the pilot of a web-based educational module that can be used by acute care nurses to identify patient need for hospice care and communicate this need to physicians. Pancreatic cancer is discussed as an exemplary diagnosis in which the content of the proposed module may be of use. Therefore, some pancreatic cancer statistics and pathophysiological information have been included; however, the module itself is intended for use by any nurse caring for a terminally ill cancer patient and in which a hospice referral may be required.

Keywords: Pancreatic CA, Hospice, Informatics, Nursing Education, End-of-Life Care, Quality of Life
CHAPTER 1 – INTRODUCTION

The Case of the Pancreatic Cancer Patient

At the time of diagnosis, pancreatic cancer is curable in 10% of cases, and unless there is an externally visible symptom of the underlying disease process, such as jaundice, pancreatic cancer is primarily diagnosed late (Ellison, Chevlen, Still, & Dubagunta, 2002; Kern et al., 2001). Only about 10-20% of pancreatic cancer patients present with a tumor that can be surgically resected, and even then, the odds that the cancer has already metastasized are high (Andre et al., 2000; Ellison et al., 2002). For those patients with a resectable tumor, 80% will develop metastasis during their first year post-operatively (Kamar, Grossbard, & Kozuch, 2003). Therefore, the average life expectancy of a newly diagnosed pancreatic cancer patient is less than five years (Ellison et al., 2002). Of all pancreatic cancer patients, only about 5% will live greater than five years (Kamar et al., 2003). When a patient presents with liver metastasis, (s)he is in the most advanced stage of the disease, stage IV, and may die within one to two months (Tempero, et al., 2005).

With surgical resectioning as the only curative treatment for pancreatic cancer, yet a viable option in only 10-20% of cases, all other patients with an unresectable, inoperable, or metastatic form of the cancer/tumor must seek palliative care or comfort care for continuing treatment (Kamar et al., 2003; Von Wichert, Seufferlein, & Adler, 2008; Tham et al., 2000; Molinari et al., 2001). Unfortunately, many of the preferred palliative care treatment modalities for this type of cancer trend towards more adverse events than true palliation and do not significantly prolong life. This subsequently results in many ethical and risk-benefit dilemmas
for medical care providers, patients, and family members (Melvin & Oldham, 2009; VanBruchem-van de Scheur et al., 2008).

The current palliative therapies for pancreatic cancer include: biliary and pancreatic-duct stenting, radiation therapy, combined-modality therapy, and comfort care/hospice (Molinari, Helton, & Espat, 2001; Ellison et al., 2002). Pancreatic-duct or biliary stenting is an invasive procedure intended to relieve pain and promote the normal physiological functioning of those organ systems (Tham et al., 2000). It is associated with the traditional post-operative complications, such as pneumonia, biliary duct injury, and infection, and it will require temporary hospitalization (Black & Hawks, 2009). Combined-modality therapy consists of a combination of radiation therapy, chemotherapy, gemcitabine monotherapy, and gemcitabine combination therapy (Andre et al., 2000; Molinari et al., 2001). These therapies can, at most, extend life by 7 months but not without their own costs (Tempero et al., 2005; Andre et al., 2000).

In Ko and Tempero (2009), the authors, two frontline experts in pancreatic cancer drug research, evaluated and advocated the integration of a newly approved gemcitabine combination drug into the palliative care treatment plan for pancreatic cancer. The authors stated that the ideal pancreatic cancer drug would bind patient-specific biomarkers, to increase the palliative effects and decrease the quantity of adverse reactions. Unfortunately, said drugs would be very costly and are still years in the making (Ko & Tempero, 2009). Thus, gemcitabine continues to be the drug of choice despite the fact that gemcitabine alone and in combination has many devastating side effects (i.e., nausea, vomiting, deep vein thrombosis, hemolytic uremic syndrome, and an acute respiratory distress syndrome) and all gemcitabine combined-modality therapies have been
listed as being both toxic and carcinogenic (Kamar et al., 2003; Molinari et al., 2001). Ko and Tempero (2009) continue to support the use of these drugs, but they also reported that there must be a limit for continuing these therapies based on the risk-benefit ratio for the individual and his/her unique prognosis.


Patient Autonomy

In 1990, with the passage of the Patient Self-Determination Act, as part of the Omnibus Budget Reconciliation Act, the American Nurses Association (ANA) declared that it was every nurse’s responsibility to educate, inform, and support patient decisions about end-of-life (EOL) care and EOL care options (ANA, 2010). Even so, the decision to stop or start any form of
treatment, palliative or curative, ultimately belongs, legally and ethically, to the patient or a designated decision maker or power of attorney (Aiken, 2004). With this, the plan of care for a patient with an unresectable adenocarcinoma, as outlined in Figure 1, becomes exceedingly more complex.

FIGURE 2. End-of-Life Decision Making


Purpose

The purpose of this paper is to determine which factors contribute to the decision to end invasive and aggressive treatments, whether palliative or curative, and transition to a regimen of care sustained by the hospice philosophy. Hospice referral timing will be critically evaluated
based on its potential to influence EOL decision making (Melvin & Oldham, 2009). The effect of hospice transition time and the continuity of care at the EOL on the quality of life (QOL) of the terminal cancer patient will also be explored. The target audience for this paper is nurses and other licensed medical professionals who maintain the power to influence the decisions made by patients and their families regarding EOL care.

**Theoretical Framework and Evidence-based Practice**

This paper was constructed on the premise that if nurses, as members of an interdisciplinary healthcare team, are better informed about patient EOL decision making and the influence of hospice referral times and/or transition times on the patient’s QOL, then they will be able to more effectively advocate for the terminal patient regarding EOL decisions (American Nurses Association, 2010; Melvin & Oldham, 2009). As a result of this paper, the framework and step-by-step instructions for constructing a web-based module for the education of acute care nurses will be established. The module content will supplement information routinely provided in an End-of-Life Nursing Education Consortium (ELNEC), and it will more specifically address the nursing skills of assessment and interprofessional communication. The author has chosen to include the 2009 adapted model of Emanuel and Emanuel’s (1998) “Geriatric-Cancer Experience at the End of Life” as the assessment tool exemplar (Buck, Overcash, & McMillan, 2009). Should the web-based module actually be implemented, any evidence-based quality of life assessment tool may be substituted. Several issues in interprofessional communication will also be discussed in this paper. With this, one of the goals for the web-based module is to teach the ways in which one can utilize the standard Situation, Background, Assessment, Recommendation (SBAR) tool when communicating QOL assessment findings with physicians. Based on the
pathophysiology and nature of pancreatic cancer, the case of the pancreatic cancer patient with an unresectable tumor and poor prognosis will continue to be used as the disease exemplar.
CHAPTER 2 – THE WHAT, WHEN, WHY, WHO, AND HOW OF END-OF-LIFE CARE DECISIONS

What is Hospice Care?

The word hospice is French in origin. It originally referred to a shelter, often maintained by monks, for the weary, sick, poor, or lay traveler (Guralnik, 1982). The word later came to be defined as “a homelike facility to provide supportive care for terminally ill patients” (Guralnik, 1982, p. 678). Frequently, the words palliative care and hospice are used interchangeably, such as in Australia where the words are considered synonymous. In the United States, however, hospice and palliative care are clearly differentiated based on national standards and requisites for funding (Melvin & Oldham, 2009, National Hospice & Palliative Care Organization, 2010b).

Palliative care can be used to refer to any treatment that is done to relieve or manage symptoms of an illness (National Hospice & Palliative Care Organization, 2010b). For example, the use of Gemcitabine for pancreatic cancer, despite its ability to diminish one’s QOL, is considered a palliative pharmacotherapy (Von Wichert, 2008). The reason that this type of drug therapy is considered palliative is because it slows tumor growth by interfering with the DNA of the cancerous cells (Ko & Tempero, 2009). Theoretically, in slowing disease progression the drug has the potential to decrease symptoms that may have arisen from uninhibited tumor growth (Von Wichert, 2008).

Hospice care, also known as supportive or comfort care, is an intensification of palliative care which serves to improve one’s QOL in the last six months of life through comprehensive symptom management. Again, the focus of hospice care is to improve QOL (National Hospice & Palliative Care Organization, 2010b). Surgery, combined-modality therapy, as defined in chapter
one, and radiation therapy would not be used for symptom management in a hospice organization even though they are all forms of palliative care (National Hospice & Palliative Care Organization, 2010a). These therapies are often not used in hospice because their primary purpose is generally not to improve QOL and frequently they are employed with the desire to prolong life regardless of consequence to QOL. Additionally, these palliative are challenging to implement due to the constraints created by the agencies which fund hospice in the United States (National Hospice & Palliative Care Organization, 2010a).

The Who’s Who of Hospice Care Decision Making

The catalyst for the hospice movement in the United States was a visit to Yale University by Dr. Dame Cicely Saunders in 1965 (National Hospice & Palliative Care Organization, 2010b). Since the early foundations and despite the testimony of Dr. Elisabeth Kubler-Ross before the U.S. Senate in 1972, it has been a struggle to keep hospice organizations well funded in the United States (National Hospice & Palliative Care Organization, 2010b).

Today, hospice in the United States is largely funded by the Medicare Hospice Benefit, which has strict guidelines to determine who qualifies to receive governmentally subsidized hospice care (National Hospice & Palliative Care Organization, 2010a). The following is a list of criteria a patient must meet or complete in order to qualify to receive governmentally subsidized hospice care: qualify for Medicare Part A, be declared by a doctor or a hospice medical director to have no more than six months of life remaining due to a naturally progressing terminal illness, sign a statement which declares (s)he will no longer seek any medical treatment for said life-limiting illness besides what is offered by hospice, and be admitted to a Medicare approved hospice organization (National Hospice & Palliative Care Organization, 2010a).
In the past, it was believed that these guidelines were being maintained as a means of cost reduction (National Hospice & Palliative Care Organization, 2010b; Lamont & Christakis, 2002). However, Pyenson, Connor, Fitch, and Kinzbrunner (2004) found that persons enrolled in hospice lived longer than persons suffering from the same diseases who did not enroll in hospice. Additionally, despite living longer, the patients who received hospice care incurred costs far lower than those patients who did not enroll in hospice. Based on the findings of Pyenson et al. (2004), it would actually save the government money to loosen the criterion for hospice admission. Aggressive, life-prolonging therapies can be very expensive and when a patient is hospitalized on a regular basis due to the consequences of these therapies and uncontrolled symptoms, costs of care increase tenfold. To ensure scientific rigor in their study, all subjects in Pyenson et al. (2004), were required to receive at least one aggressive intervention, for instance surgery if the patient had a cancerous tumor, prior to receiving supportive care. Nevertheless, costs were still lower for patients in hospice, which means that the decreased costs could be explained by not only a decrease in utilization of futile aggressive interventions but also less frequent emergency hospitalizations and factors which have yet to be extrapolated (Pyenson et al., 2004).

In 2001, Lamont and Christakis conducted a study to determine whether or not there was a relationship between hospice referral times and the discipline of the practicing physician who referred the cancer patient. This study also examined how the physician’s discipline, previous interaction with hospice, and accuracy in prognostication affect how long a terminal cancer patient is enrolled in hospice (Lamont & Christakis, 2002). The research determined that oncologists are the most likely to make late referrals to hospice, and as a result, their patients
ultimately died sooner after being admitted to hospice. This phenomenon was explained by the authors as being related to the belief that there is very little an oncologist can do once their patient enters a hospice organization based on current Medicare guidelines (Lamont & Christakis, 2002). In Italy, where there are no access restrictions, like Medicare, there was no difference between the longevity of a cancer patient who was referred by one type of specialist versus another (Lamont & Christakis, 2002). With this, it is clear that there needs to be a change in social policy and a paradigm shift about EOL care spending, if hospice referrals are to become more prevalent and timely.

**When is a Hospice Referral Considered Late?**

“Hospice is the most widely used federally funded program designed to provide end-of-life care for Medicare beneficiaries” (Adams, Bader, & Horn, 2009, p. 109). Based on Medicare’s guidelines for hospice admission, a patient can enter hospice when they have six months or less to live as the result of a terminal condition (National Hospice & Palliative Care Organization, 2010a; Kapo et al., 2005). Unfortunately, in the USA, the average length of hospice utilization among terminal patients is three weeks, indicating that funding issues may not be the only cause of late referrals (Kapo et al., 2005).

Physicians are the most influential people in “shaping how families understand a terminal prognosis” (Waldrop & Rinfrette, 2009, p. 559). It was found that cancer patients whose physicians were more accurate in their prognostication actually survived longer in hospice care than cancer patients whose physicians had made inaccurate predictions (Lamont & Christakis, 2002). Nevertheless, physicians continue to differ in their opinions about when it is appropriate to make a hospice referral. These views range from 1-52 weeks prior to the predicted date of
death (Waldrop & Rinfrette, 2009). However, when is a hospice referral actually late and what are the adverse effects as the result of said “late referrals”?

Currently, the standard of judging the timing of a hospice referral is based on the amount of time a patient lives once enrolled in hospice care (Osta et al., 2008; Morita et al., 2009). Osta et al. (2008), found that the average time from the first palliative care consult (i.e., the first mention of supportive/comfort care) to death in the advanced cancer patient was 42 days. The research also suggested that those cancer patients who have a wider range of treatment options, such as those with liquid tumors opposed to solid tumors, were more likely to hear about hospice care later in their disease trajectory (Osta et al., 2008). These same patients were more likely to die in the hospital intensive care unit than in any other setting (Osta et al., 2008). Osta et al. (2008), noted that even though palliative/hospice care is far more accessible than it has ever been in the past, late referrals are still common, causing more patients to die in the hospital setting versus their preferential choice of dying at home.

The body of literature exploring the effects of hospice referral time on the patient and family’s experience with hospice care has been growing tremendously within the past ten years. In 2005, Kapo, Carroll, Rickerson, and Casarett began a study to evaluate the opinions of 274 patients and/or family members about the timing of their hospice referrals and their hospice experience. This study was unique because it interviewed the participants once at enrollment and a second time after the patient’s death to determine if there was any change in opinion after hospice care was received (Kapo et al., 2005). A total of 76% of the subjects changed their responses in the second interview (Kapo et al., 2005). More families, an overall increase of 12%, stated that they believed that the hospice referral was too late one month after the patient’s death.
(Kapo et al., 2005). Also, much to the surprise of the researchers and contrary to common belief, the majority of the patients/families believed that the hospice referral had taken place at the right time (Kapo et al., 2005). These findings were reaffirmed by Teno et al. (2007), when 106,514 surveys were sent out to family members of patients who had died in hospice and only 11.4% of the population reported dissatisfaction with the timing of their hospice referral. Additionally, of the population which portrayed satisfaction with the timing of their referrals, over 50% of their family members had died less than one month after admission (Teno et al., 2007).

**Why Are Late Hospice Referrals Problematic?**

Waldrop and Rinfrette (2009) evaluated the opinions of 53 hospice employees, including nurses, social workers, chaplains, physicians, and clinical secretaries, and found that patients who had been referred late in their disease trajectory were more likely to suffer a “hyper-acute death,” experience uncontrolled symptoms, and/or have significant emotional/spiritual suffering (Waldrop & Rinfrette, 2009). Hyper-acute death or hyper-acute death care refers to a situation in which a patient is admitted to hospice as they are actively dying. A hyper-acute death is often characterized by uncontrolled symptoms which are immediately preceded by death (Waldrop & Rinfrette, 2009). Additionally, administering quality care for patients admitted while actively dying was reported as being exceptionally difficult. The professionals interviewed stated that they spent more time, on average, in discussion about the client’s case, were unable to personalize care, and had virtually no time to address the patient’s emotional and spiritual needs (Waldrop & Rinfrette, 2009). Similar problematic rapid deaths with a high symptom burden were noted by Teno et al. (2007), Kapo et al. (2005), and Osta et al. (2008) among the
populations of families/patients who were or believed they were referred to hospice late (Waldrop & Rinfrette, 2009).

In 2008, a team of palliative care researchers in Japan was funded to determine whether or not Japanese legislation that mandated the construction of 200 specialized palliative care units, the United States equivalent to in-patient hospices, at oncology centers in Japan, was effective in increasing the average number of hospice referrals, decreasing the rate of late hospice referrals, and increasing family satisfaction with referral times (Morita et al., 2009). The researchers found that there was no change in the timing of the referrals or the families’ levels of satisfaction with the referrals (Morita et al., 2009). However, their overall opinions of the quality of the care they received increased substantially (Morita et al., 2009). The findings of Morita et. al. (2009) suggest the following: families report satisfaction with their hospice experience and the timing of their referral even when the quality of care they are receiving is unequal (Morita et al., 2009).

Waldrop and Rinfrette (2009) also found that even though many families may report being content with the timing of their hospice referrals, there is an overall lack of knowledge among families regarding what to expect from their hospice care organization (2009). This same trend was recognized by Teno et al (2007). Therefore, what is becoming clear to researchers is that family and patient opinions, while still valuable, may not be accurately reflecting the true impact of late hospice referrals because they are uninformed in regards to the characteristic attributes of a good death and the plethora of services and advantages offered to them by hospice care.
How Can the Quality of End-of-Life Care be Improved?

There are many paradoxes surrounding EOL care which often interfere with the appropriateness and ease of the transition into hospice care. For instance, current evidence suggests that patients desire early and open conversations about EOL care planning with their primary care physicians (Dow et al., 2010). However, they are very reluctant to begin those conversations, and they are frequently relieved, and even prefer, when the topic is brought up by a doctor in a clinic, an emergency department, or the oncologist’s office (Dow et al., 2010). They often regard these discussions as being critical segues into beginning the EOL planning process with their primary doctor (Dow et al., 2010). Such sentiments from today’s critically ill cancer population indicates a break in the continuity of care during terminal illness, which could potentially be remedied with the EOL care education of floor and community health nurses (Waldrop & Rinfrette, 2009; Dow et al., 2010; LeBaron, Bohnenkamp, & Reed, 2010).

Despite progress in hospice education in recent years, many physicians remain uneasy and fearful about discussing EOL care planning and hospice with their clients (Melvin & Oldham, 2009). Even in places such as Australia, where there are no access restrictions, physicians still relate that they have fears about losing control of their patients if they refer them to hospice (Melvin & Oldham, 2009). They also state that they feel as though they are failing when they have to refer their patients to hospice (Melvin & Oldham, 2009; Quill, 1996). Regardless, both physicians and nurses who work in the hospice setting can just as easily relate the detrimental effects a non-referral or late-referral to hospice can have on the terminal cancer patient (Waldrop & Rinfrette, 2009; Melvin & Oldham, 2009; Quill, 1996). With this, it is necessary that patients are referred early to hospice so that they can truly reap and enjoy the
benefits of hospice, such as individualized care planning for effective sustained symptom management and holistic patient/family centered care (Waldrop & Rinfrette, 2009; Melvin & Oldham, 2009). Furthermore, based on the premise that patients desire conversations about EOL planning to be initiated before seeing their primary care physician, the evidence that such conversations are more likely to improve the physician’s confidence in making a hospice referral sooner than later, and the ANA’s emphasis on the nurse’s role to promote autonomy by fully informing patients about their EOL options, creating a formula for educating nurses about EOL care planning and initiating discussions about hospice may be the best practice for improving hospice referral times (American Nurses Association, 2010; Quill, 1996; Melvin & Oldham, 2009; Dow et al., 2010; Waldrop & Rinfrette, 2009; Osta et al., 2008; Lamont & Christakis, 2002).
CHAPTER 3 – ENACTING CHANGE

Introduction to the Palliative Care Resource Nurse and ELNEC

Despite mandates made by the World Health Organization (WHO) and the International Council of Nurses (ICN), the quality, quantity and effects of attempts made to disseminate palliative care education to nurses and physicians throughout the world have been suboptimal (LeBaron, Bohenkamp, & Reed, 2010). For example, in Japan referrals to palliative care facilities remain late even with the propagation of educational legislation and an increase in the availability of palliative care resources (Morita et al., 2009). This is also true in Australia and New Zealand, where there are no access restrictions and palliative care education has been disseminated since the 1960s, yet physicians still report a lack of knowledge as the number one reason for a non-referral (Melvin & Oldham, 2009). Additionally, the amount of technology available for sustaining human life against all odds is now increasing at an exponential rate (Minick & Harvey, 2003). Critical care nurses are being challenged by more complex, severely ill patients than ever before, causing the differential between the high acuity do not resuscitate (DNR), do not intubate (DNI) patient and the palliative care patient to become increasingly vague and confusing (Minick & Harvey, 2003; LeBaron, Bohenkamp, & Reed, 2010). It is the nurse’s job to detect the most subtle changes in patient condition while administering bed-side care, from psychosocial to physiological (Minick & Harvey, 2003). Unfortunately, many nurses have very little to no palliative care education and are therefore being handicapped by their inability to make accurate judgments about a patient’s hospice care need (LeBaron, Bohenkamp, & Reed, 2010; Malloy, 2010).
In 2000, with funding from the Robert Wood Johnson foundation, the American Association of Colleges of Nursing launched their very first End-of-Life Nursing Education Consortium (ELNEC) (Malloy, 2010). ELNEC began in the United States as an educational initiative to provide nursing faculty, administrators, and community members with the necessary information and tools to disseminate palliative care education throughout their surrounding medical communities (Malloy, 2010). ELNEC became an international phenomenon in 2006, and today, 66 countries and over 11,650 nurses and other healthcare professionals have utilized the ELNEC curriculum as a means for disseminating palliative care education (Malloy, 2010).

The content of ELNEC focuses on eight specific areas of EOL: pain management, symptom management, ethical/legal issues, cultural considerations, communication, the elements of loss, preparation for/performing care at the time of death, and nursing responsibilities at the end-of-life (Malloy, 2010).

LeBaron, Bohenkamp, and Reed (2010) used ELNEC to create a team of palliative care resource nurses (PCRNs) for the University Medical Center (UMC) in Tucson, Arizona. The premise of the LeBaron, Bohenkamp, and Reed study was that if one nurse was taken from every floor of a hospital and educated using the ELNEC format, then it would be possible to create an approachable and accessible group of educated professionals with whom traditional floor nurses could consult when an EOL issue or concern arose (LeBaron, Bohenkamp, Reed, 2010). The desired outcomes of the LeBaron, Bohenkamp, and Reed (2010) study were as follows:

“Empower PCRNs with the knowledge to advocate for optimal symptom management of their seriously ill patients, serve as mentors and disseminators of information to colleagues, identify appropriate referrals for formal palliative care consultation, foster community partnership in building UMC’s capacity to deliver palliative care services to its most vulnerable patients and caregivers, and provide a forum for professional collaboration among community stakeholders.”
The sample population for this study consisted of UMC nurses as well as rural health care providers, who were able to access all of the module/lectures via telemedicine technology on live broadcasting (LeBaron, Bohenkamp, & Reed, 2010). The average number of attendees to each of the ELNEC’s nine modules/lectures was 73, with 34 nurses in attendance for all nine sessions (LeBaron, Bohenkamp, & Reed, 2010). As a means for evaluating the lecture content and the level of retention by study participants, the 34 nurses who completed all nine modules were invited to a series of workshops. Of the 34 invitees, 18 were able to attend the workshops (LeBaron, Bohenkamp, & Reed, 2010).

While the ELNEC was conducted as a lecture series, the workshops were conducted as a series of six small group interactive sessions (LeBaron, Bohenkamp, & Reed, 2010). According to Price (2010), workshops empower nurses with knowledge, encourage them to emulate the best-practice habits embodied by the clinical leaders conducting the sessions, and allow them to learn through action and free-flow discussion. Additionally, the main purpose of a workshop is not to provide bulk quantities of knowledge to the participants, but to embellish the information they have already been given and provide them with the necessary tools to utilize their new skills (Price, 2010). In the LeBaron, Bohenkamp, & Reed (2010) study, they embellished the information by further discussing the Domains of Excellent Quality of End-of-Life Care, as outlined by the National Consensus Project for Quality Palliative Care and how to communicate and act based on assessment findings within each domain. According to the National Consensus Project for Quality Palliative Care, the domains of excellent quality of care at the end of life are: spiritual, physical, emotional, and psychosocial (NCP, 2010). Both free-flow discussions and
role-play were utilized to make the LeBaron, Bohenkamp, & Reed (2010) workshops more interactive (LeBaron, Bohenkamp, & Reed, 2010).

While the reviews from the participants in the LeBaron, Bohenkamp, & Reed (2010) study reflected positive outcomes, 99.4% of the 18 workshop series attendees reported “acquisition of knowledge/new skills,” this study had several limitations (LeBaron, Bohenkamp, & Reed, 2010). The most significant limitations of the study are as follows: high attrition rates and a lack of robust pre- and post-test assessments (LeBaron, Bohenkamp, & Reed, 2010). Although post-educational attrition is not uncommon, post-educational events are essential in determining whether or not the evidence-based information taught will be utilized by learners in the workplace (Price, 2010). Pre- and post-tests serve as a means for quantifying learning and retention, and can either strengthen or weaken a study’s validity, especially for studies in which the goal was to educate (Jayaratne, Lyons, & Palmer, n.d.). Additionally, it is always important for any workshop to be completed in three parts: pre-workshop, workshop, and post-workshop (Price, 2010). For the 18 participants who engaged in the workshop series, the ELNEC would have served as the pre-workshop event (LeBaron, Bohenkamp, & Reed, 2010; Price, 2010). The post-workshop for this study has yet to come, as LeBaron, Bohenkamp, & Reed (2010) still desire to expand on the series in the future (Virginia LeBaron, personal communication, June 8, 2010).

One effective post-workshop teaching modality is web-based learning. Web-based modules are easy to access and continue to engage and stimulate thought without overwhelming workshop graduates (Price, 2010). Therefore, in order to further promote evidence-based practice implementation and address the workshop attendees concerns pertaining to assessing and
communicating hospice referral need to physicians, a proposal for a web-based learning module to educate the PCRNs from the LeBaron, Bohenkamp, & Reed (2010) will be outlined and the means for dissemination will be discussed.
CHAPTER 4 – A WEB-BASED LEARNING MODULE FOR PCRNS

Web-based Learning and Teaching

In 2006, the National Cancer Institute partnered with Northwestern University to create a web-based continuing education program for nurses and physicians. It was intended to be a means for disseminating palliative care education to healthcare communities across the United States (Arenella, Yox, Eckstein, & Ously, 2010). The program was entitled Education in Palliative and End-of-Life Care for Oncology or EPEC™-O and consisted of:

“15 content modules, three plenary sessions, and two teaching modules and covered topics in models of comprehensive care; charting the future; pain and symptom management; loss, grief, and bereavement; survivorship; last hours of living; physician communication; negotiating goals of care; clinical trials; withdrawing nutrition; advanced care planning; cancer physician burnout (Arenella, Yox, Eckstein, & Ously, 2010, n.p.).”

The EPEC™-O was posted on Medscape and for two weeks following its posting, e-newsletters, and mailings were sent to all Medscape readers. It is estimated that within the first seven months after its posting, 109,283 people used the EPEC™-O, 247,859 people visited the site but did not complete all of the EPEC™-O training, and 20,061 people participated and earned continuing education credit (Arenella, Yox, Eckstein, & Ously, 2010). Nearly two-thirds of the site’s users were nurses. The first EPEC™-O was so successful that Medscape and the National Cancer Institute prepared a second version of the EPEC™-O that was released in 2008 and entitled, “End-of-Life Care in the Setting of Cancer. Withdrawing Artificial Nutrition and Hydration” (Arenella, Yox, Eckstein, & Ously, 2010).

There are over 200 peer-reviewed articles supporting the use of web-based modules for the continuing education of health care practitioners available today (Arenella, Yox, Eckstein, & Ously). Unfortunately, Carter, Rukholm, and Kelloway (2009) found that as of 2001, nurses
were still very hesitant about using educational technologies. Today, this trend has abated, but many nurses still feel as though they lack competency in regards to use of the Internet, computer, keyboarding, videoconferencing, Web-casting, and Internet discussion boards. Carter, Ruckholm, and Kelloway (2009) decided to create a web-based program for educating nurses about stroke, and in the process, assess how the use of these technologies enhanced their feelings of technological competence. Carter, Ruckholm and Kelloway (2009) found that not only were nurses satisfied with the educational materials, their perceived level of competency in using the Internet increased from 48% to 83%, in using the keyboard from 46% to 74%, in using videoconferencing from 39% to 50%, in using Internet discussion boards from 32% to 63%, and in using Web-casting from 23% to 39%. Additionally, Carter, Ruckholm, and Kelloway (2009) discovered that use of said technologies substantially increased access to and thus participation in continuing education programs amongst nurses working in rural clinics.

Furthermore, web-based tutorial programs are the best way for teaching large and diverse populations the same information without requiring synchronicity in scheduling. Web-based modules may include interactive components which are almost always rated positively amongst learners. Web-based modules can be revisited by learners, have been proven effective in enhancing evidence-based practice implementation in the hospital-setting, and are an easy way to ensure that all of the intended audience has access to the information (Paavilainen & Salminen-Tuomaala, 2010).

**Creating an Interactive Web-based Module**

A simple web-based module can be put together using Microsoft® Office Publisher. According to www.office.microsoft.com, Microsoft® Office Publisher 2010 currently costs
$139.99. In Microsoft© Office Publisher 2010, educational modules can be created and then saved in html format for publication on the Internet. Java Script can be used to add animations and interactive components. Traditionally, space on the Internet would need to be purchased with an associated monthly fee. However, as in the case of the EPEC™-O project, existing parent web-sites, like Medscape, are generally willing to partner in the creation of a web-based educational module and loan space. Hospitals wishing to teach the content to their staff may also be willing to offer space on their own websites. For this project, the University of Arizona-College of Nursing has agreed to make room on their web-page for the pilot of this module.

**Module Content**

**How to Identify a Patient in Need**

According to the National Cancer Institute (2006), patient perceived QOL should be used as the guide for directing all patient care. There are four major domains, each representing either the physiological, psychological, emotional, or spiritual needs of the individual, that directly influence patient perceived QOL (NCP, 2010). Functional status or the ability to perform the activities of daily living has also been linked to changes in patient perceived QOL. When patient needs are met in each of the four domains, then the patient’s QOL improves even when the patient’s functional status does not. Hospice care is intended to meet patient needs in all four of these domains and, in turn, increase the patient perceived QOL despite a steady decline in functional status (Buck, Overcash, & McMillan, 2009).

Unfortunately, QOL can be difficult to assess and conceptual models to empirically assess patient perceived QOL are limited (Buck, Overcash, & McMillan, 2009). For this reason, Buck, Overcash, & McMillan (2009) decided to test an adapted model of the Geriatric Cancer
Experience in the End of Life originally piloted as Emanuel’s Framework of a Good Death in 1998. They compared the findings of their assessment tools to patient-reported QOL, and those assessments or assessment tool combinations with the greatest correlation to patient perceptions were adapted into the model. Quantity of uncontrolled symptoms and an attention to spiritual well-being were found to be the strongest predictors of patient perceived QOL. It is important to note that the sample populations for the Buck, Overcash, & McMillan (2009) study came from two non-profit hospice organizations. Theoretically, and for the pilot of this module, hospitalized patients with a prognosis of six months or less and who score lower on the QOL index based on the adapted model than the Buck, Overcash, & McMillan (2009) study participants would be the most suitable candidates for a hospice referral if they have yet to receive one. The assessment protocol based on the adapted model of the Geriatric Cancer Experience in the End of Life that will be included in the web-module can be found in Appendix A. In the web-tutorial itself, the learner will be asked to complete a case study involving a pancreatic cancer patient and in which they will conduct an assessment using the tools provided in Appendices A and D. Recently, several collaborators from around the United States have offered their QOL assessment scales for use in this module. Should one of these assessment scales become available for use prior to the piloting of this project, it could be used in place of Appendices A and D.

**How to Communicate Patient Needs to Physicians**

Despite efforts for improvement, nurse-physician communication remains problematic (McCaffrey et al., 2010). This was manifested in the LeBaron, Bohenkamp & Reed (2010) study when many of the PCRNs requested further information about how to communicate their assessment findings with physicians. Nurse-physician communication is frequently in the
spotlight because it creates safety issues and improved communication was identified by the Joint Commission on Safety as a national safety goal in both 2007 and 2008. Poor communication results in decreased patient satisfaction in many areas, not just EOL care (McCaffrey et al., 2010; Tija et al., 2009). Additionally, when effective communication does occur, patient and family problems are resolved in a more timely manner, which for EOL care, means that transitional decisions are being made earlier in the disease trajectory (McCaffrey et al., 2010).

A study by McCaffrey et al. (2010), found that doctors and nurses have different desires and perceptions of what is expected while communicating. To the physician, it is important that nurses anticipate the physician’s needs and conduct abbreviated discussions that focus on medical issues. With this, templates and SBAR tools can be very useful. They improve both nurse and physician satisfaction with communication. Templates and SBAR tools can help minimize confusion, keep conversations brief, and allow nurses to organize the dialogue in advance (McCaffrey et al., 2010; Tija et al., 2009; Whitson et al., 2008). Whitson et al. (2008), unaware of the SBAR tool at the time, created the Chief Complaint and Context/Code Status, History, Assessment, and Talk (CHAT) tool, depicted in Figure 3, which could be linked to charting templates to address the specific area of concern. Whitson et al. (2008) found that the CHAT tool increased all levels of satisfaction and even noted that the CHAT could most likely be substituted for an SBAR and be equally effective. Appendix B contains a modified SBAR tool that will be included in the web-module and can be used to communicate hospice need assessment findings. Appendix C contains a chart of additional communication problems and
solutions identified in the Tija et al. (2009) and McCaffrey (2010) studies that will also be included in the web-based module.

FIGURE 3. CHAT Communication Tool

CHAPTER 5 – OBTAINABLE GOALS AND FUTURE PREDICTIONS

The goal for this project is to educate readers about the complexity of EOL transitional decisions, increase awareness about the overriding need for earlier hospice referrals among terminally ill cancer patients, and devise a means for ultimately encouraging earlier referrals to hospice in the patient’s illness trajectory. This paper was intended to educate readers about a cancer condition in which all of the issues discussed are relevant and to which the proposed protocol can be applied. This paper also detailed the steps necessary for creating a web-based educational module that would include a proposed protocol for assessing and communicating hospice referral need and ultimately expand on the information taught in the LeBaron, Bohenkamp, & Reed (2010) study. If the web-based module were piloted, it would be tested on a sample of 18 PCRNS currently employed at UMC in Tucson, Arizona. These selected PCRNs would have participated in the LeBaron, Bohenkamp & Reed (2010) study, in which they completed ELNEC training followed by six additional workshops where they voiced collective concern about how to best assess and communicate hospice care needs to physicians.

The usability of the module will be measured based on participant responses to imbedded questions throughout the content and a final survey at the end of the module. Every several slides participants will be prompted to answer recall-recognition questions. Participants must answer the questions correctly before they may advance to the next topic in the module. Only the participant’s first attempt at a question, whether they answer correctly or incorrectly, will be used for qualitative analysis and inclusion in the results. All participant responses to the final survey questions will be evaluated qualitatively. Participants will answer all survey questions as
either useful or not useful and helpful or unhelpful. Boxes below survey questions will allow for participant comments.

The short term objectives for this study are as follows: all study participants will complete the educational module and final survey, greater than 50% will rate the module as useful, greater than 50% will answer all learning objective questions correctly on the first attempt, greater than 50% will state increased comfort when assessing and communicating hospice referral need to physicians. The long term objectives for this study are as follows: the web-module will be implemented as a post-workshop for PCRN training by 2013, hospice referrals will become timelier and patient perceived QOL at EOL will improve at UMC by 2023. In the future, this web-based module should become an easily accessible means for educating all acute care nurses about assessing and communicating hospice referral need, and a fitting post-session for all ELNEC participants regardless of their geographic locale.
If yes, perform hospice care education prior to completing the QOL assessment. The patient may wish to receive aggressive interventions until the date of death. If so, he or she is not a candidate for a hospice referral. Instead, the assessment tools to the right may be used as introspective educational tools for this patient and to track symptom management.

If no, use the tools to the right to perform an assessment of this patient’s current quality of life. For the MSAS, average all scores before keying them.

Does the patient have a terminal diagnosis of 6 months or less until the prognosticated date of death?

If yes, the patient currently undergoing or seeking aggressive therapies which may prolong life?

Key: Tally the number of times the patient scored in each color category. The patient’s color and scores can be used to indicate this patient’s QOL and their need for a hospice referral. Always begin with green, and progress through the actions up through the patient’s color.
APPENDIX B
### Situation

I am calling about <patient name and location>.

The patient’s code status is <code status>.

Date of admission (if applicable) mm/dd/yyyy

The problem I am calling about is his/her need for a hospice referral.

I have just assessed the patient personally for hospice referral need.

I am concerned about the patient’s quality of life and I believe they are in need of a hospice referral.

### Background

The patient has been suffering from ____________.

His/her estimated prognosis is: days to weeks weeks to months months to years

The patient’s current physicians are ________________________________________.

The patient has completed his/her advanced directives Yes or No

The patient has an appointed power of attorney Yes or No

The patient is currently residing: At home In a skilled nursing facility Other

### Quality of Life Assessment

<Detail assessment findings from the completed MSAS and Spiritual Needs Inventory>

Would I be surprised if this patient died in the next 6 months? Yes = not ready for hospice No = ready for hospice

### Recommendation

I suggest or request that you <say what you would like to see done>.

- Transfer the patient to critical care
- Come to see the patient at this time
- Talk to the patient or family about code status
- Refer the patient to hospice
- Ask for a hospice consultant to see the patient now

Is there anything you wish for me to discuss, ask, or disclose to the patient/family at this time?

APPENDIX C
## Communicating with Physicians: Problems & Solutions

<table>
<thead>
<tr>
<th>Problem</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>28% of nurses felt hurried or rushed during the conversation (Tija et al., 2009)</td>
<td>Be self-aware during the conversation, and speak clearly and slowly even when feeling rushed. Just remember, it saves more time to get it right the first time. Additionally, calls can be bundled and meetings can be scheduled in advance, especially when it is not an emergency (Tija et al., 2009).</td>
</tr>
<tr>
<td>17% of nurses believed the physician did not want to deal with the problem (Tija et al., 2009)</td>
<td>According to Tija et. al. (2009) and McCaffrey et. al. (2010), nurses must be persistent and relentless in fostering true collaboration.</td>
</tr>
<tr>
<td>13% of nurses did not think that physicians consider nurses views (Tija et al., 2009)</td>
<td>Interprofessional immersion activities and communication programs are now being included in the educational curriculum for doctors and nurses at many major universities. They have increased awareness among doctors and nurses of the scope of practice and the type of education received by either profession (McCaffrey et al., 2010). Be informed and confident, and the physician will listen.</td>
</tr>
<tr>
<td>15 out of 21 nurses report a lack of preparedness when calling physicians (Tija et al., 2009)</td>
<td>Nurses who use communication tools, such as the SBAR, can improve physician satisfaction with the conversation. The nurse may get to say everything (s)he initially wanted to, but SBAR tools can be used to improve preparedness and ensure that the key points are relayed and the patients needs are met (McCaffrey et al., 2010). Organizational tools can also be used by nurses to identify areas in which (s)he still needs more information prior to placing the call (Tija et al., 2009). Nurses must fully understand the patient’s needs prior to attempting to communicate with physicians, which is just one more reason why using an assessment protocol and SBAR is helpful (Tija et al., 2009; Whitson et al., 2008).</td>
</tr>
</tbody>
</table>

## Keys to Communication Success (McCaffrey et al., 2010)
- Be honest
- Be open as both a communicator and a listener
- Listen with interest
- Keep emotions out of the conversation
- Organize dialogue in advance
- Avoid jargon and vague terminology
- Be caring
- Assign responsibilities, do not dump them
- Be self-aware, especially of body language
APPENDIX D – ADDITIONAL RESOURCES
Memorial Symptom Assessment Scale (MSAS)

<table>
<thead>
<tr>
<th>DURING THE PAST WEEK</th>
<th>IF YES, How OFTEN did you have it?</th>
<th>IF YES, How SEVERE was it usually?</th>
<th>IF YES, How much did it DISTRESS or BOTHER you?</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>DID NOT HAVE</em></td>
<td>Rarely</td>
<td>Occasionally</td>
<td>Frequently</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Lack of energy</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Cough</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling nervous</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Nausea</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling drowsy</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Numbness/tingling in hands/feet</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling bloated</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Problems with urination</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Vomiting</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling sad</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sweats</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Worrying</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Problems with sexual interest or activity</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Itching</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Dizziness</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling irritable</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Retrieved from: http://www.npcrc.org

**Spiritual Needs Inventory (Selected Items)**

This questionnaire contains 27 phrases that describe needs (activities, thoughts, or experiences) that some people have said they have during their illness. For some people, these needs relate to the spiritual part of them. They define spiritual as that part of them that tries to find meaning and purpose in life. They believe a spiritual need is something they need or want in order to live their lives fully. I am interested in finding out what you consider spiritual needs to be and which of these needs you currently have.

**Directions:** Read the need in column A, then answer the questions in columns B, C, and D, before going on to the next need in column A.

<table>
<thead>
<tr>
<th>Column A</th>
<th>Column B</th>
<th>Column C</th>
<th>Column D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please rate the items in the column below. For every item in Column A that you answer 2, 3, 4, or 5, please answer yes or no in Columns C and D.</td>
<td>Do you consider this activity to be a spiritual need?</td>
<td>Is this need being met in your life now?</td>
<td></td>
</tr>
</tbody>
</table>

**In order to live my life fully, I need to**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sing/sit listen to inspirational music.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Laugh</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be with friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Read inspirational materials.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Pray</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

(Hermann, 2006)
REFERENCES


