

HOW TO EVALUATE THE ROLE OF A PALLIATIVE CARE DNP-PREPARED
APRN EMBEDDED IN AN ONCOLOGY OUTPATIENT SETTING

by

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ABSTRACT

Studies show that palliative care APRNs are effective in mitigating patient symptoms and improving quality of life (QOL). Unfortunately, there are no theory-driven models that guide and evaluate the role of an APRN embedded in an outpatient oncology setting.

Purpose. The primary purpose of this study is to evaluate the feasibility and effectiveness of a palliative care theory-driven APRN intervention using the newly developed Hanna QOL-Symptom Control Model[©] on the following patient-, provider-, and financial-related outcomes: symptom control, QOL, patient satisfaction; time in and location of APRN follow up; provider satisfaction, number and timing of referrals; and Emergency Room visits and hospital, versus home versus hospice deaths.

Methods: Design. Longitudinal, quasi-experimental pre-posttest feasibility study.

Sample/Setting. All oncology patients referred to the Palliative Care APRN over one year at St. Jude Heritage Healthcare, Orange County, CA. **Intervention:** APRN practice translation of National Comprehensive Cancer Network (NCCN) evidence-based symptom management guidelines. **Instruments.** St. Jude Electronic Medical Record Demographic and Medical Record Data; Patient and Provider Satisfaction Surveys; Quality Oncology Practice Initiative Data (ASCO-QOPI); The Edmonton Symptom Assessment System (ESAS) and single item validated QOL scale, **Data Analysis.** Descriptive and Inferential Statistics.

Limitations. Non-randomized study evaluating the role of a single Palliative Care APRN provider in one clinical setting with a primarily Caucasian sample will affect the study's generalizability.

Implications. Study results will be used to revise the intervention and Hanna QOL-Symptom Control Model[©] and to disseminate results to St Jude Stakeholders and others via presentations and publications. A future comparative effectiveness study is planned using these findings as baseline data.

CHAPTER 1 - INTRODUCTION

Advanced Practice Nurses (APRN) are qualified to provide comprehensive, compassionate and cost-effective care in palliative care settings (Dahlin, Campbell, & McCorkle, 2002). Studies show that palliative care APRNs are effective in mitigating symptoms and improving quality of life (QOL) (Prince-Paul et al, 2010; Meier & Beresford, 2006). While there are a variety of models and guidelines designed to improve QOL for patients and families experiencing life-threatening illness, there is no current theoretical framework or conceptual model in palliative care designed to formally guide or evaluate an APRN's practice (Reed, 2010).

New evidence is supporting the use of palliative care programs in general to reduce Medicare and third-party payer expenditures during hospitalization (Morrison et al, 2008). Few have evaluated the impact of palliative care programs delivered in the outpatient setting or evaluated the role that an APRN who is doctorally-prepared (Doctor of Nursing Practice or DNP-prepared) can play in a palliative care program or on associated costs in the outpatient setting. Thus the reason for undertaking this study.

Purpose and Research Questions

Purpose

The primary purpose of this study is to evaluate the feasibility and effectiveness of a palliative care theory-driven APRN intervention using the newly developed Hanna QOL-Symptom Control Model[©] on patient-, provider-, and financial-related outcomes in an oncology outpatient setting.

Research Questions

1. What is the feasibility of implementing a palliative care theory-driven APRN intervention using the Hanna QOL-Symptom Control Model[®] in an outpatient oncology setting (i.e., patient attrition rates and missing data)?
2. What is the effectiveness of the palliative care intervention on patient-related outcomes (i.e., patient symptom control, [ESAS], patient QOL [0-10 scale], patient satisfaction [St Jude Heritage Survey], and patient time in and location of APRN follow up)?
3. What is the effectiveness of the palliative care intervention on provider-related outcomes (i.e., provider satisfaction, number and timing of patient referrals)?
4. What is the effectiveness of the palliative care intervention on financial-related outcomes (i.e., Emergency room visits, hospital, versus home versus hospice deaths)?

Definitions

The following section describes the definitions that guide this study. For more detail on these definitions, please refer to the study's review of literature that follows in chapter 2.

Advanced Practice Nurse (APRN)

The APRN is a registered nurse who meets the criteria of the American Association of Colleges of Nursing consensus statement (AACN, 2008).

Doctor of Nursing Practice (DNP).

The APRN who is DNP-prepared meets the ACCN's (2004) position statement that describes the essential areas of scholarship and practice.

Embedded

Embedded denotes a health care provider who is physically on site and able to directly offer palliative care education and patient interventions to manage symptoms in collaboration with a primary oncologist (Muir et al, 2010).

Palliative Care

Palliative care is both an interdisciplinary approach and a philosophy of healthcare that focuses on alleviating suffering and improving QOL for patients and families living with a chronic or terminal illness. It occurs over a continuum of care from diagnosis and treatment to end of life care including bereavement follow up for family survivors (Reed, 2010; World Health Organization, 2002; National Consensus Project for Quality Palliative Care, 2004; Coyle, 2006; National Consensus Project for Quality Palliative Care, 2009). Symptom management is one of its major domains (ASCO, 2009).

Patient Satisfaction

Patient satisfaction measures a patient's perception of their overall happiness with the services provided by a health care provider, hospital or system (Brumley et al, 2007). It is operationally defined by scores on the St. Jude Heritage Healthcare Patient Satisfaction Survey.

Provider Satisfaction

Provider satisfaction measures a provider's perception of overall happiness with the services provided by another health care provider's services. It is operationally defined by scores on the St. Jude's Healthcare Provider Satisfaction Survey and by the number and timing of patient referrals made to the APRN (Brumley et al, 2007; Johnson et al, 2009).

Quality of Life

Siddiqui, Kachnic and Movsas (2006) define health-related QOL as something that affects the entire range of a person's emotions, values and understanding of life. HR-QOL includes general health, physical symptoms, emotional well-being, role and social functions, sexual functioning, spiritual issues, financial concerns and living conditions. It is operationally defined by a score on the single item 0-10 QOL numeric rating scale.

Supportive Care

Many organizations consider supportive care to be synonymous with palliative care. Some suggest that supportive care is a better term to use than palliative care as it may be perceived as being less stigmatizing and less synonymous with death and dying than is the term palliative care (Bonebrake et al, 2010; Bruera & Hui, 2010). Others state that it addresses symptom management only and does not include care of the family (Bruera & Hui, 2010).

Summary

This chapter has introduced the important roles an APRN can play in palliative care by affecting patient-, provider-, and financial-related outcomes. The overall purpose

of the study, research questions, and definitions are identified. Chapter 2 which follows details the review of literature undertaken for this study.

CHAPTER 2 – REVIEW OF THE LITERATURE

This chapter describes the review of literature that was undertaken for this study. Palliative care definitions, conceptual models and evidence-based guidelines are reviewed. Measures are identified that can be used to evaluate the roles that a palliative care APRN embedded in an oncology outpatient setting can play on affecting patient-, provider-, and financial-related outcomes. Finally a new QOL-Symptom Control Model[©] is proposed that guides this APRN's theory-based intervention.

Search Methodology

Key Words

A broad search of the literature was conducted using the keywords listed in Table 1 that retrieved 1,283,310 abstracts, articles and presentations. By limiting the search strategy to only articles in English, adults over the age 19 and published in 2006-2011, this initial number was reduced to 359,271. Keywords were then combined to create 39 searchable categories with a final number of 124 evaluable articles and abstracts retrieved (Hanna, 2009). Two evidence-based practice guidelines well known to the author were retrieved directly from each organization's website (<http://www.nationalconsensusproject.org/>; <http://www.nccn.org/>).

Table 1

Search Key Words

General	Expanded
Oncology	Cancer, neoplasm, neoplasm (recurrence)
Advanced Practice	Advanced practice nursing, nurse practitioner, nurse practitioner (oncology), nurse practitioner (palliative care), nurse clinicians, evidence based practice, financial constraints, cost/benefit, patient education
DNP	Doctor of nursing practice, advanced practice, practice doctorate
Palliative Care	Cancer, oncology, costs, benefits, advanced practice, quality improvement, patient satisfaction, environment of care
Symptom Management	Oncology, cancer, side effects, treatments, patient satisfaction, nurse practitioner, environment of care, costs
Environment of Care	Home care, death, patient preferences, costs and constraints, palliative care, delivery of health care, managed care
Financial Concerns	Nurse Practitioners, palliative care, home care, hospital care, delivery of health care, managed care, healthcare business models, financial management (hospital, integrated systems)
Quality of Life	End of life, palliative care, cancer, treatment of cancer, symptom management, nurse practitioner, environment of care, measurement of
Theoretical Models	Palliative care, oncology, best practices, supportive care, conceptual models, conceptual frameworks
Evaluation	Evaluation models, evaluation frameworks, oncology, palliative care, new programs
Assessment Tools	Symptom assessment tools, Edmonton Symptom Assessment System, reliability, validity, palliative care, oncology

Databases

Multiple databases were searched to ensure that all salient articles were retrieved. A general search of Google and Google Scholar was undertaken. These search strategies were complemented by using author-specific searches and by retrieving articles from the original article's reference list. Table 2 lists the databases used in the search strategy (Hanna, 2009).

Table 2

Databases Searched

Databases	Years Searched
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	1982-2011
OVID Medline	1996-2011
Allied and Complementary Medicine (AMED)	1985-2011
Evidence Based Medicine reviews (Cochrane, DSR, ACP Journal Club, DARE, CCTR, HTA, NHSEED)	1966-2011
OVID Health Star	1966-2011
Google and Google Scholar	N/A

Table Abbreviations	
DSR	Data Set Ready
ACP	American College of Physicians
DARE	Database of Abstracts of Review of Effectiveness (Cochrane Library)
CCTR	Cochrane Controlled Trials Register
HTA	Health Technology Assessment
NHSEED	National Health Service Economic Evaluation Database

Introduction to Palliative Care

Background and Significance of the Problem

In the United States, the population is aging and with increased age comes an increased rate of people being diagnosed with cancer. Globally, ten million people worldwide are diagnosed annually and of these 60% will die (Ferris et al, 2009). Studies anticipate that both the incidence and mortality statistics will increase by 50% by the year 2020 (Ferris et al, 2009). However, as the incidence increases so too does cancer survival with the end result indicating that many people are living longer with treatment and cancer-related disabilities (i.e., cancer survivors) (Ferris et al, 2009). Morrison et al (2008) note that while many of these patients are living longer with serious illnesses, they may still be receiving poor quality medical care characterized by unmet symptoms and personal care needs, high caregiver burden and low patient and family satisfaction.

Partly due to this aging population and the increase in the diagnosis of cancer, healthcare costs are soaring, placing the federal government's Medicare and Medicaid programs in precarious financial positions (Higginson & Foley, 2009; Ferris et al, 2009; Smith & Hillner, 2011). Fully 25% of a person's Medicare expenses are incurred during the last year of life. The costs of new medications are profoundly expensive for insurers and many of these newer agents have significant side effects with questionable cost-benefit profiles (Smith & Hillner, 2011). As a consequence, the terminal phase of cancer care is the most costly, even more so than the potentially curative treatment phase (Johnson et al, 2009).

Higginson & Foley (2009) conclude that palliative care is no longer a luxury but a necessity. Palliative care is now recognized as a public health need and Ferris et al (2009) recommend that it be available to all patients and their families regardless of setting or stage of disease. Others recommend that it be available for all patients with a significant illness from the time of their initial diagnosis (Emmanuell et al; 2001) and be implemented in conjunction with curative treatment and symptom management (Bonebrake et al, 2010).

Unfortunately many in healthcare have difficulty distinguishing palliative care and supportive care from end-of-life or hospice care. Medical textbooks are deficient in discussing palliative care.

Palliative Care Definitions

In reviewing definitions for palliative care, many contain four basic domains of care: physical, psychological, social and spiritual.

For example, the American Society of Clinical Oncology (ASCO) (Ferris et al, 2009) defines palliative cancer care as:

The integration into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and have an impact on the quality of their lives. Palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near.

The World Health Organization (WHO) (2011) defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The WHO states that palliative care is the management of pain and other symptoms, a process that neither hastens nor slows death but regards death as being part of the normal progression of life, enhances quality of life and may positively affect the length of that life, is appropriate at any stage of illness, and should be used in conjunction with other standard cancer therapies being administered.

The National Comprehensive Cancer Network (NCCN) defines palliative care as:

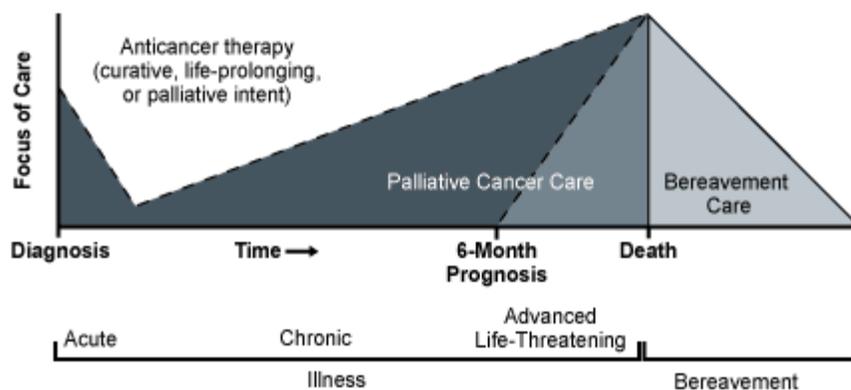
Both a philosophy of care and an organized, highly structured system for delivering care to persons with life-threatening or debilitating illness. Palliative care is patient and family-centered care that focuses upon effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and culture(s). The goal of palliative care 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. Palliative care can be delivered with life-prolonging care or as the main focus of care.

Palliative Care Conceptual Models

The ASCO Model of Palliative Care (Figure1) includes phases of care dependent upon disease progression over a period of time. This model shows palliative care being

delivered over the continuum of care from diagnosis to death with bereavement care offered to family survivors. All major organizations including ASCO, the NCCN, the National Quality Forum (NQF), the American Academy of Hospice and Palliative Medicine (AAHPM), the Hospice and Palliative Care Nurses Association (HPNA) and the Center to Advance Palliative Care (CAPC) recommend this continuum of care in their guidelines and position statements (Ferrell, Paice & Koczywas, 2009). The ASCO model reflects a higher need for palliative care at the time of diagnosis that gradually reduces in need through treatment and increases again over time until patients reach an estimated prognosis of less than six months to live at which point care is transitioned to hospice care. This model does not address patients who may have a higher requirement for palliative care during their entire cancer experience.

Figure 1 – *ASCO Model of Palliative Care*

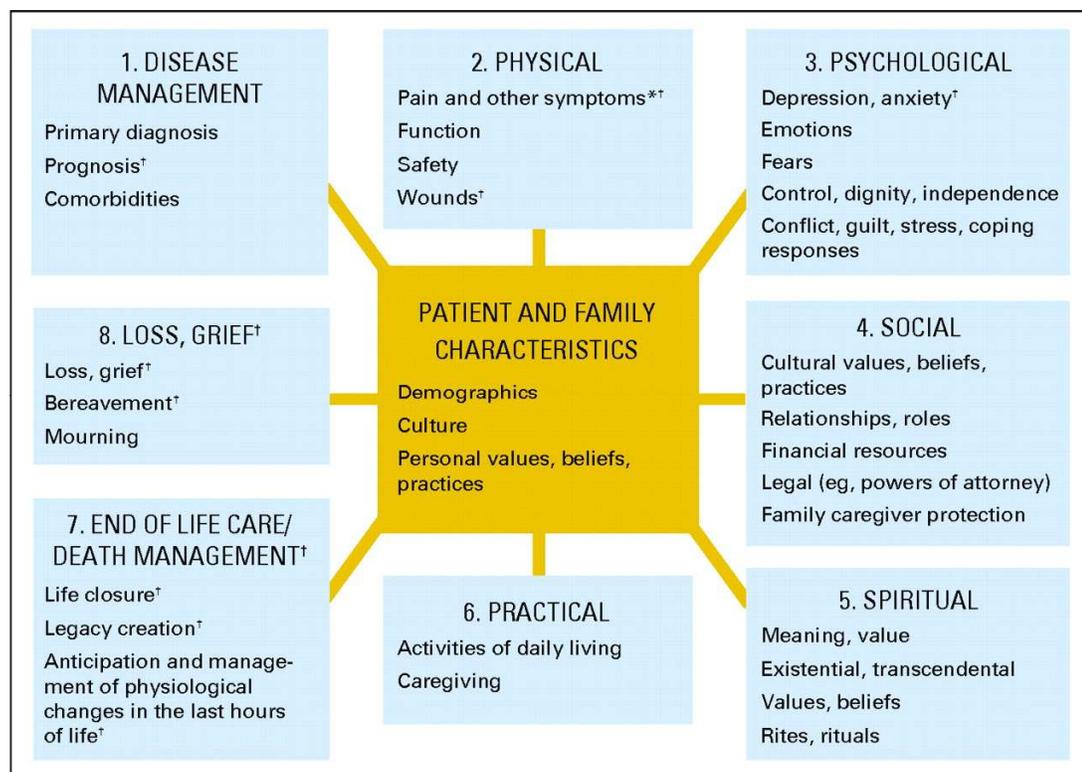


Palliative care should be provided from diagnosis of cancer to end-of-life, along side cancer treatments. The dark gray regions denote palliative care involvement; the medium gray triangle represents hospice involvement; the light gray portion corresponds to the bereavement phase. Reprinted with permission. © 2008 American Society of Clinical Oncology. All rights reserved.

In addition, ASCO created a model for suffering that considers a patient and their family's quality of life (QOL) (Figure 2). This framework contains eight domains which broaden Ferrell's (2008) classic four components of QOL (physical, psychological, social

and spiritual) to include loss and grief, end of life and death management and the practical aspects of living with a malignant diagnosis. All eight are affected by patient and family characteristics in the center of the model that includes demographics, culture and personal values, beliefs and practices. These domains are accepted by the National Quality Forum (NQF) as the minimum basic standards for quality palliative care. Each of these domains are evidence based and have been created through a coalition of palliative and hospice care services in the United States (Ferrell, Paice & Koczywas, 2009).

Figure 2 – *ASCO Framework for Suffering*



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The WHO's conceptual model for palliative care is virtually identical to that of ASCO's except the WHO's model has a straight line indicating the absence of palliative

care at diagnosis and increasing palliative care needs at the end of life. The WHO model does not specify when or if hospice care is included.

The NCCN's palliative care model includes prognostic time frames based on life expectancy phases: years to months, months to weeks and weeks to days. Patient and family education and care requirements can differ depending on the estimated prognostic time. For example, patients with a longer life expectancy following their initial diagnosis may need information appropriate to what they are experiencing at the time of diagnosis, treatment, and related symptoms and to know what they can anticipate over the coming months. In contrast the imminently dying patient and their family members may require more support for anticipatory grieving and symptom management and education about the dying process.

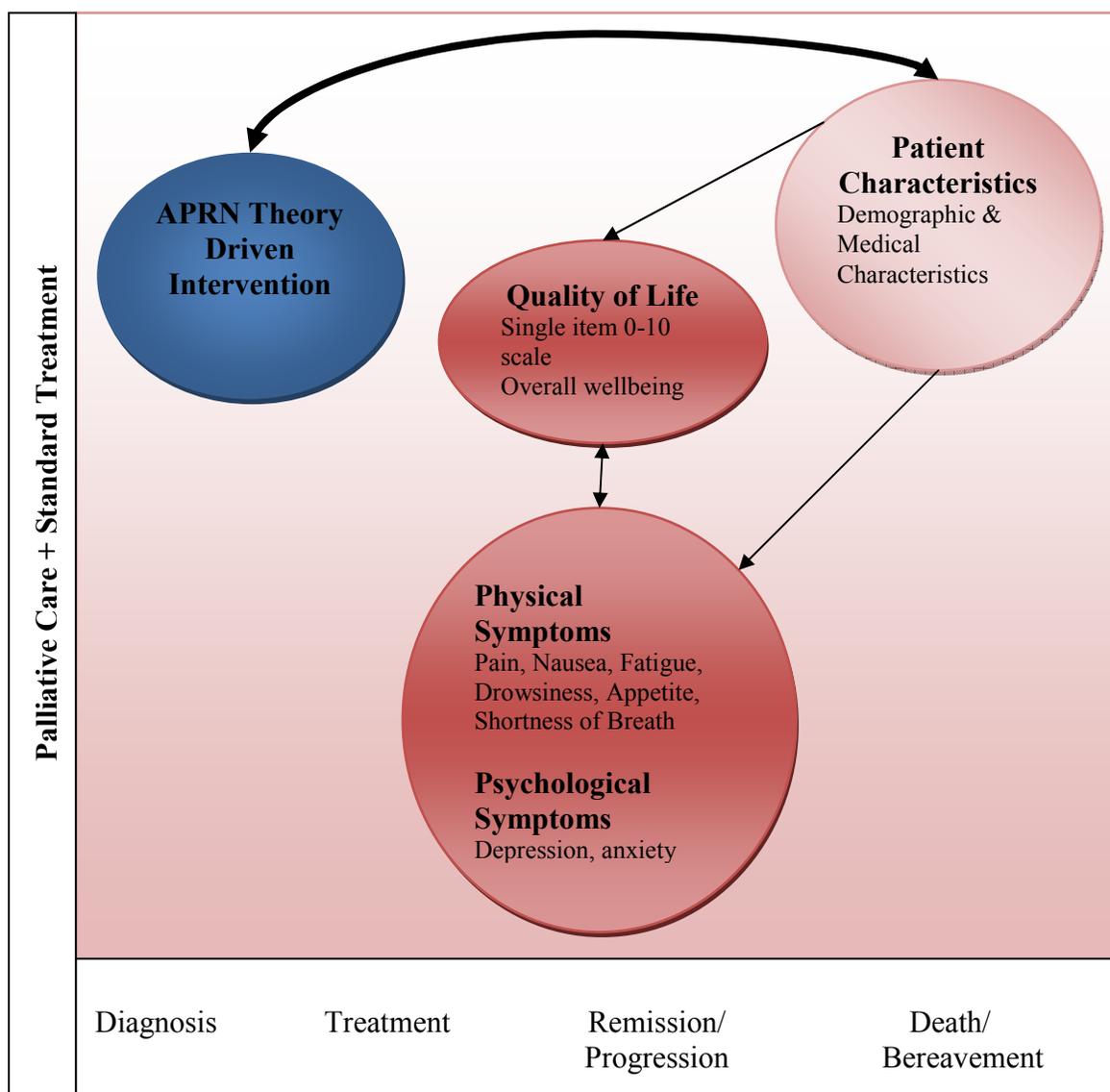
Hanna QOL-Symptom Control Palliative Care Model ©

The newly developed Hanna QOL-Symptom Control Palliative Care Model (aka the Hanna Model[©]) includes components of the ASCO Palliative Care Model (Figure 1) that views palliative care as an essential part of cancer treatment over a continuum of care (diagnosis, treatment and end of life). It incorporates ASCO's physical and patient domain characteristics contained within its suffering model (Figure 2). In the Hanna Model[©] (Figure 3) patient characteristics (demographic and medical characteristics) are viewed as moderators of the APRN theory-driven intervention. A moderator affects the direction and/or strength of the relationship between the independent variable in this case the APRN theory-driven intervention and the dependent variables, in this case symptom control and QOL (Baron & Kenny, 1986). The patient's demographic and medical

characteristics affect how the intervention (see chapter 3 under methods) is tailored to a specific patient.

For example, a patient's demographic characteristics such as age, marital status, living arrangements, financial status and health insurance can affect the APRN's decision-making about how the intervention will be tailored to the patient's needs and resources. A senior with cancer may be dependent upon Medicare for insurance coverage and may not have good medication coverage. The APRN takes these factors into consideration when selecting a medication to manage a patient's symptom. In addition physical and mental symptoms do not occur in isolation with one another (i.e., tachycardia occurring concurrently with anxiety) and are intimately involved in how the patient may view their QOL.

Figure 3 - *Hanna QOL-Symptom Control Palliative Care Model*[®]



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Palliative Care Evidence-Based Guidelines

Many organizations have created guidelines for the management of specific diseases, disease-related symptoms and treatment-related side effects. Currently there are two evidence-based practice guidelines in palliative care. These include the clinical

practice guidelines for quality palliative care from the National Consensus Project for Quality Palliative Care (NCP-QPC) (2009), a group created from four other national organizations specifically to create these guidelines; and the guidelines promulgated by the National Comprehensive Cancer Network's (NCCN) (2009) palliative care committee, a group consisting mainly of physician specialists.

The National Consensus Project for Quality Palliative Care (NCP-QPC) Guidelines. The NCP-QPC guidelines are based on eight domains which include structure and process of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual, religious, and existential aspects of care, cultural aspects of care, care of the imminently dying patient and ethical and legal aspects of care. These eight domains are remarkably similar to the eight domains contained within the ASCO suffering model. These guidelines apply to all types of patients who might benefit from palliative care and cover all ages. The steering committee was interdisciplinary and included physicians and APRNs. These guidelines are extensive and evidence-based but do not provide specific information useful to clinicians about how best to manage patient symptoms, concerns or problems.

The NCCN Palliative Care Guidelines. The NCCN recommends in their 2011 Palliative Care Guidelines that all patients be screened for palliative care from their initial visit, regularly thereafter and receive education that palliative care is an integral part of their cancer care regardless of their diagnosis or stage of disease. The NCCN guidelines cover all domains contained within the ASCO models. The NCCN guidelines are specific

to cancer patients although the information they contain can be utilized for all palliative care patients.

The members of the NCCN committee that developed these guidelines included mostly physicians. Thus disease, and treatment-based algorithms take precedence but they are specific enough to guide practice for clinicians. The symptom assessment and management algorithms contained within the guidelines can be used for all patients not only those diagnosed with cancer. Treatment algorithms are tailored to the patient's life expectancy and the differences in care that may be needed (patient who has potentially years to live versus the person who is imminently dying). The guidelines address physical, psychological, social and spiritual care and referral recommendations. The guidelines also address end of life management issues such as handling requests for physician assisted suicide (PAS) or euthanasia and terminal sedation. The evidence used to create these guidelines is 2A (NCCN criteria) which means that they are based at a lower level of evidence than randomized trials but there is overall NCCN consensus that the interventions are appropriate. The use of clinical guidelines is recommended for all providers within the St Jude Heritage Healthcare Network and the NCCN guidelines already are being used by the author to manage patient symptoms.

Symptom Management

Symptom management is one of the most important patient concerns and its effectiveness can have a major impact on a patient's QOL (Shoemaker et al, 2011; Dodd et al, 2001; Zafar et al, 2010; Reville, Axelrod & Maury, 2009). Shoemaker et al (2011) believe that health care providers need education on symptom management. Dodd et al

(2001) cautions healthcare providers not to make inferences about a patient based upon their presenting problems but rather they should query the patient about their symptomatology and accept that a person's symptom is whatever they say it is.

Symptoms of advanced cancer can often become chronic and patients can rate them as being moderate to severe in intensity (Shoemaker et al, 2011). Each symptom can vary in intensity and is dependent upon the perception of the patient (Dodd et al, 2000). Common symptoms experienced by cancer patients include pain, fatigue, weakness, anorexia, nausea and vomiting, dry mouth, constipation and dyspnea. In this study, the NCCN Palliative Care Guidelines and symptom management algorithms (i.e., palliative care, pain, distress, fatigue, and the elderly) will be used to guide the APRN's theory-driven intervention.

Symptom Measurement

While there are many scales available that measure specific individual symptoms, use of multiple individual symptom inventories can increase the burden for completing these scales for palliative care patients. In addition many patients experience not just one symptom at a time but rather experience multiple coexisting symptoms concurrently (Shoemaker et al, 2011). Thus a short non-burdensome multiple symptom inventory is preferable to use with these patients. Time may also be a concern for providers as many patients may require assistance to complete these tools.

The NQF recommends that standardized scales be used to measure and document pain, constipation, dyspnea and other symptoms as well as anxiety and other psychological symptoms. Abernethy, Wheeler & Currow (2010) recommend tools that

use “patient reported outcomes” or PROs and that these be integrated into standard oncology practice to improve patient care and outcomes. Given that it is the most commonly used tool in assessing the symptoms of a palliative care patient, the ESAS will be used at St Jude Heritage for the measurement of symptoms by the APRN as part of the Palliative Care Program.

The Edmonton Symptom Assessment System (ESAS). Abernethy, Wheeler & Currow (2010) considered the positive and negative aspects of many performance status and patient screening tools used in palliative care. They document that the most widely used measure for symptom assessment in palliative care is the Edmonton Symptom Assessment System (ESAS). The ESAS can be administered as often as needed as it is not considered too burdensome for patients or providers to complete. Results can be graphed for ease of viewing and for following symptom intensities and their patterns over time.

The ESAS was originally developed by the Regional Palliative Care Program, Capital Health in Edmonton, Alberta to evaluate symptoms in palliative care patients who were admitted to an inpatient hospice. Initially, 101 consecutive patients were evaluated upon admission to the unit and every twelve hours thereafter with the results documented on a graph. Patients’ average initial scores were 410 +/- 95 and then 363 +/- 83 by day five. The initial creators and authors, Bruera et al (1991), noted that these results were statistically significant ($p < .01$) and concluded that this tool was a simple and effective method of measuring symptom distress over time in a palliative care population. The tool has been recommended for use in palliative care patients due to its easy accessibility,

thoroughness yet simplicity, its evidence based foundation, sensitivity to symptom fluctuations (Institute for Clinical Systems Improvement, 2009), the brevity of time required to complete (approximately five minutes) and the use of the most common symptoms that patients complain about (Bruera et al, 1991; Chang, Hwang & Feuerman, 2000).

Chang, Hwang & Feuerman (2000) performed a prospective study in cancer patients with the purpose of validating the ESAS. 240 participants were asked to complete the ESAS, the Functional Assessment of Cancer Therapy – General (FACT-G), the Memorial Symptom Assessment Scale (MSAS) and the Brief Pain Inventory (BPI) if indicated. Of the initial 240 participants 233 completed both the initial test and the re-test. Statistical analysis was then performed to compare the results of the ESAS with the MSAS and FACT-G tools. Participant enrollment began in May of 1994 with the accrument goal of 100 outpatients and 140 inpatients being attained by December of 1995. This study was performed in a Veterans Administration Center with the result being that the majority of participants were male (225 to 8), with a median age of 69 and most having either a genito-urinary or pulmonary malignancy. Veterans' administration IRB approval was obtained and all patients signed informed consent prior to participation.

Statistical analysis was performed for each individual symptom and for distress. Cronbach alpha correlation coefficients were calculated with the overall result being .79, Spearman or Kendall coefficients were calculated between corresponding items on the different tools with Spearman calculations also being performed for test-retest correlation

coefficients and their corresponding p values. The Wilcoxon rank sum test was used to compare mean values for ESAS variables for outpatients and inpatients, and the chi-square test was used to compare the frequency of symptoms for inpatients and outpatients. Box plots comparing the ESAS with MSAS were created for the four most frequently reported symptoms; pain, shortness of breath, anxiety and drowsiness. The results showed that distress was higher for inpatients compared to outpatients with significant correlation noted between the ESAS and MSAS ($r = .73, p < .0001$). Similar statistically significant results were noted between each individual symptom on the ESAS and on the MSAS and FACT-G equivalent items ($p < .0001$). Test re-test Spearman correlation coefficients were statistically significant for all items at two days ($p < .0001$) but only for pain, activity, depression, shortness of breath and distress at five days ($p < .005$). The authors state that these results meet the criteria for internal consistency, criterion, and concurrent validity. Internal validity was established with Cronbach's alpha. The authors note the limitation of the participants being mainly older males and recommend further studies including more females and younger patients. Again is noted the lack of psychological assessment questions but no recommendations are made about how best this should be further studied or assessed. Although the authors note that the ESAS is lacking in psychological content, this study did prove that the tool is a valid and useful survey for assessing physical symptoms in patients with advanced cancer. The ESAS with its 10 questions was compared to two tools both of which contain significantly more questions, 32 for the MSAS and 33 for the FACT-G. The brevity of the ESAS is an important consideration when asking patients with advanced cancer to

participate in such a study as they may be suffering too much to complete a tool that is lengthier.

Nekolaichuk, Watanabe & Beaumont (2008) performed a review of 15 years worth of ESAS validation studies. Performing a literature review they identified thirteen articles in peer reviewed journals that were available in English. Of the thirteen studies eleven were on cancer patients. There was a wide variation in formatting across studies with differences in items selected and number reviewed. Eight of the studies looked at reliability estimates with few considering validity. None looked at the items from a patient's point of view. The authors recommend further studies to improve accuracy and validity including having information from a patient's perspective.

Watanabe et al (2009) performed a qualitative "think-aloud" study to evaluate patients' thoughts about the ESAS. Inclusion criteria included adults over the age of 18, cognitively intact with a diagnosis of advanced cancer that could complete the ESAS independently. IRB approval was obtained prior to enrolling any participants. 20 patients (50% male, average age 56) were enrolled at which point they reached data saturation. Patients were asked to complete the ESAS and talk aloud about any difficulties they were having with the tool. Each patient was recorded while completing the tool with the transcripts being coded and analyzed using content analysis. Data and investigator triangulation, audit trail and oral and written transcript comparison were used to maintain trustworthiness. The results showed that patients had trouble defining and differentiating between certain symptoms; i.e. tiredness versus drowsiness, depression and anxiety, appetite and well being. Participants suggested adding other components like irregular

bowel movements, concentration, and financial and emotional difficulties. The authors recommend clarification of the problematic terminology and having the assistance of a health care provider as will be done in this study to complete the document, at least for the first time. Future research recommendations include evaluating the ESAS in patients without cancer, in complex patients with multiple symptoms and in a larger sample of patients.

Richardson & Jones (2009) performed a review of the reliability and validity of the ESAS. They identified 39 peer reviewed papers from 25 different institutions, 33 of which involved cancer patients. These authors note that reliability is established for daily use but overall the scores were skewed with a floor effect. The mean scores however were similar across the studies. Emotional symptoms were again noted to be poorly met. In conclusion, the authors note that the ESAS is reliable but has restricted validity. Recommendations for research include expansion of the physical symptoms and the renaming of the ESAS to be specific for physical symptoms and the creation of an equivalent tool for emotional distress.

What the above mentioned studies fail to discuss is the fact that two of the ESAS symptom categories are actually psychological. Depression and anxiety are standard symptoms on the ESAS and can be measured, assessed and managed the same as any of the physical symptoms. Within the algorithms of the NCCN guidelines are treatment management recommendations for these symptoms which include the use of certain medications and referrals to additional providers as needed. These guidelines will be utilized in the APRN's theory-driven intervention.

Palliative Care Program Evaluation

Given that studies show the importance of palliative care in patient, family and provider satisfaction and in reducing costs, it is important to continuously evaluate programs to show that they are meeting the needs of the population served. In the case of the St Jude Heritage Palliative Care Program, an evaluation is appropriate to show the benefit of a new program and to encourage stakeholders' further involvement with advancing the program. Ferrell, Paice and Koczywas (2009) recommend that future research focuses on the QOL of patients, their families and their satisfaction with treatment.

The Center for Disease Control (CDC) (2011) defines program evaluation as “the systematic investigation of the merit, worth or significance of an object”. To fully evaluate a program each of these three interconnected areas must be considered; merit is the quality of the program, worth is the cost effectiveness of a program and significance is how important/useful the program is. For the purposes of this study, program evaluation will include patient and provider APRN satisfaction surveys; monitoring provider referral patterns; and costs associated with emergency room visits, hospitalizations, and hospital deaths (if easily retrievable).

Patient Satisfaction

Patient Satisfaction St Jude Heritage Healthcare. Patient satisfaction is usually measured by the use of a survey to assess overall happiness with the services provided by a health care provider, hospital or system (Brumley et al, 2007). At St Jude Heritage an outside company performs quarterly patient satisfaction surveys analyzing 30 patients per

provider and then benchmarks the data against national standards. These surveys are sent to patients and scored independently of the providers delivering the care.

Provider Satisfaction and Evaluation

There are many outcome scales available to evaluate provider satisfaction with care given to their patients by another provider. The majority are surveys created by individual organizations. These surveys are frequently based upon national competencies created by professional organizations such as the Board of Medicine or Nursing or from position statements such as “Advanced Practice Nurses Role in Palliative Care” developed by the Promoting Excellence in End-of-Life Care Program (Robert Wood Johnson Foundation) (2002). Provider satisfaction is evaluated at St Jude Heritage in a similar manner to the patient satisfaction surveys (Johnson et al, 2009).

Palliative Care Financial Evaluation

Studies in the cost of palliative care programs in the hospital setting have shown a variety of different cost benefits from approximately \$1,000,000 in the first year for a hospital (Stephens, 2008) to daily benefits of between \$300 (Smith & Cassell, 2009) and \$400 (Morrison et al, 2008) in savings. European studies have also shown the financial benefit of hospital palliative care programs however they are more difficult to interpret given the differences in health care systems between Europe and the US (Cartoni, et al, 2007; Paz-Ruiz et al, 2009).

Brumley et al (2007) reported on patient satisfaction with care and the accompanying reduction in costs of an in-home palliative care service. This was a randomized controlled trial of 298 patients with a life expectancy of one year or less

performed in two health maintenance organizations in two states (Colorado and Hawaii). The intervention consisted of in-home palliative care plus usual care versus usual care. Patients were interviewed within 48 hours of study enrollment and then every 30, 60, 90 and 120 days to evaluate satisfaction with care. Additional demographics were taken from the medical records and included site and date of death and providers completed the palliative performance scale to measure severity of illness. Patient interviews were completed using the Reid-Grundlach satisfaction with services instrument to measure overall satisfaction. Statistical analysis consisted of two-tailed *t*-tests for continuous variables and chi-square tests for discrete variables. Survival was analyzed by Kaplan-Meier curves and there was no difference noted between groups. Ordinary least squares regression was used to evaluate costs. Patient satisfaction improved in the intervention group and those patients were less likely to use the emergency room or be hospitalized ($p < .001$). Significant financial savings were noted with a 33% reduction in costs in the intervention group ($p < .001$) and those patients were more than twice as likely to die in their own homes as patients in the usual care group.

Chenoweth et al (2008) considered the financial implications of having an on-site nurse practitioner. Although this study was performed in an industrial metal and plastics manufacturing firm and not in palliative care the results of this study clearly show the financial benefit of having an embedded provider. In the first year of NP service, savings were noted to be \$1,313,756. The authors attribute this to improved productivity, reduction in on-site injury and illness and also to the “novelty factor” of having a healthcare provider located on-site. After a three year analysis these results were verified

with an average of just over \$1,000,000 in savings per year. Limitations included the inability to assess for other benefits that may have reduced health care costs and the lack of an evaluation of the company's own wellness initiative program. The authors recommend further long-term analyses of NP led programs to verify this cost saving. Meier & Beresford note that NPs are less costly than physicians with comparable outcomes. Bauer (2010) comments on the financial aspects of NP care stating that "all the evidence supports using nurse practitioners as one of the most cost-effective and feasible reforms to solve America's serious problems of cost, quality and access in healthcare".

Most studies considering cost effectiveness compare palliative care, either inpatient or outpatient, to standard of care (hospitalizations, length of stay, QOL). All studies reviewed considered the QOL in patients who received palliative care interventions in addition to the standard of care. Given the currently precarious state of Medicare and Medicaid there is great interest in patients receiving appropriate levels of care that are financially prudent. The above mentioned studies clearly show the benefit of having an embedded nurse practitioner regardless of the setting. Patients are more satisfied with care, less likely to use the emergency room and more likely to die at home. These studies show a significant cost saving both in the in and out-patient setting. It is therefore reasonable to assume that the implementation of an embedded nurse practitioner in an oncology setting would increase patient satisfaction while also being cost-effective.

Implementation costs for St Jude Heritage's palliative care program include the cost of conducting an employee search, hiring and paying an appropriately qualified NP

to create and implement the program. There is anticipation that some of the costs might be defrayed by the reduced hospitalization of patients enrolled in the program. For example, Prince-Paul et al (2010) showed an 84% reduction in the hospitalization of patients receiving palliative care.

In 2009 Dudgeon et al reported on the development, implementation and process evaluation of a palliative care program in Canada. The palliative care integration project (PCIP) was developed to improve continuity of care and to reduce variations of care in patients with cancer. Participants included all cancer patients who were considered incurable (n = 1347) and were mostly located in a semi-rural or rural area of Ontario, Canada. The program had six objectives which included the following: 1. improved access to palliative care; 2. improved symptom management; 3. increased home and long term care facility deaths; 4. decreased emergency room visits and hospitalizations; 5. use of common evaluation methods; and 6. use of evidence based practice. The program began by creating a steering committee (stakeholders) and expert working groups to plan the program development, implementation and evaluation. A logic model was created at this time. Self administered surveys and focus groups were used to evaluate the program. Unfortunately the authors received very few responses which made it difficult to definitively analyze the program. The results did show that over the three year study period there was a consistent decrease in length of stay and emergency room visits, more patients died at home and there was improvement in patient symptom burden however none of the results reached statistical significance. Many of these same elements have been incorporated into this study.

Follwell et al (2008) performed a prospective study to evaluate the effect of an outpatient palliative care clinic on patient symptoms and their satisfaction with care. This was a non-randomized study with the inclusion criteria of patients over 18 with metastatic cancer who were new referrals to the palliative care clinic. Study approval was obtained from the organization's research ethics board and all participants signed informed consent. Target sample for a power analysis was 147 with 150 of 204 people approached consenting to participate. This number was calculated for a two tailed significance of $p = .5$ allowing for a 30% attrition rate. Participants completed the ESAS and family satisfaction with advanced cancer care (FAMCARE) tools at baseline, one week and one month. 123 participants completed the tools at week one and 88 completed week four evaluations. Statistically significant results were obtained for pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, dyspnea, insomnia and constipation at weeks one and four with $p < .0001$. Statistically significant improvement was obtained from improving FAMCARE scores with $p < .0001$. Given the significance of these findings the authors recommend the performance of randomized controlled trials to verify the results. This study utilized the ESAS in addition to the FAMCARE tool and even with an almost 30% attrition rate still achieved statistical significance for the most common symptoms that patients complain about. The ESAS will be incorporated into this study.

In 2010 Temel et al performed a randomized study comparing early palliative care plus standard oncologic care versus standard oncologic care in patients with newly diagnosed metastatic non-small-cell lung cancer. All eligible participants were enrolled within eight weeks of diagnosis and randomly assigned to one of the two groups in a 1:1

ratio without stratification. Eligibility criteria included pathologically confirmed disease and an Eastern Cooperative Oncology Group (ECOG) performance status of zero, one or two (zero = asymptomatic; one = symptomatic but ambulatory; two = symptomatic but spending less than 50% of the day in bed). Study was approved from the appropriate IRB and all participants signed informed consent. The primary outcome was the change in quality of life at 12 weeks with participants completing the functional assessment of cancer therapy – lung (FACT-L), hospital anxiety and depression scale (HADS) and the patient health questionnaire 9 (PHQ-9). Information obtained from the medical record included anticancer therapies, prescriptions, hospice referrals, hospital admissions, emergency room visits, resuscitation preferences and location of death. 151 participants completed the initial, baseline assessment with 107 completing the evaluation at 12 weeks (27 participants died). Statistical analysis was completed using two-sided Fisher's exact tests and chi-square tests for categorical variables and *t*-tests for continuous variables. Multivariate linear regression tests were used to evaluate the effect of early palliative care interventions on quality of life and Kaplan-Meier curves were used for survival.

The results showed that patients who were in the palliative care arm had better quality of life and the number was statistically significant ($p = .03$). The most remarkable result of this study however, was on survival. Results show that although patients in the palliative care group had less aggressive therapy their median survival was longer (11.6 months vs. 8.9 months) and this was again statistically significant at $p = .02$. This seminal article is one of the first to show a true survival benefit and should be replicated to verify

this result. The authors are very interested in having their results validated and to help with this have made their entire protocol and statistical analysis plan available on the New England Journal of Medicine website. This was a very exciting study particularly considering the increased life expectancy of lung cancer patients even when they received less aggressive therapies. These researchers also noted the anticipated 30% attrition rate in participants due to patient death. This study verifies ASCO and NCCN recommendations that palliative care is beneficial from diagnosis onwards. This is an important consideration for the Hanna Model[©] as it shows the need to include all patients who are diagnosed with cancer, not only those with advanced, metastatic disease or who are at the end of their lives.

Advanced Practice Nursing in Palliative Care

In “Notes from the Field”, Meier & Beresford (2006) comment that APRNs play a pivotal role in the care that patients receive; from a nursing, medical and financial standpoint. They comment that nurse practitioners (NPs) have everything that a palliative care patient could want or need: the holistic viewpoint of a nurse combined with a physician’s ability to diagnose, prescribe and otherwise manage a person’s medical condition.

The American Association of Colleges of Nursing’s consensus statement (AACN, 2008) defines an APRN as a registered nurse (RN) who has: 1) completed an accredited graduate education program; 2) passed a national certification examination and maintains competency through recertification; 3) acquired advanced clinical knowledge and skills that enable the RN to provide direct care to patients; 4) built on the practice and shows an

increased depth and breadth of knowledge, increased complexity of skills and greater autonomy; 5) become educationally prepared to be accountable for health promotion and maintenance and diagnosis and management of disorders; 6) the clinical experience to show depth and breadth of knowledge; and 7) obtained a license to practice as a certified registered nurse anesthetist (CRNA), clinical nurse specialist (CNS), certified nurse-midwife (CNM) or certified nurse practitioner (CNP).

This study will focus on the care provided by an adult nurse practitioner (NP) (APRN) in the field of palliative care. Prince-Paul et al (2010) list the responsibilities of a NP working with palliative care patients as comprehensive physical assessment, pain management and symptom control, advance care planning, patient and family education, emotional support, forming of goals of care and evaluating spiritual needs.

Doctor of Nursing Practice

Given that the practice doctorate is a relatively new field it is not surprising that there is no information available about how a DNP can impact patient care. To date research on the DNP has focused on its implementation and the positive and negative concerns nursing has regarding its implementation, particularly as nursing schools begin to phase out master's level advanced practice education and replace it with the DNP (Kaplan & Brown, 2009; Montgomery, 2011; Draye, Acker & Zimmer, 2006). Research is needed to evaluate the differences a DNP-educated APRN can have on direct clinical practice and health care systems (Montgomery, 2011).

Kaplan & Brown (2009) state that the DNP is the next level of advanced practice nursing needed to meet the complex needs of patients, families and communities in the

current and future health care situation. Montgomery (2011) states that nurses prepared at the DNP level are ideally suited to become leaders in health care and their advanced educational background will allow them to innovate within complex health systems. Draye, Acker & Zimmer (2006) state that just as the original NPs did 40 years ago the new DNPs will be clinical experts focused in practice-based research and be change agents for health care delivery and quality.

The AACN's (2004) position statement on the DNP notes seven essential areas of scholarship and practice. These areas are 1) the scientific underpinning for practice; 2) advanced nursing practice; 3) organization and system leadership, quality improvement and system thinking; 4) analytic methodologies related to the evaluation of practice and the application of evidence for practice; 5) utilization of technology and information for the improvement and transformation of healthcare; 6) health policy development, implementation and evaluation; and 7) interdisciplinary collaboration for improving patient and population healthcare outcomes.

Studies Evaluating the Impact of the APRN in Palliative Care

Bakitas et al (2009) performed a study to evaluate the effect of a nurse-led initiative on patients' QOL, symptom intensity, mood and resource use in patients with advanced cancer. This study was known as the project ENABLE (educate, nurture, advise, before life ends) II trial and was a randomized controlled study comparing usual care with a palliative care intervention on newly diagnosed patients. 322 cancer patients (41% gastrointestinal, 36% lung, 12% genitourinary and 10% breast) participated in this study which was conducted at a rural National Cancer Institute (NCI) designated

comprehensive cancer center, its affiliated clinics and a Veterans Administration (VA) facility.

Each group contained 161 patients with no statistically significant differences at baseline between the groups. IRB approval was obtained from both the cancer center and the VA with all patients signing informed consent. Participants completed three questionnaires plus demographic information at baseline, and the same questionnaires at one month and at three monthly intervals thereafter until death. The tools utilized were the Functional Assessment of Chronic Illness Therapy– Palliative Care (FACIT-PC), Edmonton Symptom Assessment System (ESAS) and the Center for Epidemiological Studies Depression Scale (CES-D). Statistical analysis included confidence intervals (CI) and p values with $p < .5$ as significant. Baseline covariates were assessed with Kaplan Meier curves utilized to evaluate survival in both groups.

The results show that QOL and depressed mood had improved in the treatment group and were statistically significant at $p = .2$. Symptom intensity scores were similar in both groups during the study. It is important to note that the intervention in this study was educational and although referrals could be made there was no direct intervention to improve symptom management which may have negatively affected their results. The results of the survival analysis showed improvement for patients within the intervention group, who had a mean survival of 14 months versus 8.5 months for those in the usual care group. These authors note that their study was limited due to a mostly Caucasian population and by the fact that most of their intervention was performed by telephone and may have lost some effect due to the lack of “personal touch”. The authors’ only

recommendation for further study is to evaluate the best method of care delivery in this patient population. These results are interesting given the minimum intervention performed. Patients completed multiple tools, one of which was the ESAS which is the planned tool for patient evaluation in this protocol. The intervention proposed in this study may offer even better results for patients with cancer because of the different locations in which it will be offered.

In 2010, Prince-Paul et al reported pilot study results that evaluated the effects of integrating an advanced practice palliative care nurse into a community oncology center. The primary aim of the study was to compare advanced cancer patients who receive palliative care from an APRN versus those who received usual care. This study was comparative and descriptive with a pre/post test design. Data were collected at enrollment and again at four months. Initially, 101 subjects participated with 83 completing the follow up survey. 52 patients were accrued over a five month period of time for the usual care arm and 49 were accrued in the five months following the implementation of the NP. Inclusion criteria were age 18 or older with documented metastatic disease; most patients were continuing to receive aggressive therapies and none were considered to be end of life. Patients were not excluded due to participation in any other clinical trial and study approval was given by the IRB of the University Hospitals of Cleveland. Both groups were similar with the only statistically significant difference being that the usual care group had lower levels of physical performance.

Patients were asked to complete five different scales with staff evaluating performance using the ECOG scale and Charlson comorbidity index. Participants

completed the memorial symptom assessment scale (MSAS), profile of mood states – short form (POMS-SF), functional assessment of chronic illness therapy – spiritual well-being (FACIT - Sp), functional assessment of cancer therapy – social well-being (FACT-SWB), and a single item quality of life question.

Statistical analysis was conducted using independent *t*-tests to assess the mean difference with any significant differences being further analyzed by an analysis of covariance (ANOVA). Bivariate logistic regressions were run to evaluate outcomes of hospitalization and mortality. If these were significant then multi-variate regression analysis was conducted to control for variables such as comorbidities, cancer stage, performance score, physical symptoms, depression and anxiety, social and spiritual well-being, quality of life and chemotherapy. An unadjusted odds ratio confirmed that those in the palliative care arm were 67% less likely to be hospitalized with the adjusted odds ratio showing an 87% decrease in the likelihood of hospitalization. For mortality, the unadjusted odds ratio showed that patients in the palliative care group were 9.6 times more likely to be alive at four months than those in the usual care arm; after adjustment this rose to 24.6 times more likely to be alive. Prince-Paul et al note that this the first study to show that the integration of an APRN in palliative care can have an impact on the length of life even after controlling for all covariates. Limitations include the sample size which gives rise to the possibility of a type II error and the use of a 96% Caucasian population which may affect generalizability to other races. Recommendations for future study include the use of multiple sites, more diverse populations and random assignment to treatment arms. Patients within this study completed five different, lengthy tools which

may be difficult to replicate in other studies given the anticipated weakness and fatigue level in patients. It is, however, an exciting study that shows the benefit of the implementation of a palliative care program by an advanced practice nurse. As this study will be implemented and evaluated by a single provider it will be necessary to simplify Prince-Paul et al's (2010) protocol although it is hoped the results will further increase knowledge and strengthen Prince-Paul et al's results.

Settings of Palliative Care

Multiple authors have noted the benefit of location in the care of advanced cancer patients (Rasmussen & Edvardsson, 2007; Griffith, Lyman & Blackhall, 2010) with some recommending palliative care in the ambulatory setting (Griffith, Lyman & Blackhall, 2010) and others recommending care in the patient's own home environment (McCorkle et al, 2000; Melin-Johannsson et al, 2009), while others make the recommendation for care wherever the patient requires it (Ferris et al, 2009).

McCorkle et al (2000) evaluated the length of survival of older post operative cancer patients who received specialized home care from an APRN versus standard care. This randomized controlled study evaluated 375 patients aged from 60 to 92 with 190 in the intervention group and 185 in the standard of care group. The intervention consisted of a four week program with three home visits and five telephone calls offering comprehensive clinical assessments, monitoring and education both of the patient and their families. Patients were followed for 44 months with 93 dying during this period. Statistical analysis using Cox's proportional hazard model to adjust for significant baseline covariates showed that patients in the standard care arm were more than twice as

likely to have died as those in the intervention group. The authors recommend further study evaluating home care interventions on quality of life and survival of cancer patients. This study will extend these results by offering patients palliative care regardless of their location.

Melin-Johansson et al (2009) studied the quality of life of patients with incurable cancer after designation to a palliative homecare team. Inclusion criteria included patients who were aware of diagnosis and prognosis, were over 18 years of age, spoke Swedish, could complete the questionnaires independently and wanted their care in their own homes. 63 patients (57% male, median age 72, median survival 3.6 months) participated in the study. Patients completed an assessment of quality of life at the end of life (AQEL) tool at baseline and two weeks later. Results showed that there was a significant improvement in six areas; hours recumbent during day, nausea, anxiety, getting hold of staff, care received and global quality of life. In addition there was an observed improvement in depression, pain and meaningfulness (related to global quality of life). This study's main limitations are the lack of randomization and control making it more difficult to generalize to other patients. The authors do not make any recommendations regarding further studies. The majority of studies recommend patients be able to receive palliative care wherever they want it, including in their own homes. The palliative care program at St Jude Heritage is available wherever patients are: home, office, board and care facility, skilled nursing facility or any other extended care location.

Limitations of Literature Review

This literature review was limited by retrieving articles only in English from 2006 onwards and only if they were available in full text through the University of Arizona's library.

Summary

This chapter summarizes the literature review that informed the APRN's theory-driven intervention and the newly developed Hanna Model[©] that guides this study. As the Palliative Care Program is a new program at St Jude Heritage Healthcare it is hoped that this program evaluation will inform the stakeholders of the need for continuance of support and perhaps additional levels of support to ensure the best possible care for patients. Dissemination of this study's findings may enable other programs to use the APRN's theory-driven intervention and Hanna Model[©] in the evaluation of their own programs and as an aid in demonstrating the pivotal role an APRN can play for patients receiving palliative care.

Quality of life and its components are of paramount importance to the cancer patient, regardless of type or stage of disease. Palliative Care is an essential component of a patient's care and is viewed as a routine part of all cancer treatment (Ferrell, Paice & Koczywas, 2008) fully integrated into the continuum of care from diagnosis, through treatment, remission and death. Chapter 3 that follows describes the study's methodology.

CHAPTER 3 – METHODOLOGY

This chapter describes the methodology that will be used in this study. Guidelines for developing this proposal were followed (Burns & Grove, 2009; National Institutes for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC), 2011; Arain et al, 2010; Goodrich et al, 2011; Hu et al, 2011; Barnato et al, 2008; Brown et al, 2010; Garfinkel & Mangin, 2010)

Design

This is a longitudinal, quasi-experimental one group pre-posttest feasibility study.

Sample

The study's eligibility criteria include all cancer patients referred to the embedded palliative care APRN beginning one year after program implementation (i.e. January 1, 2012). Based on preliminary data obtained by the APRN during the program's initial year of operation (2011), this number is anticipated to be at least 80 Caucasian patients, who are over the age of 65, and who have predominantly lung, gastrointestinal, or pancreatic malignancies.

Setting

St Jude Heritage Healthcare is the North Orange County, California, medical practice of the St Joseph health system. This not for profit organization consists of over 160 physicians covering the majority of specialties and over 40 nurse practitioners and physician assistants; seven of whom are board certified oncologists who work with one APRN a doctorally-prepared nurse practitioner who is an advanced oncology certified nurse practitioner (AOCNP). Within this practice there is a dedicated out-patient cancer

center, the Virginia K Crosson Cancer Center, accredited by the American College of Surgeons Commission on Cancer (ACOS-COC). The custom built building housing the center includes an infusion center, a breast center, radiation oncology, laboratory and x-ray department as well as examination rooms and provider offices. Patients requiring inpatient care are transferred to the inpatient oncology floor of St Jude Medical Center which is located directly across the street from the cancer center (St Jude Heritage, 2011).

APRN Theory-Driven Intervention

The APRN intervention will consist of symptom management tailored to each patient's needs and resources using the evidence-based practice guideline algorithms (palliative care, adult cancer pain, antiemesis, cancer-related fatigue, distress management and senior adult oncology) of the National Comprehensive Cancer Network (NCCN) (2011). Symptoms will be measured by the Edmonton Symptom Assessment System (ESAS) (Appendix D); QOL by the 0-10 numeric rating scale (Appendix B). The theory-driven intervention will include both comprehensive and focused physical assessments, assessment and prescription of all medications, evidence-based symptom management, patient-family education, referrals to other providers (i.e., social services, nutritional support and physical therapy) and bereavement follow up with families. The theory-driven intervention will be offered every two weeks in the palliative care office with home or other location visits available depending upon patient needs. Visits may also include telephone calls between the biweekly scheduled visits. This APRN palliative care intervention will be available for as long as the patient remains in palliative care (i.e., from diagnosis, through remission, relapse and progression) until death occurs or the

patient is referred to hospice. Bereavement support will be available for families following the patient's death.

Measures

The Edmonton Symptom Assessment System (ESAS)

The ESAS measures nine symptoms: pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath on a horizontal Likert 0-10 scale (0= no symptom; 10= the worst symptom possible). Patients are instructed to rate their symptoms "at this moment in time" (Abernethy, Wheeler & Currow, 2010) and can add one additional symptom of their choice. It is recommended that the first time patients complete the ESAS they receive provider assistance as will be done in this study. The ESAS is part of the patient's electronic medical record (See Appendix D). ESAS scores can range from 0-90. 10 points are given for the additional self-identified symptom. The higher the ESAS score, the worse are the symptoms.

Studies show that the ESAS is reliable but has restricted validity mainly due to the absence of emotional symptoms that the patient may have (Richardson & Jones, 2009). Other concerns lie with the wording of the symptoms and some confusion that patients may have with the wording (Watanabe et al, 2009). Richardson & Jones (2009), Watanabe et al (2009) and Nekolaichuk, Watanabe, & Beaumont (2008) recommend that patients receive assistance to complete this tool, at least the first time it is used. For this study the APRN will administer the ESAS to evaluate patient's symptoms directly and will enter the information into the system. Patients will not be required to independently complete the scale.

Quality of Life

Quality of life will be measured using a validated single item 0-10 numeric rating scale. Single item QOL scales have been evaluated in patients with cancer (Boer, et al, 2004; Locke et al, 2007; Bush, 2010), HIV (Cohen et al, 1996), cystic fibrosis (Yohannes et al, 2010) and in clinical trials (Bernhard et al, 2001). Patients rate their overall QOL on a scale from zero to ten with zero being no QOL at all and ten being the best QOL possible (Appendix B). These scales have been shown to be sensitive, responsive, valid and quick and easy to complete.

Boer et al (2004) performed a study to evaluate the validity, responsiveness and reliability of a single item QOL scale compared with multi-item scales. 83 patients with esophageal cancer participated in this study completing the single item QOL scale, the medical outcomes study short form – 20 and the Rotterdam symptom check-list. These tools were completed at baseline, five weeks, three months and twelve months. Convergent and discriminant validity, test–retest reliability and both distribution-based and anchor-based responsiveness were evaluated. The results showed the single item QOL scale was highly correlated with the components of the other two tools and that this correlation continued over time. The authors concluded that the single item tool has good validity, excellent reliability, moderate distribution-based responsiveness and good anchor-based responsiveness compared to multi-item QOL questionnaires. The authors recommend using this tool to evaluate QOL in cancer patients.

Patient Satisfaction

Patient satisfaction with the APRN will be measured by the St Jude Heritage Healthcare Patient Satisfaction Survey (See Appendix E). An outside agency performs the quality analysis of all providers every three months and presents the data quarterly. 30 patients are randomly selected to complete the ten question survey which is performed on the telephone by an agency representative. Patients are asked to grade their response from one through five with one meaning poor and five meaning excellent. These questions are evaluated on an annual basis and may be adjusted at that time.

Provider Satisfaction

Provider satisfaction with the APRN will be measured in two ways. Providers will be sent the standardized Provider Satisfaction Survey used by St. Jude Heritage Healthcare annually (Appendix A). Additional data will be collected by the APRN on the source of provider referrals and patient life expectancy. Baseline data indicate that 6 of the 7 medical oncologists have referred 1-18 (Mean=8.8) patients to the APRN during the first year of her employment. Most patients referred had a life expectancy of less than 6 months and only three in this particular sample were referred to hospice. It is hoped that these referral patterns might improve during the second year of the program. If these data can be easily retrieved, additional descriptive data will be obtained that address patient life expectancy, number of APRN visits and their locations (home, clinic, hospital, skilled nursing facility [SNF], and phone), time in follow up with the APRN, and time to hospice care referrals by physicians.

St Jude Heritage Healthcare participates in the Quality Oncology Practice Initiative (QOPI) of ASCO. An oncology Clinical Nurse Specialist collects data on an ongoing basis for QOPI and evaluates these results quarterly. For the first quarter of this year (2011), 76% of all patients were referred to hospice and/or palliative care prior to death. 52% were referred to hospice. Of the 18/34 referred to hospice, 5 (28%) were referred within 3 days of death; 38% were referred more than 3 days before their deaths; 28% (5/18) were referred within 7 days of their death.

Financial Evaluation

If data can be easily retrieved, the number of visits to the Emergency Room, hospitalizations, and hospital deaths at St Jude Heritage Healthcare in patients referred to the APRN will be tracked to estimate the cost savings of the APRN.

Procedures

Informed consent will be obtained from all participants (Appendix C) following the study's approval by The St Jude Heritage Healthcare Institutional Review Board (IRB). All cancer patients referred to the palliative care APRN will complete the study's informed consent at their initial referral visit along with the ESAS and QOL item. The ESAS and QOL item will be completed at each subsequent two week visit. The APRN will see the patient initially in a face-to-face meeting that may take place in the clinic, hospital, SNF or home setting. Subsequent face-to-face visits will be held at two-week intervals or by phone. The APRN will follow the patient on an ongoing basis until the patient is referred to hospice or dies.

Data will be collected by the APRN responsible for the palliative care program and will be analyzed quarterly. Demographic and medical characteristics will be retrieved from the electronic medical record to include age, diagnosis and stage of disease, marital and family status, living arrangements, ethnicity and date and location of death. Study attrition of approximately 30% will be anticipated and hopefully will be minimized by quarterly analysis. All data are part of the medical record and will be electronically submitted. Patient and family satisfaction surveys will be sent every three months and the APRN will be evaluated annually by the referring providers to assess their satisfaction with their patients' care.

Data Analysis

All data will be entered into an Excel spreadsheet for subsequent importing into an SPSS program for analysis. Descriptive and inferential statistics will be used to evaluate the data. Basic demographic and medical characteristics will be summarized and presented in a frequency table that describes means, ranges and percentages for gender, ethnicity, age, marital status, living arrangements and diagnoses. The ESAS will be scored following the system's scoring instructions and will be summarized by individual symptoms and by total scores with graphs depicting the initial visit scores to those scores over time to aid in visualizing patterns. The QOL item will be similarly analyzed. A repeated measures ANOVA or time series analysis in consultation with a statistician will be performed to evaluate changes in the ESAS and QOL scores over time. A plan for analyzing data at three month intervals will be developed in consultation with the

statistician given the anticipated high study attrition rates due to patient death between baseline and three months later.

Study Timetable

The APRN plans to submit the proposal for IRB approval in early January, 2012.

Study Limitations

Most patients are anticipated to be Caucasian and will be seen by one APRN thereby limiting the study's generalizability. Since this is a feasibility study, there will be no control or comparison group or random assignment to groups that could strengthen the design and the generalizability of its findings.

The study population is limited to a single setting and may not be representative of all patients with cancer. All patients have some type of insurance and this study may not include those who do not have access to such a level of care. Sample attrition may be high given the type of patients who receive palliative care. Studies (Bakitas et al, 2009; Ferris et al, 2009) have noted a 30% attrition rate, generally related to the death of a patient after completing the initial assessment but prior to completing the follow-up visit.

Although there are validity issues relating to the ESAS tool it is widely used in oncology and palliative care settings. It is specifically a scale for evaluating symptoms in patients and covers a variety of common problems for cancer patients. It is a simple tool that is quick and easy to complete for a very sick patient. This is an important consideration given the length of some tools and the life expectancy anticipated for many of these patients.

Dissemination of Study Findings

The APRN hopes this study will show the benefit of a palliative care APRN embedded in an outpatient oncology center. Findings will be reported to the St Jude Heritage stakeholders such as the Medical Director, Chief Executive Officer, Chief Financial Officer, Chief Operating Officer, Director of Nursing and Oncology Division Medical Director to ensure the continuation of services for the patients. Nursing and ancillary staff will be updated on the progress of the program at their monthly staff meetings. Finally, the APRN plans to submit an article based on the evaluation results for publication in a peer reviewed journal.

Conclusion

This chapter details the study's methodology, limitations, and plans for dissemination. Previous studies have shown the benefit of an embedded APRN in an Oncology setting and this study and its evaluation seeks to advance the science and practice knowledge previously reported by others.

APPENDIX A

ST JUDE HERITAGE HEALTHCARE
NP/PA APPRAISAL FORM

ST JUDE HERITAGE HEALTHCARE
NP/PA APPRAISAL FORM

Employee: _____ Return by date: _____ Site: _____

Guidelines for scoring evaluations:

4 – Exceptional Performance – Consistently exceeds established goals and performance expectations. As a role model others in all competencies critical to job performance. Seeks opportunity to share expertise and serves as a mentor to others. ****Must cite a specific example of consistent behavior/project of going above expectation.**

3 – Above Target – Often exceeds established goals and performance expectations. Demonstrates strengths in competencies critical to job performance. Continually grows in role and seeks opportunities to expand responsibilities/knowledge.

2 – On Target – Successfully meets established goals. Demonstrates competencies critical to job performance. Maintains knowledge base required to perform job responsibilities.

1 – Development Opportunity – Meets some, but not all required goals. Is developing competencies critical to job performance. Further coaching is required.

0 – Needs Improvement – Established goals and responsibilities are not met. Does not demonstrate competencies critical to job performance. Continued guidance/supervision is required to meet expectations. Needs to improve immediately.

Essential Functions/Job-Specific Competencies

Rating 0-4

1. Demonstrates the ability to provide health assessment, diagnosis and treatment in the ambulatory care setting
Example:
2. Demonstrates the ability to prescribe medications appropriately for medical conditions and in accordance with the organizational formulary (perfect care)
Example:
3. Demonstrates the ability to act in the best interest of the patient by providing information to make informed decisions in their care (perfect care)
Example
4. Demonstrates the ability to understand the unique needs of the adult/pediatric patient as evidenced by the quality of care (perfect care)
Example:
5. Demonstrates appropriate clinical judgment in providing care by consulting/referring to the appropriate physician, as needed (perfect care)
Example:
6. Consistently demonstrates appropriate and thorough documentation in the medical record for care provided and recommended (sacred encounter)
Example:

7. Maintains and/or is available to meet productivity standard for number of patients seen and patients seen in a timely manner (sacred encounter)

Example:

Physician Signature: _____

(Please use back side for additional comments. Return this completed form to the office manager)

APPENDIX B
SINGLE ITEM 0-10 QUALITY OF LIFE SCALE

SINGLE ITEM 0-10 QUALITY OF LIFE SCALE

0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>										

Diagram description: A horizontal scale from 0 to 10. The number 0 is labeled 'Completely dissatisfied' and the number 10 is labeled 'Completely satisfied'. Below each number is a square box, and the boxes are connected by horizontal lines.

APPENDIX C
CONSENT TO PARTICIPATE IN STUDY (DRAFT)

CONSENT TO PARTICIPATE IN STUDY (DRAFT)

St Jude Heritage Healthcare

Study Title: Symptom Management in Patients with Cancer using the Edmonton Symptom Assessment System (ESAS) and Single Item Quality of Life (QOL) Tool.

Principal Investigator: Lisa Hanna, DNP, RN, ANP-C, OCN

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to participate.

You may or may not benefit as a result of participating in this study. Also, as explained below, your participation may result in unintended or harmful effects for you that may be minor or may be serious, depending on the nature of the research.

1. Why is this study being done?

To better assess and manage symptoms in cancer patients which may help improve their overall quality of life.

2. How many people will take part in this study?

All patients diagnosed with cancer who are referred for palliative care will be asked to participate.

3. What will happen if I take part in this study?

During your scheduled visit you will be asked a series of questions regarding your symptoms and quality of life. You will be asked to complete two short scales that measure 10 symptom items and one quality of life item. It is anticipated that it will take you 2-5 minutes to complete these scales. Each is rated on a 0-10 scale. Depending on your scores the palliative care nurse practitioner will discuss methods that may help you manage your symptoms better. This includes, but is not limited to the use of supportive medications, education, and possible referral to ancillary departments such as social services, physical therapy or case management. You will be followed by the palliative care nurse practitioner every two weeks either in the

clinic, your home, or by telephone. You will be asked to complete the symptom and quality of life scales at each two week visit.

The Palliative Care nurse practitioner in collaboration with your primary oncologist will manage your symptoms using all appropriate tools and resources available (e.g. medications, referrals). Your primary oncologist will be updated after each visit/contact.

4. How long will I be in the study?

You can participate in the study for as long as you are receiving palliative care.

5. Can I stop being in the study?

Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your usual benefits. Your decision will not affect your future relationship with St Jude Heritage Healthcare. If you are an employee of St Jude Heritage Healthcare, your decision will not affect your employment status.

6. What risks, side effects or discomforts can I expect from being in the study?

There are no risks, side effects or discomforts anticipated from being in the study.

7. What benefits can I expect from being in the study?

It is anticipated the better assessment and management of your symptoms and quality of life will occur over time.

8. What other choices do I have if I do not take part in the study?

You may choose not to participate without penalty or loss of benefits to which you are otherwise entitled.

9. Will my study-related information be kept confidential?

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law.

Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies
- The St Jude Heritage Healthcare Institutional Review Board or Office of Responsible Research Practices
- The sponsor supporting the study, their agents or study monitors

10. What are the costs of taking part in this study?

There are no costs to you. Your insurance will be billed for the palliative care visit.

11. Will I be paid for taking part in this study?

There is no payment for participating in this study

12. What happens if I am injured because I took part in this study?

If you suffer an injury from participating in this study, you should seek treatment. St Jude Heritage Healthcare has no funds set aside for the payment of treatment expenses for this study.

13. What are my rights if I take part in this study?

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

You will be provided with any new information that develops during the course of the research that may affect your decision whether or not to continue participation in the study.

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled.

An Institutional Review Board responsible for human subjects research at St Jude Heritage Healthcare reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and policies designed to protect the rights and welfare of participants in research.

14. Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact Lisa Hanna, 714-356-6529_____.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at St Jude Heritage Healthcare.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact Lisa Hanna, 714-356-6529_____.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study. I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject	Signature of subject
	Date and time AM/PM
Printed name of person authorized to consent for subject (when applicable)	Signature of person authorized to consent for subject (when applicable)
Relationship to the subject	Date and time AM/PM

Investigator/Research Staff

I have explained the research to the participant or the participant's representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or to the participant's representative.

Lisa Margaret Hanna, DNP, RN, ANP-C, OCN Printed name of person obtaining consent	Signature of person obtaining consent
	Date and time AM/PM

APPENDIX D
EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS)

EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS)

Edmonton Symptom Assessment Scale (ESAS)										
Date of completion					Time					
Please circle the number that best describes:										
0	1	2	3	4	5	6	7	8	9	10
No pain									Worst possible pain	
0	1	2	3	4	5	6	7	8	9	10
Not tired									Worst possible tiredness	
0	1	2	3	4	5	6	7	8	9	10
Not nauseated									Worst possible nausea	
0	1	2	3	4	5	6	7	8	9	10
Not depressed									Worst possible depression	
0	1	2	3	4	5	6	7	8	9	10
Not anxious									Worst possible anxiety	
0	1	2	3	4	5	6	7	8	9	10
Not drowsy									Worst possible drowsiness	
0	1	2	3	4	5	6	7	8	9	10
Best appetite									Worst possible appetite	
0	1	2	3	4	5	6	7	8	9	10
Best feeling of wellbeing									Worst possible feeling of wellbeing	
0	1	2	3	4	5	6	7	8	9	10
No shortness of breath									Worst possible shortness of breath	
0	1	2	3	4	5	6	7	8	9	10
Other problem										
ESAS completed by:										
<input type="checkbox"/> Patient <input type="checkbox"/> Health professional <input type="checkbox"/> Family <input type="checkbox"/> Assisted by family or health professional										
Version date December 11, 2002										

APPENDIX E

ST JUDE HERITAGE HEALTHCARE
PATIENT SATISFACTION SURVEY QUESTIONS 2011

ST JUDE HERITAGE HEALTHCARE
PATIENT SATISFACTION SURVEY QUESTIONS 2011

Scoring instructions:

Place a check mark in the appropriate box depending upon the patient's rating of the provider for each specific question.

1 = poor

2 = below average

3 = satisfactory

4 = good

5 = excellent

Questions	1	2	3	4	5
Ease of contacting the staff by telephone (appointments, concerns)					
Waiting time in the reception area					
Waiting time in the examination room					
The courtesy of the person who took your call					
Explanation of procedures or test results					
Calls returned within an appropriate amount of time					
Communication with provider					
Satisfaction with medical examination					
Convenience of office hours					
Ease of parking					

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