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Clinicians' Perspectives on Adopting a Lung Cancer Palliative Care Intervention

Shaunna Siler

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Clinicians' Perspectives on Adopting a Lung Cancer Palliative Care Intervention

by

Shaunna Siler

_____

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Nursing

_____

June 2017

Each person whose signature appears below certifies that this dissertation in her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

_____ , Chairperson
Iris Mamier, Associate Professor of Nursing

_____
Betty Ferrell, Professor of Nursing, City of Hope

_____
Betty Winslow, Professor of Nursing

DEDICATION

I would like to dedicate my dissertation to my grandmother, Minnie Hightower. My grandmother taught me the meaning of hard work and commitment at a young age, and to have faith in God. Her prayers and love have carried me. Thank you, grandma, for always encouraging me to "keep my eyes on Jesus."

I would also like to dedicate my dissertation to the One who has sustained me. It is only by God's grace that I have made it this far. I thank God for always providing for me and sending me the best mentors, friends, and family to encourage me along the way. My prayer is that I continue to bear much fruit, and that God receives all the honor and praise. *"I am the vine; you are the branches. If you remain in me and I in you, you will bear much fruit; apart from me you can do nothing." John 15:5; NIV.*

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CONTENT

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ABBREVIATIONS

ASCO   American Society of Clinical Oncology

FCG   Family Caregiver

HRQOL   Health-related Quality of Life

NCI   National Cancer Institute

NCP   National Consensus Project

NIH   National Institute of Health

NSCLC   Non-small Cell Lung Cancer

PCI   Palliative Care Intervention

QOL   Quality of Life

RE-AIM   Reach, Efficacy, Adoption, Implementation, Maintenance

SCLC   Small-cell Lung Cancer

WHO   World Health Orginization

ABSTRACT OF THE DISSERTATION

Clinicians' Perspectives on Adopting a Lung Cancer Palliative Care Intervention

by

Shaunna Siler

Doctor of Philosophy, Graduate Program in Nursing
Loma Linda University, June 2017
Dr. Iris Mamier, Chairperson

Despite the significant progress in implementing palliative care interventions for cancer patients, few intervention studies seek healthcare clinicians' input prior to implementation. The purpose of this research was then to explore palliative care and oncology clinicians' (e.g., physicians, nurses, social workers, and chaplains) perspectives on current challenges and useful practices in meeting the quality of life needs of lung cancer patients and family caregivers, and to increase the likelihood of the adoption of a palliative care intervention based on understanding current trends in palliative care delivery at three outpatient oncology sites. The conceptual framework used for this study was the RE-AIM Model: Reach, efficacy, adoption, implementation, and maintenance of intervention research to successfully translate and sustain evidence-based practice. This was a multi-site qualitative study using focus group and key informant interviews with oncology and palliative care clinicians. Focus groups and individual phone interviews were conducted with 19 clinicians, who addressed useful practices and challenges in the following areas: (a) early palliative care; (b) interdisciplinary care planning; (c) symptom management; (d) addressing psychological and social needs; and (e) providing culturally respectful care, including spiritual care. In preparation for the intervention, specific

education needs and organizational challenges were revealed through focus group and individual interviews with clinicians. These challenges included timing and staffing constraints, the need for clinician education on palliative care services to increase organizational buy-in and referrals, and support and education in providing spiritual support for patients and family caregivers. These findings highlight an important, often overlooked, step in the translation of palliative care intervention studies and may inform education and training in the areas of palliative care and spiritual care for lung cancer patients. Further, these findings pattern the adoption component of the Re-AIM Model for intervention studies in eliciting organizational support prior to implementation.

CHAPTER ONE

INTRODUCTION TO THE STUDY

Foreword

This dissertation study was conducted in collaboration with an R01 National Institute of Nursing Research (NINR) study, *Translation of a Lung Cancer Palliative Care Intervention (PCI) for Clinical Practice* (2016-2017). Data collected from this dissertation study was used to inform the palliative care intervention to meet the needs of non-small cell lung cancer (NSCLC) patients and family caregivers through qualitative focus groups and key informant interviews with palliative care and oncology clinicians (i.e. nurses, physicians, social workers, and chaplains). This research allowed investigators to better understand the perceived needs of the PCI recipients as well as the needs of clinicians as they prepared to support patients and family caregivers across quality of life dimensions (physical, psychological, social, and spiritual needs). This dissertation study contributed to Aim 1 of the parent study: To adopt a lung cancer PCI tested in a NINR-funded program project for dissemination in other oncology settings.

The overall goal of this research was (a) to identify how clinicians address the quality of life needs of lung cancer patients and their family caregivers; (b) to identify challenges in addressing the quality of life needs of patients with lung cancer and their family caregivers; and (c) to identify the perceived needs of interdisciplinary palliative care and oncology clinicians in adopting the PCI into clinical practice.

Background

Epidemiology of Lung Cancer

In 2017, an estimated 222,500 Americans are projected to develop lung cancer,

and 155,870 people are expected to die from this disease (American Cancer Society, 2017). Survival rates in people with lung cancer vary depending on the cancer stage and classification, as well as the age and overall health of the patient when the cancer is diagnosed. A diagnosis at an advanced stage (stages III-IV) has a decreased survivability as opposed to earlier stages (stages I-II). Depending on the classification and stage of the lung cancer, people who develop this disease may experience a rapid decline following diagnosis, accompanied by poor survival rates. The prognosis for lung cancer patients is often poor due to the advanced stage of the disease when patients first seek medical help, which greatly reduces the likelihood of effective treatments.

Lung cancer is categorized into two major classifications: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). NSCLC is more commonly diagnosed (80%) than small cell lung cancer (14%). Generally, an advanced stage of cancer implies that it has spread to surrounding tissues and glands or has metastasized (spread) to other organs in the body. As the cancer progresses, it becomes increasingly difficult to eradicate the cancer cells with treatments such as chemotherapy and radiation. Since only 15% of lung cancer cases are diagnosed at an early stage, before the cancer has spread to surrounding tissues, glands or organs the survival rates for people with lung cancer is low (American Cancer Society, 2017).

Risk Factors of Lung Cancer

Cigarette smoking is the number one risk factor for lung cancer. In the U.S., cigarette smoking is linked to about 80% of lung cancer deaths. Using other tobacco products, such as cigars or pipes, also increases the risk of lung cancer. Other factors can place a patient at a higher risk for lung cancer, such as airborne substances (secondhand

smoke, pollution, and radon) as well as a history of radiation treatment to the chest. However, smoking cigarettes has received the most attention from healthcare professionals and the public since it accounts for the vast majority of lung cancers (American Cancer Society, 2017). Overall, the chance that a man will develop lung cancer in his lifetime is about 1 in 14; for women, the risk is about 1 in 17, combining both smokers and non-smokers. The risk for smokers is higher (American Cancer Society, 2017).

Quality of Life Needs for Lung Cancer Patients and Family Caregivers

Lung cancer patients and family caregivers (FCGs) often struggle with unmet quality of life (QOL) needs related to physical, psychological, social, and spiritual well-being. Symptom burdens in patients with advanced lung cancer have a negative impact on QOL and are perceived as a major concern (Maguire et al., 2013). Symptoms often include pain and breathing problems, amongst others (Maguire et al., 2013; Simoff et al., 2013). Similarly, FCGs have physical burdens related to caring for a family member with lung cancer. Studies show that as the patients' illness progresses their symptoms increase; as do the caregivers' physical burdens (Northouse et al., 2012) and psychological distress (Mosher et al., 2013), with research showing that both patients and FCGs suffer from depression and anxiety (Akechi et al., 2006). Higher levels of social support have been associated with adoptive coping in illness and with fewer depressive symptoms for lung cancer patients (Walker, Zona, & Fisher, 2006). Perceived social support from family, friends, and healthcare personnel positively influence QOL (Luszcynska et al., 2012). A study of the literature reveals the effect of spirituality in improving QOL, helping patients and caregivers find meaning and purpose in life (Puchalski, 2007; Maguire et al., 2013).

At its core, the purpose of quality palliative care is to improve the quality of life of patients and their families (World Health Organization, 2008). It is therefore essential to understand the historical evolution and concepts of palliative care in order to implement effective interventions to improve quality of life that will improve the QOL for patients with lung cancer and their FCGs.

Introduction to Palliative Care

The historical evolution of palliative care in the U.S dates back to the 1960s. The terms palliative care and hospice have historically been used interchangeably. In fact, it was not until the mid-1980s when the two concepts were given separate and distinct definitions in order to meet the needs of people with progressive terminal illness.

The concept of palliative care in the U.S. evolved from the modern hospice care movement, which began in the United Kingdom (U.K.) in the sixties. The hospice movement gained momentum in subsequent years and was readily adopted in the 1970s by Florence Wald, Dean of the Yale University School of Nursing, who became an early advocate of hospice. In those early years of the movement, cancer was the disease used as a model the development of hospice. With cancer almost synonymous to dying and needing hospice care, it is not surprising that the terms palliative and hospice care were used interchangeably (Meghani, 2004).

The first home hospice program was based in New Haven, Connecticut. By 1975, a second hospice was established, including services such as inpatient care, home care, outpatient clinics, and bereavement counseling for families. In 1980, the Federal Health Care Financing Agency (now the Center for Medicare and Medicaid Services) started the first Hospice Demonstration Project (Meghani, 2004). By 1982, the U.S. Congress

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authorized hospice benefits under Medicare Part A. The participation protocol for hospice care included a diagnosis of an incurable malignant disease, a projected life expectancy of 6 months or less, and waiver of all rights and privileges to receive curative treatment in favor of hospice care. This was widely accepted and appealing both to healthcare providers and the general public due to the low costs associated with low-tech and non-curative care for cancer patients before the end of life (Meghani, 2004).

By the early 1990s, the trajectory of illness began to shift; people who were diagnosed with terminal illness were living longer due to improved health care technologies. With this new paradigm, the goals of hospice and palliative care model were re-examined in order to meet the needs of people with non-malignant and progressive terminal illness. In response, the concept of palliative care was redefined, no longer based on life expectancy or diagnosis. Palliative care began to be recognized as a specialty area of care, apart from hospice, by the late 1990s.

Current Trends in Palliative Care

Today, the purpose of palliative care is to provide the best QOL to the increasing numbers of people with chronic and life-limiting illnesses. A growing number of palliative care programs provide this care in a variety of settings: hospitals, outpatient settings, and community programs within home health organizations. Within these settings are interdisciplinary teams of physicians, nurses, social workers, chaplains, counselors, nursing assistants, rehabilitation specialists, speech and language pathologists, and other healthcare clinicians. These providers are skilled in facilitating patient-centered communication and decision-making and coordinating continuity of care across settings throughout the disease continuum (National Consensus Project for Quality

Palliative Care, 2009).

The Palliative Care Model in Lung Cancer

Palliative care in lung cancer patients begins at the time of diagnosis of a serious

disease, continues through treatment, cure, or death, and involves the family during the

bereavement period (National Consensus Project for Quality Palliative Care, [NCPQPC]

2009). Figure 1 illustrates this concept.

Figure 1. Palliative Care in Lung Cancer (National Consensus Project for Quality
Palliative Care, 2009).

National Consensus Palliative Care Guidelines

The mission of the National Consensus Project for Quality Palliative Care is to

create clinical practice guidelines to improve the quality of palliative care in the U.S.

Specifically, the *Clinical Practice Guidelines for Quality Palliative Care* are designed to

promote quality and reduce variation in new and existing programs, develop and

encourage continuity of care across settings, and facilitate collaborative partnerships

among palliative care programs, community hospices, and a wide range of other

healthcare delivery settings. This is a dynamic process as the field continues to grow. The

Clinical Practice Guidelines for Quality Palliative Care are intended to strengthen

existing programs and foster a solid foundation for newly created programs and those in

development (NCP, 2009). Guidelines are based on the domains of quality palliative care

and 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.

An Interdisciplinary Palliative Care Intervention for Lung Cancer Patients

An interdisciplinary palliative care intervention (PCI) for patients with non-small cell lung cancer (NSCLC) and their primary family caregivers has been shown to improve patient quality of life (Ferrell, et al., 2015; Sun et al., 2015a; Sun et al., 2015b). This PCI was disseminated into three outpatient cancer centers. A two-group, prospective, sequential, quasi-experimental, tandem enrollment design was used for this project, in which the usual care group was accrued and followed during Phase 1 (month 7 - month 18) and the intervention group accrued and followed during Phase 2 (month 22-42). The conceptual frameworks used were the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) model (Glasgow, Vogt, & Boles, 1999) and the National Consensus Project Guidelines for Quality Palliative Care (NCP, 2009). The three components of this intervention included: (a) attention to the comprehensive patient and family caregiver quality of life dimensions (physical, psychological, social, and spiritual needs); (b) support for interdisciplinary team input in the plan of care; and (c) patient and family caregiver education.

Introduction to Study

Statement of the Problem

The purpose of the NINR-funded study was to test the dissemination of a palliative care intervention (PCI) for patients with non-small cell lung cancer (NSCLC)

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and their primary family caregivers. The intervention was designed based on expressed needs by this specific population; however, this perspective did not include plans to assess the perceptions of supportive needs as identified by members of the interdisciplinary palliative care team (physicians, nurses, social workers, chaplains, and administrators) who were involved in adopting and implementing the three elements of the PCI. Elements of the PCI included attention to the comprehensive patient and FCG quality of life (QOL) dimensions (e.g., physical, psychological, social, and spiritual needs), support for interdisciplinary team input in the plan of care, and patient/family caregiver education.

Purpose of the Study

As the palliative care team's support for the PCI was crucial, we solicited team input before implementing the intervention. The purpose of this dissertation research was to inform a PCI for NSCLC patients and their family caregivers prior to implementation by eliciting the diverse perspectives of palliative care and oncology clinicians on the QOL needs of patients and family caregivers through focus groups and key informant interviews. This research allowed investigators to better understand the perceived needs of the PCI recipients as well as the educational needs of clinicians as they prepared to support patients and family caregivers across QOL dimensions.

Research Aims and Questions of Study

The three specific research aims and questions were as follows:

Aim 1. Identify clinicians' perspectives on how to address patient and FCG QOL dimensions (physical, psychological, social, and spiritual needs) through palliative care.

Research question 1: How do clinicians address QOL dimensions of patients and

FCGs with lung cancer through palliative care?

Aim 2. Identify clinicians' perspectives on challenges in addressing patient and FCG QOL dimensions (physical, psychological, social, and spiritual needs) through palliative care services.

> **Research question 2:** What are clinicians' perspectives on the challenges of
> addressing patient and FCG QOL dimensions (physical, psychological, social, and
> spiritual needs) through palliative care?

Aim 3. Identify the needs of palliative care clinicians in order to support patient and FCG across QOL dimensions.

> **Research question 3a:** What are the needs of palliative care clinicians in
> supporting patient and FCG across QOL dimensions?
>
> **Research question 3b:** What are clinicians' perspectives on adopting
> and implementing the PCI?

Theoretical Framework

The theoretical framework used for this study is the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) model (Glasgow, Vogt, & Boles, 1999), a conceptual framework used to evaluate the effectiveness of translating intervention research into practice. RE-AIM is used as an evaluation at an individual level, an organizational level, or both. The model is used to reach the intended target population; to be both effective and efficacious; to be adopted by target staff, settings, or institutions; to be implemented consistently with costs and adaptations made during delivery, and to maintain the intervention's effects by individuals and settings over time (Glasgow, Vogt, & Boles, 1999). This framework was used by the NINR parent study to

disseminate research into practice. To contribute further to the successful implementation and dissemination of the PCI, the third dimension of RE-AIM, Adoption, was used to guide this study.

Definitions of Core Concepts

The following core concepts, defined below, are central to this research:

Palliative Care

Drawing on the World Health Organization's (2008) definition of palliative care, "palliative care constitutes an approach to cancer care that improves the quality of life of patients and their families facing the problems associated with life-threatening illness" (para. 1). This definition contends that palliative care pertains to the improvement of quality of life of both, patients and families early in the trajectory of illness. Strategies for providing palliative care should include the prevention and relief of suffering by means of early identification and attention to the treatment of pain and other physical, psychosocial, and spiritual needs (WHO, 2008).

Family Caregiver

In the context of patients with cancer, the term "family caregiver" has been defined by the American Cancer Society (2012) as an unpaid caregiver or informal caregiver. In many cases, the main (primary) caregiver can be a partner or family member. When family is not around, close friends or co-workers may fill this role. The family caregiver plays an important role in the management of care and is part of the care team. The care team consists of the patient, medical staff, and the family (American Cancer Society, 2012). In the present study, the term family caregiver is used broadly referring to a primary individual who plays an important role in the cancer patients' care.

Interdisciplinary Palliative Care Teams

An interdisciplinary palliative care team is described in the Clinical Practice Guidelines for Quality Palliative Care (NCP, 2009) as health care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, and rehabilitation specialties (NCP, 2009). In essence, an interdisciplinary team is, "a group of health care professionals from diverse fields who work in a coordinated fashion toward a common goal for the patient" (Miller-Keane, 2009). In this research, the interdisciplinary palliative care teams included the professions of medicine, nursing, social work, and chaplaincy which are specialized in providing palliative care for patients and family caregivers.

Quality of Life

Quality of life is a construct of central concern to all aspects of palliative care. There are many definitions that operationalize the concept, one being Health-Related Quality of life, which is similarly defined as a "multidimensional construct that involves an individual's perceived health status, life satisfaction, and physical, social, and psychological well-being" (Owen et al., 2007, p. 878). For the purpose of this study, however, quality of life is the concept used and is understood as "a multidimensional concept that addresses the impact of traumatic events such as cancer on aspects related to physical, psychological, social, and spiritual well-being" (Owen, Boxley, & Klapow, 2007, p. 878). Therefore, the quality of life construct implies a perspective that discerns these four core dimensions of the patient experience.

CHAPTER TWO

REVIEW OF LITERATURE

Introduction to Literature Review

A cancer diagnosis can greatly impact the quality of life (QOL) for both patients and family caregivers (FCGs). Over the past decade, there has been an increase in reported palliative care intervention (PCI) studies and guidelines to meet the needs of lung cancer patients and FCGs. However, there is a notable gap in the current evidence base regarding (a) the successful dissemination of PCIs into community-based settings; (b) interdisciplinary clinicians' perspectives on the perceived facilitators and challenges to PCI implementation; and (c), clinicians' perceptions of the challenges of meeting QOL dimensions (e.g., physical, psychological, social, and spiritual) of lung cancer patients and FCGs through palliative care services. A comprehensive assessment on effective approaches and PCIs currently being used for lung cancer patients and FCGs may provide insight on the successful dissemination of these interventions into community-based palliative care settings. Furthermore, incorporating an evaluation of the perspectives of palliative care and oncology clinicians may promote an understanding of the "real world" issues by illuminating the experiences and challenges of clinicians providing care to lung cancer patients/FCGs.

The goals of this literature review is to first summarize the QOL needs of lung cancer patients and their family caregivers; second, to provide an overview of current lung cancer palliative care interventions being used to meet these needs; and third, to provide a review of clinicians' perceived facilitators and challenges in meeting lung cancer patient QOL needs and implementing evidence-based PCIs into clinical settings.

This review will conclude with a brief review of the theoretical framework, RE-AIM

(Glasgow, Vogt, & Boles, 1999) and its use in the dissemination of intervention studies.

Literature Population Inclusion

The vast majority of lung cancer patients (80%) present with non-small cell lung

cancer (NSCLC), which is the focus of the palliative care intervention discussed here; the

remainder of lung cancer patients are often diagnosed with small cell lung cancer

(SCLC). Many studies report on both NSCLC and SCLC simultaneously, typically

providing a general report of the illness experiences of lung cancer patients and their

FCGs as well as providing an overview of the current PCIs available. Although it may be

possible to meticulously distinguish between all studies on both types of lung cancers, the

focus of this literature review is on NSCLC patients and FCGs.

Overview of Quality of Life and Health Related Quality of Life in Lung Cancer

According to the National Consensus Project (NCP) for Palliative Care (2009),

the aim of palliative care is to maintain the highest possible level of QOL for patients and

their families throughout the illness experience. The very core of palliative care is to

improve QOL through interventions, which assess and meet the diverse needs of patients

with life-threatening illnesses (NCP, 2009). Quality of life is a multidimensional concept

that addresses the impact of traumatic events such as a cancer diagnosis on the physical,

psychological, social, and spiritual well-being of individuals (Owen, Boxley, & Klapow,

2007). Health-related quality of life (HRQOL) is a "multidimensional construct that

involves an individual's perceived health status, life satisfaction, and physical, social, and

psychological well-being" (Owen et al., 2007, p. 878). According to the Department of

Health and Human Services (DHHS) Healthy People 2020 objectives (2016),

"HRQOL goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life. A related concept of HRQOL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction."

The concept of HRQOL is then to assess the influence of illness on QOL. Whereas the conceptualization of QOL and HRQOL are used interchangeably in palliative care (Owen et al, 2007), in this study we will use the generalized concept of QOL, which focuses on addressing the multidimensional needs of lung cancer patients' and family caregivers' physical, psychological, social, and spiritual needs.

The clinical significance of the QOL construct has been underscored by research that identified QOL as an independent prognostic element for survival (Claasens, et al., 2011; Sloan, Zhao, Novotony, Wampfler, Clark & Yang, 2011; Temel et al., 2010). Thus, QOL is a critical aspect of living with lung cancer. In a longitudinal study, Sloan et al. (2011) followed 2,442 patients with NSCLC over a 10-year time span. In the first 6 months after receiving a lung cancer diagnosis, the QOL of participants was assessed using a single-item measure of overall QOL. Even after controlling for numerous variables such as age, sex, disease stage, smoking and treatment type, the overall QOL of patients at the time of diagnosis had a significant impact on their survival rate.

Quality of life is not only a strong predictor of NSCLC patients' survival rates, but also of the desire of patients and FCGs to actively strive for QOL during the patient's remaining years of life. Sloan et al., (2011) concluded that interventions designed and tailored for patients with lung cancer may improve both their QOL and likelihood of survival. It is therefore crucial that interdisciplinary teams assess QOL in clinical practice, detect deficits, and identify patients who may benefit from specific attention to

their expressed needs.

Family Caregiving in Lung Cancer

When an individual is diagnosed with cancer, family members often are plunged into the challenging role of primary caregivers, providing support following major surgeries, chemotherapy, and radiation. The tasks placed on cancer FCGs may increase over time and at specific intervals, such as during transitions (i.e., when cancer treatments begin and end) of care (Given, Sherwood, & Given, 2011; Northouse, Williams, Given, & McCorkle, 2012). The role of FCGs is multifaceted and increasingly complex: FCGs may be expected to become experts in symptom management at home, or assume the responsibility for keeping records, dispensing medications, and even performing procedures generally requiring nursing expertise (e.g., injections, catheter care, and management of infusion devices) (Given et al.,2011; Northouse et al., 2012). Besides these practical skills, family caregivers play key roles in emotional support, communication, personal care, providing for meals, and arranging transportation for medical appointments (Given et al., 2011). Finally, FCGs are often given legal and medical decision-making responsibilities, including treatment decision-making, goals of care, advanced directives, managing finances and home care assistants, facilitating transitions of care, and preparing for the patient's death (Glajchen, 2004). FCGs are often suddenly catapulted into this new role without a complete understanding of the complexity of their responsibilities; neither are they aware of the life-altering impact that this new role will have on their own lives (Teschendorf, Schwartz, Ferrans, O'Mara, Novotny, & Sloan, 2007). As a result, FCGs often experience high levels of physical, psychological, and spiritual distress related to their caregiving role (Sun et al., 2015). It is

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therefore critical to understand the QOLneeds and experiences of FCGs as well as the patients themselves.

Patient and Family Experiences in Lung Cancer

Symptom Burden in Patients with Lung Cancer

The symptom burden in patients with advanced lung cancer is high and has a negative impact on QOL (Iyer, Roughley, Rider & Taylor-Stokes, 2014). The term symptom burden relates to unmet physical needs associated with the disease. Physical needs are perceived to be a major concern by people with lung cancer throughout their illness (Maguire et al., 2012). The symptom burden may vary depending on the primary site of the cancer, metastatic status of the disease, treatment received, and manifestations of underlying comorbidities (National Cancer Institute [NCI], National Institutes of Health [NIH], 2016). More specifically, these symptoms include breathing problems, cough, pain, constipation, fatigue, sleep problems, nausea and vomiting, and loss of appetite/weight loss (Maguire et al., 2012). Of these, the most distressing are breathing problems, cough, pain, fatigue, and sleep problems (Simoff, et al., 2013). Maguire et al. (2012) explored the supportive needs of patients living with lung cancer in a systematic review of the literature and found that a number of these symptoms are present even before treatment begins. One of the most common unmet needs of patients was fatigue or lack of energy, which was often an issue during or after the first 2 years of diagnosis.

In light of the severity of symptom burden, symptom management is key to providing quality palliative care. Physical symptoms must be assessed and readily managed by knowledgeable interdisciplinary teams (NCP, 2009). This conclusion can be drawn from evidence of a number of studies on the disease burden of NSCLC patients

(Iyer et al., 2014; Liao et al., 2010; Mosher, Bakas, & Champion, 2013).

One of the key studies in this realm is a cross-sectional, observational study conducted by Iyer et al. (2014) in the U.S. The researchers explored the disease burden of 450 advanced NSCLC patients, comparing the perspectives of patients and physicians with regard to the severity of lung cancer-related symptoms and their impact on patient-reported QOL. This study identified a similar set of symptom burdens experienced by patients with lung cancer as those previously reported by Maguire et al. (2012) and Simoff et al. (2013). Iyer and colleagues (2014), reported that health-care providers may underestimate the actual disease burden and its impact on patient QOL compared to patients' own perceptions of their disease burden. A limitation of this study was that it only assessed patients' physical symptom burden, disregarding other possible areas of distress such as psychological and spiritual needs, which also contribute to QOL. Another noted limitation of the study was its focus on the perceptions of patients and physicians only, with no input from other members of the interdisciplinary team. As nurses, social workers, and chaplains also vital roles in caring for the QOL needs of patients with lung cancer, future studies should incorporate their perspectives.

Physical Burden in Family Caregivers

Family caregivers also experience physical burdens related to caregiving. The current literature provides some preliminary insights into the physical burden of cancer caregiving. As the patient experiences increasing disease and treatment-related symptoms, the cancer caregiver also experiences symptoms related to the burden of caregiving (Glajchen, 2004; Mosher, Bakas, & Champion, 2013). Research also shows that the physical demands of caregiving can be related to the patient's medical situation;

as a patient's disease progresses, the physical well-being of their caregiver may decrease (Northouse et al., 2012). Thus, common symptoms in caregivers resulting from the provision of care include sleep disruption and fatigue (Northouse et al., 2012; Carter, 2006). In addition, the physical demands placed on caregivers may also restrict their social involvements and activities. An emerging body of literature suggests that higher caregiver burden is associated with increased mortality risk for caregivers (Northouse et al.,2012). It has been reported that caregivers who reported higher burden during a 4-year follow-up had a 63% greater mortality risk than family members who were not providing care (Given, Sherwood, & Given, 2011).

Psychological Distress in Patients with Lung Cancer

The complex physical symptoms of lung cancer are unfortunately accompanied by psychological symptoms. Specifically, studies have concluded that one out of four NSCLC patients experienced psychological distress or depression (Pirl et al., 2012; Simoff et al., 2013). Various types of psychological distress, depression, and anxiety are especially common, with 23% to 47% of lung cancer patients experiencing these problems at some point in their illness; in addition, these patients experience higher levels of psychological distress than patients suffering from other cancer types (Liao et al., 2010).

A study conducted by Akechi et al. (2006) surveyed 85 late-stage NSCLC patients, and found that the initial psychological response after diagnosis was the most relevant predictor of subsequent psychological distress. It is therefore recommended that a systematic assessment of patients' distress is conducted following the diagnosis of lung cancer and reassessed throughout the plan of care.

Psychological Distress in Family Caregivers

Family members of cancer patients who serve as caregivers of experience a great deal of psychological stress due to the heavy responsibilities associated with this role. Studies on the patient-caregiver relationship have shown that caregiver's QOL is affected by the care recipient's psychological state. Caring for a family member with lung cancer often entails intense emotions in dealing with their loved one's depression and anxiety (Mosher et al., 2013). In a study of caregivers that included significant others, relatives and friends, depressive symptoms, exhaustion, and the emotional well-being of patients dying from lung cancer were assessed. As many as 40% of the caregivers reported high stress levels in one or more assessment areas and experienced psychological distress (Ostlund, Wennman-Larsen, Persson, Gustavsson, & Wengstrom, 2010).

Psychological distress is a common area of strain for both patients and FCGs dealing with cancer, and even more so in lung cancer diagnoses (Akechi et al., 2006). While it is recommended that a systematic assessment of patients' and caregivers' psychological needs be incorporated into clinical care, it is unknown how often this recommendation is followed. Further interventions consisting of symptom management, continued counseling, and preparation for transition from active treatment to treatment completion are essential to improving quality of care for patients with lung cancer (Liao, et al., 2010).

Social Needs in Patients and Family Caregivers with Lung Cancer

Maguire et al. (2012) reported in a systematic literature review of the unmet social and family-related needs of patients with lung cancer. A frequent concern was related to the impact of illness on family members. Many studies reported on the patients' worries

regarding the effect their death may have on their families' ability to cope and continue life without them. Expressing their emotions and feeling acknowledged and valued by their families and social network was positively related to the patients' and families' ability to cope with illness (Maguire et al., 2013). The type of social support available to patients with lung cancer predicts a more adaptive coping in the early stages of the disease (Ferrell, et al., 2011). Support that allows for responsibility and autonomy of the patient is associated with a higher level of adaptive coping in illness and fewer depressive symptoms (Walker, Zona, & Fisher, 2006).

In addition, social support is positively related to QOL (Ferrell et al., 2011). Such findings have implications for interventions promoting social support among lung cancer patients that include social support from healthcare professionals. Luszcynskas et al. (2012) showed that support by health care professionals improved both the perceived and actual quality of life outcomes of patients and family caregivers experiencing lung cancer. Effective interventions that aim at influencing all QOL aspects should incorporate support from various sources, such as family, friends, and healthcare personnel (Luszcynska, et al., 2012).

Spirituality in Patients and Family Caregivers with Lung Cancer

Terminal illness can cause a person to question the very meaning and purpose of their lives. It can also cause people to suffer deeply. Patients often turn to spirituality to help them find hope in the midst of their anguish. Terminal illnesses such as cancer often lead people to search for deeper meaning in their lives as well as in their suffering. This meaning can be referred to as transcendent meaning. Transcendent meaning may come from deeply held values, beliefs, spiritual practices, and relationships with significant

others as well as an awareness of a transcendent reality/God/ the Divine (Pulchalski, 2009). The term "spirituality" generally refers to a connection with a larger reality that provides meaning to life and can be experienced through private rituals (e.g., devotions or meditation, nature, or art) and/or communal spiritual activities such as church gatherings or worship (Peteet & Balboni, 2010).

Palliative care patients report spirituality as an important aspect to adjusting to terminal conditions. Addressing spiritual needs and providing spiritual care are fundamental components of quality cancer care from diagnosis to the end of life, and needs to be supported as reflected in clinical practice guidelines (NCP, 2011). The National Comprehensive Cancer Network's clinical practice guidelines recognize spiritual distress as a key element of a comprehensive psychological distress screening (National Comprehensive Cancer Network [NCCN], Clinical Practice Guidelines for Distress Screening, 2015). Furthermore, healthcare professionals are required to assess spiritual needs and provide services to address these needs (Joint Commission International, 2013).

Spirituality and Coping

Finding meaning in life is critical to effective coping, but the isolation and suffering associated with a terminal illness can make this especially difficult. Effective coping, including spiritual coping, can result in healing and the restoration of wholeness (Puchalski, 2009). Examples of spiritual coping include prayer, seeking comfort from one's faith, and obtaining support from members of a church (Abernethy, Chang, Seidlitz, Evinger, & Duberstein, 2002). Albernethy et al. (2002) reported a significant association between spiritual coping and depression: Spouses who used moderate levels

of spiritual coping were rated as less depressed than those who used lower levels.

Spiritual Distress in Lung Cancer

Unaddressed spiritual needs may be associated with higher levels of spiritual distress, which may also occur in situations where religious beliefs and practices fail to provide meaning or have a negative meaning, such as feeling abandoned by God (Peteet & Balboni, 2013). As reported in a systematic review on unmet supportive care needs of patients with lung cancer by Maguire et al., (2013), spiritual needs were identified as an area of major distress for patients. The inability to find meaning and purpose in life, and concerns about the ability to maintain a positive outlook and reprioritize the remaining time were common. It was reported that patients noted the importance of God or fate in situations of illness that were out of one's control, as "Gods will." Patients also described their experiences as moving between hope and despair (Maguire et al., 2013).

One important finding was that cancer patients who constructed meaning from their illness exerted a positive influence on their caregivers' well-being. Interventions that focus on supporting patients in finding meaning in their illness not only benefit patients but also enhance the quality of life for their caregivers (Puchalski, 2007). This provides support for interventions that encourage patients to reevaluate their situation.

Summary of Patient and Family Caregivers Experiences with Lung Cancer

Patients who experience lung cancer often present with an advanced disease stage; therefore, approaches to treatment and care are focused on maximizing quality of life (QOL) through aggressive symptom management. The above review of the literature reveals the intense multidimensional needs that influence the experience of patients with lung cancer as well as their family caregivers. Palliative care studies demonstrate that

starting palliative care early in the illness improves cancer patients' and their family

caregiver's QOL and survival (Nipp et al., 2015). Despite the extreme distress

encompassed with a diagnosis of lung cancer, attention should be on improving QOL and

meaning in life (Puchalski, 2007). Though the needs of lung cancer patients and FCGs

are well documented, there is evidence that many needs remain unmet by healthcare

providers (Maguire et al., 2013). Additionally, FCGs receive minimal attention within the

current health care system, since the focus is primarily on the needs of patients (Sun et

al., 2015).

Being aware of the experiences of patients and FCGs may inform health care

clinicians and researchers in the development and dissemination of palliative care

interventions for this diverse patient population. Palliative care intervention studies must

address both the patient and FCG and seek to incorporate means to improve QOL

(physical, psychological, social, and spiritual) across the illness trajectory. These

interventions should also be based on established palliative care guidelines and

incorporate interdisciplinary teams, who together can satisfy the individualized needs;

furthermore, interventions should be focused on encouraging the best possible QOL for

lung cancer patients and families facing this serious life-threatening illness.

Review on Lung Cancer Palliative Care Interventions

Over the past decade, evidence from the research literature has shown an upward

progression in the identification of supportive components which improve QOL

outcomes for patients and FCGs with lung cancer. Project ENABLE [Educate, Nurture,

Advise, Before Life Ends], a nurse-led palliative care intervention was conducted at

multiple sites, over several phases, and involved patients with a range of advanced stage

cancers.

Project ENABLE II, conducted by Bakitas et al. (2009) examined the effects of this PCI on clinical outcomes in patients with advanced lung, breast, and gastrointestinal cancer. The components of this intervention study included an advanced-practice nurse–administered, telephone-based, intensive curriculum, and ongoing assessment and coaching in problem solving, advanced care planning, family and health care team communication strategies, symptom management and crisis prevention, and timely referral to palliative care and hospice resources. Interdisciplinary teams were responsible for all medical decisions, including medication and inpatient care management; however, the advanced practice nurses, in consultation with the team, could facilitate referrals to ancillary resources. The interdisciplinary team included a palliative care–certified nurse practitioner and physician, psychologists, and other team members. These members met biweekly to review the advanced practice nurses' audiotaped educational sessions and to provide feedback on difficult patient management issues. Participants enrolled in the intervention were encouraged to invite their caregivers to attend monthly group medical appointments by a certified palliative care physician and nurse practitioner. These appointments allowed participants and caregivers to ask questions about medical problems or related issues (e.g., symptom management, insurance, social services) and to have more in-depth discussions. Quality of life including symptom intensity and mood was measured at baseline, 1 month, and every 3 months until death or study completion. Intensity of service was measured as the number of days in the hospital and in the intensive care unit (ICU) and the number of emergency department visits recorded in the electronic medical record. Patients receiving this nurse-led PCI reported higher scores

for QOL and mood; however, they did not show improvements in symptom intensity scores or fewer hospital days or emergency department visits (Bakitas et al., 2009).

While the components of this intervention were clearly reported, the components that accounted for the improved patient mood and QOL scores could not be determined. Though FCGs were involved in this study, their QOL needs and benefits from being involved in interdisciplinary team meetings were not measured and discussed. A limitation of this study is its focus on advanced cancer patients. One of the study recommendations included an evaluation of whether PCIs delivered to earlier-stage patients improved patient and family outcomes.

Following recommendations of Bakitas and colleagues, Temel et al. (2010) examined the effect of introducing palliative care after diagnosis of patient-reported outcomes and end-of-life care among 151 patients newly diagnosed with metastatic NSCLC presenting at an outpatient thoracic oncology clinic. General guidelines for palliative care visits in the outpatient setting were adopted from the National Consensus Project for Quality Palliative Care, (NCP, 2009). Randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer received either early palliative care concurrent with standard oncologic care or standard oncologic care alone. Patients who were assigned to early palliative care met with a member of the palliative care team, which consisted of board-certified palliative care physicians and advanced-practice nurses, within 3 weeks after enrollment and at least monthly thereafter in the outpatient setting until death. Additional visits with the palliative care service were scheduled at the discretion of the patient, oncologist, or palliative care provider. Quality of life and mood were assessed at baseline and at 12 weeks. The primary outcome was the change in the

quality of life at 12 weeks. Data on end-of-life care were collected from electronic

medical records. The study showed that patients assigned to early palliative care had a

better quality of life than patients assigned to standard care. In addition, fewer patients in

the palliative care group had depressive symptoms those in the standard care group.

This study provided preliminary outcomes of implementing early concurrent

palliative care according to which standard oncology treatment had an impact on medical

decision making. This treatment was further investigated and reported in a subsequent

study by Temel et al. (2011). The aims of this follow-up study were to explore

perceptions of prognosis and goals of therapy in metastatic NSCLC patients and to

examine the effect of early palliative care interventions on patient perceptions over time.

One hundred and fifty-one participants with metastatic NSCLC completed a baseline and

longitudinal assessment of their perceptions of their prognosis and the goals of cancer

therapy over a 6 month period. Temel et al. (2011) found that many patients with

metastatic lung cancer have inaccurate views of their prognoses and the goals of cancer

therapy. These misperceptions place patients at risk for making unsuitable choices for

their care and subsequently at the end-of-life. Specifically, prolonged use of

chemotherapy at the end of life and delayed palliative care services can be attributed to

these misperceptions. The researchers found, however, that early implementation of

palliative care can enhance the understanding of diagnosis and goals of treatment. Hence,

implementing palliative care earlier in the illness trajectory was supported by the

evidence presented in this study.

Greer et al. (2012) conducted a secondary analysis of the above randomized

controlled trial (Temel et al., 2010; Temel et al., 2011) to investigate if early palliative

care affects the frequency and timing of chemotherapy use and end-of-life care. Findings revealed that early palliative care optimized the timing of final chemotherapy treatments and the transition to hospice services. Participants receiving early palliative care were less likely to receive chemotherapy within 60 days of death and had a higher enrollment in hospice care for longer than 1 week. The results of this study added to the evidence supporting the utility of early palliative care integrated with standard oncology care in outpatient settings for patients with metastatic NSCLC. This model of care offers an approach designed not only to improve multiple patient outcomes but also to enhance oncology practice in conforming to expressed goals for the highest quality cancer care.

While these intervention studies acknowledged the potentially limited generalizability of these single-site studies with a specialized group of oncology and palliative care clinicians to other care settings and patients, the fact that several studies of early palliative care interventions at different sites showed similar outcomes is nonetheless noteworthy. That said, more intervention studies are needed with ethnically diverse patient groups (Temel et al., 2011).

Further investigation of outcomes from the ENABLE II intervention included patients' perspectives on the benefit and burdens encountered while participating in this study. Maloney et al. (2012), reported on a qualitative descriptive study using semi-structured interviews with 53 of the 72 patients who were alive after the intervention study was complete. The results of this study showed that participants felt the PCI provided them with enhanced problem solving and coping skills, as well as reassurance and feelings of empowerment. Intervention participants also felt they were helping future patients and contributing to science. Areas identified by patients to improve the PCI

included the travel distance to monthly medical appointments with a palliative care physician and nurse practitioner to discuss in detail symptom management and/or availability of resources. Attendance of these appointments was especially difficult when the patients' symptoms were exacerbated. Additionally, some patients felt the intervention was only helpful when their symptom burden was high as opposed to when they were asymptomatic or without symptoms (Maloney, Lyons & Li, 2012).

Participant feedback inspired the question, "when is the optimal time to initiate palliative care and how can asymptomatic patients benefit from palliative care, especially in providing tools for self-care and healthy living?" (Maloney et al., 2012). Although the patients had suggestions for improvement, it was concluded that the overall outcomes of the ENABLE II intervention outweighed the burden of participation.

In response to the question of when to initiate palliative care, Bakitas et al. (2015) conducted phase III of the ENABLE project, a randomized controlled trial examining the effects of early versus delayed initiation of concurrent palliative and oncology care on patients' mood, QOL, and symptoms. This study targeted patients with advanced cancer and compared patients with usual care (oncology treatments alone) versus an intervention group (palliative care and oncology treatment together) at 3 months into care. The 3-month delay in initiating care was in response to patient perspectives that the intervention was more helpful when more symptoms were present. Those who were not enrolled into the intervention group were considered to be delayed 3 months of receiving palliative care. This study included patients with lung, breast, and gastrointestinal cancers at a National Cancer Institute Center, Veterans Affairs Medical Center, and community outreach clinics. The intervention components of ENABLE III were modified from phase

II to include three components: first, a three-session life review component; second, a separate but parallel intervention for caregivers; and third, a fast-track study design. These modifications were also in response to patient input. In examining the point in the disease trajectory to refer patients to palliative care, this study first defined "early" as within 30-60 days of diagnosis, and compared these patients with those who were referred to palliative care after 90 days (3 months). Studied outcomes included QOL, symptom impact, mood, 1-year survival, and resource use (hospital/intensive care unit days, emergency room visits, chemotherapy in last 14 days, and death location). This study supported findings that early palliative care (30-60 days after diagnosis) improves overall survival of patients living with cancer. In contrast to studies reported by Temel and colleagues (2011), there were no significant findings related to overall QOL, mood, or symptom management for patients referred to palliative care early in their disease trajectory. Bakitas and colleagues (2015) then raised the question that if QOL and mood are presumed to improve survival, how exactly do QOL and mood improve survival? Further, the optimal timing to initiate palliative care needed further clarification to include the impact of early versus late palliative care on quality and cost. Accordingly, a retrospective cohort study compared matched cancer patients who received early (84% outpatient) versus late (82% inpatient) palliative care consultation and found that early palliative care was associated with less intensive medical care, improved quality outcomes, and approximately $6,000 in cost savings per person at end-of-life for patients (Scibetta, Kerr, Mcguire, & Rabow, 2016). This study utilized an analysis of cancer registry, administrative, and billing databases to compare health care utilization and quality of care for patients with cancer who died having received early versus late

palliative care. It was concluded that in spite of findings, that palliative care should be offered early and to all patients with metastatic cancer, palliative care services continue to be underutilized (Scibetta et al., 2016).

Interventions for Family Caregivers

Few studies focused specifically on interventions which improved quality of life for patients and FCGs living with lung cancer. A literature review conducted by Northouse et al., (2012), determined the effect of psychosocial interventions on patients and FCGs with cancer in general. Three types of interventions were identified: (1) psychoeducational, which provided information about management of patients' symptoms, physical care of patient, and some attention to the emotional aspects of care; (2) skills training, which primarily addressed the development of caregivers' coping, communication, and problem-solving skills, and (3) therapeutic counseling, which primarily focused on strengthening patient-caregiver relationships, managing conflict, and dealing with loss. Sixty-three percent of these interventions were delivered to patient and FCGs. Overall these interventions improved coping skills, knowledge, and quality of life in FCGs. For patients, these interventions decreased symptoms, reduced mortality, and improved QOL. Despite these positive effects on patient and FCG psychological outcomes, interventions are not often put into practice for both patients and FCGs.

Taking the results of the 29 randomized controlled trials by Northouse et al. (2012), the ENABLE III project reported on the initiation of early versus late intervention for 122 family caregivers of patients with advanced cancer in a largely rural setting (Dionne-Odum et al., 2014), to include components that reduce FCG psychological distress, specifically, providing emotional, informational, and problem solving support

(Dionne-Odum et al., 2014). The intervention was a telehealth palliative care intervention led by nurses and included being randomly assigned to receive three structured weekly telephone coaching sessions, monthly follow-up, and a bereavement call either early after enrollment or 3 months after the death of the patient. The nurses were trained to discuss caregivers' psychological needs to include coping, control of their own problems, their family member's circumstances, and emotional and social support. The FCG intervention was delivered parallel with the ENABLE III patient intervention.

Outcome measurements for the FCG were quality of life (QOL), depression, and burden (objective, stress, and demand). The early-referral group had lower depression scores at 3 months and lower depression and stress burden in the terminal decline analysis. However, there was no significant difference found between QOL and burden demand between the early and late groups. The study concluded that FCGs should be included in palliative care and offered resources as early as possible to maximize benefit. A limitation to this study included the challenge of recruiting and retaining family caregivers due to their increased care demands, which may have affected their ability to participate. In addition, there was a limited diversity of participants, limiting generalizability. Specifically, all participants were white, had at least a high school education, were female, and lived in the same geographical area. This further confirms the need for PCIs to be tested in diverse populations to include minorities, lower education, and in different settings.

Summary of Findings

Integrating palliative care with oncology treatments early in the trajectory of lung cancer has been shown to optimize the timing of final chemotherapy treatments and the

transition to hospice services (Greer et al., 2012), improve the QOL and mood of patients (Temel et al., 2011), and improve survival rates (Temel et al., 2011; Bakitas et al., 2015).

Additionally, the specific components of PCIs that improve patient QOL have not been clearly identified. Cancer care includes interdisciplinary attention to improving areas of QOL (physical, psychological, social, spiritual, and existential concerns) for the patients and family, yet there are few interventions which report specifically on how these interventions improve QOL outcomes for patients and FCGs. Generalizability to other populations was a limitation mentioned earlier. Little is known about the effect of similar PCIs in diverse ethnic and racial populations and more investigation is needed. This review focused on a PCI which addressed the QOL needs of non-small cell lung cancer patients and FCGs, and itemized the components of the intervention and outcomes. Additionally, this intervention focused on both early and late stages of NSCLC. This PCI was specifically selected as the foundational intervention used in this research for its potential in community-based settings to increase participation by diverse populations and communities.

Selected Lung Cancer Palliative Care Intervention

The selected intervention for this research was an interdisciplinary PCI developed and tested at a National Cancer Institute (NCI)-designated comprehensive cancer center. The research design was a two-group prospective quasi-experimental study in which the usual care group was accrued first, followed by the intervention group. The purpose of this study was to test the effectiveness of an interdisciplinary PCI in patients diagnosed with stage I-IV NSCLC and their FCGs. This intervention was delivered concurrently with oncology and disease-focused therapies. Improved outcomes were reported on both

patients and FCGs, particularly with regard to quality of life (Ferrell et al., 2015; Sun et al., 2015a; Sun et al., 2015b).

<p align="center">***PCI Components***</p>

Borneman et al. reported on the educational components of this interdisciplinary palliative care intervention in 2015. The intervention, founded on NCP's Clinical Practice Guidelines for Quality Palliative Care (NCP, 2009), was confirmed by several pilot studies (Koczywas et al., 2013; Borneman, et al., 2008). The components of this intervention involved a comprehensive, baseline QOL assessment with the patient and FCG completed by a study nurse, patient and family caregiver education based on concerns of the patient and FCG (from greatest to least concern to include physical, psychological, social and spiritual well-being), and interdisciplinary team meetings for each professional to make recommendations for the plan of care. Recommendations were documented in the interdisciplinary palliative care plan. The interdisciplinary team was compromised of nurses, palliative medicine physicians, thoracic surgeons, medical oncologist pulmonologists, a social worker, a chaplain, a dietitian, and a physical therapist.

Ferrell et al. (2015) reported on the preliminary analysis of patient outcomes from this interdisciplinary PCI. A total of 491 patients with NSCLC were included in the primary analysis of the data. Patients who received the intervention had significantly better scores for QOL symptoms, spiritual well-being, and lower psychological distress at 12 weeks after controlling for baseline scores, compared to patients in the usual care group (standardized palliative care). Patients in the intervention group also had significantly higher numbers of completed advanced care directives and supportive care

referrals (Ferrell et al., 2015). Although not statistically significant, there was a 6-month difference in the survival rate of patients who had received the interventions versus those who had not. The benefits were seen primarily in the earlier stage patients versus those with late state, stage IV disease.

Sun et al., (2015a) reported on the effectiveness of this interdisciplinary PCI for FCGs of lung cancer patients. A total of 366 caregivers were included in the primary analysis. FCGs who received the interdisciplinary PCI had significantly better scores for social well-being and lower psychological distress scores at 12 weeks compared to FCGs receiving usual care. Additionally, FCGs had less caregiver burden compared with FCGs in the usual-care group.

Sun et al. (2015b) explored spiritual well-being outcomes of lung cancer patients and FCGs enrolled in this study. Patients were asked to state their religious affiliations. It was found that patients who received the spiritual education components of the intervention had significant better scores in finding meaning/peace. Findings revealed that patients who reported no religious affiliation had better outcomes in relation to a sense of harmony within oneself. The researchers recommended that PCIs include constructs such as meaning and faith for lung cancer patients and FCGs with or without religious affiliation. Additionally, PCIs should include content that targets the spiritual needs of both patients and FCGs.

In a subsequent study, components of this interdisciplinary PCI have demonstrated an improvement in the quality of life of lung cancer survivors after surgical procedures (Raz et al., 2016).

Summary of Findings

This interdisciplinary PCI provides evidence of improving patient and FCG quality of life (QOL), including spiritual well-being, in a large population of patients with lung cancer and their family caregivers. The PCI embraces comprehensive assessments of patients and FCGs, interdisciplinary team input to the plan of care, and patient/FCG education by study nurses as recommended by the NCP clinical practice guidelines (2009). A limitation to the primary study was its limitation to a single site at a well-established cancer center, representing less than 20% of non-Hispanic/non-white populations (Ferrell, 2015). In addition, the perspectives of the interdisciplinary clinicians about ways to best address the QOL concerns of patients and FCGs and the perceived challenges to implementing this intervention are not known.

Dissemination of the Selected Lung Cancer PCI

This intervention was recently (2015-present) recognized by the National Cancer Institute (NCI) and researchers were given the opportunity to disseminate the PCI components in three community-based palliative care settings for NSCLC patients and family caregivers. This dissemination study consists of equivalent components to those implemented at the primary site. Study nurse-researchers provided several education sessions to prepare the interdisciplinary teams to implement this intervention into the palliative care settings. Several interdisciplinary teams at multiple sites are anticipated to maintain the components of the PCI post-implementation. It is then vital to understand the perceived challenges in implementing and maintaining palliative care programs.

Clinicians' Perspectives on Useful Practices and Challenges of PCIs

Qualitative research studies were explored to better understand the perceived

useful practices and challenges in palliative care by interdisciplinary clinicians.

Following the PCI study conducted by Temel and colleagues (2010), two focus groups

and one individual interview were completed in November 2011 with the palliative care

clinicians who had participated in this randomized trial of early palliative care for

metastatic lung cancer. Back et al. (2014) explored palliative care clinicians' perspectives

on their approach to early palliative care in outpatient settings. Clinicians included board

certified physicians (*n=6*) and advanced practice nurses (*n=2*). These participants

described their roles in providing early palliative care as having three distinct tasks (1)

managing symptoms to improve functional status and as a bridge to other discussions

such as emotional issues. Clinicians explained that starting with concrete physical

symptoms, such as pain or nausea, also built rapport with the patient; (2) engaging

patients in emotional work to facilitate coping, accepting, and planning; and (3) ensuring

that the oncologist and patient each understand and are able to discuss prognosis and

treatment. In this way, the aims of early palliative care assist in the communication

between patient and oncologist (Back et al., 2014).

Focus groups were used rather than individual interviews to enable clinicians to

see their own perspectives more clearly. A strength of this study is that it explored

clinicians' perspectives in an outpatient setting community setting, shedding light on the

particular challenges faced by palliative care clinicians who follow patients in the

community over time. Implications for this study were to lay a foundation for developing

training programs for clinicians involved in early integrated palliative care. This study

was limited by its single-site location and small number of palliative care clinicians

(*N=8*). Further, perspectives from oncology and primary physicians were not included;

these perspectives are vital in understanding the challenges and useful practices to PCI implementation and the collaborative referral process between palliative care, oncologists, and primary physicians. This need is further emphasized by palliative care researchers who reported on implementation challenges during phases of the ENABLE study design, including sampling, clinician cooperation in referrals, and recruitment. Two issues reported were trying to "win over" or achieve buy-in from oncologists to prevent gate-keeping, and possible clinician bias about who is referred to palliative care programs and intervention studies compared to the inclusion criteria (Bakitas, Dixon, & Ahles, 2006; Bakitas, Lyons, Hegel, Balan, & Barnett, 2009). These issues were then viewed by researchers as essential to exploring oncology clinicians' perspectives on the concurrent oncology/palliative care model.

Bakitas et al. (2013) conducted a qualitative interview study to explore oncology clinicians' perspectives on the care of advanced cancer patients following the completion of the ENABLE II project on the concurrent oncology palliative care model. Oncology (*n=35*) clinicians were interviewed to understand their approach to patients with advanced cancer and the effect of the ENABLE II-randomized control trial. Oncology clinicians believed that integrating palliative care at the time of an advanced cancer diagnosis enhanced patient care and complemented their practice. Four themes were identified which described the self-assessment of their practice with advanced cancer patients: 1) treating the whole patient, 2) focusing on quality versus quantity of life, 3) "some patients just want to fight," and 4) helping with transitions; timing is everything. Five themes comprised oncologists' views on the complementary role of palliative care: 1) "refer early and often," 2) referral challenges: "palliative" equals hospice;

"hematology patients are different," 3) palliative care as consultants or co-managers, 4) palliative care "shares the load," and 5) ENABLE II project facilitated the integration of palliative care with oncology. The theme, "treating the whole patient," involved the importance of a comprehensive approach to advanced cancer patient treatment to include QOL of physical, emotional and spiritual dimensions. This approach included the supportive and disease-specific care of patients.

Clinicians discussed the challenges of advanced cancer patient care and referrals, such as "some patients just want to fight." This was described as patients who do not want to hear about palliative care and want to fight and continue aggressive treatments. Another theme, the patient "not being ready" was described as not being able to shift the patients' goals from fighting to accepting palliation for their disease. Some patients were described as not being psychologically ready to accept palliative care due to feeling overwhelmed. It was found to be helpful when palliative care clinicians stepped in to help identify the best time for the patient to transition to palliative care. Referral challenges discussed by the clinicians involve the use of the label "palliative care," due to the misperception that it equals hospice and death. Clinicians in this study minimized this challenge by normalizing palliative care by introducing it early and as standard of care. It was concluded that palliative care referrals resulted in a positive outcome and were a helpful resource to patients and the oncologist. This was described by oncologists as "sharing the load" -- working with palliative care clinicians and introducing the concept of palliative care to patients as the standard of care. Oncology clinicians reported feeling supported when the palliative care team worked beside them in the oncology clinic. Challenges were associated with the patient not being ready, the patient lacking

preparation for referral, or the misconception of palliative care as associated with death. Bakitas et al., (2013) reported clinicians identifying a new advanced cancer diagnosis as a prompt or trigger for palliative care referral; however, knowing when to refer patients to palliative care remained a barrier for some clinicians.

One limitation to this study was its location in an academic, National Cancer Institute (NCI)-designated cancer centers; oncology and palliative care were already integrated at these settings; however, this is not the case at most oncology practices in the U.S. Additionally, the ethnic and racial backgrounds of patients and clinicians were not diverse, possibly making translation to a larger and complex health system difficult (Bakitas et at., 2013).

Le et al. (2014) identified perceived barriers to the acceptability of early integration of palliative care, specifically for incurable lung cancer patients. A qualitative exploration using focus groups and interviews with lung cancer clinicians focused on the current experiences of engaging with palliative care and their views of barriers and benefits of referring to palliative care. Twenty-eight clinicians took part in focus groups. In addition to oncology physicians, this study included the disciplines of social work, radiation oncology, thoracic surgery, nuclear medicine, respiratory, and oncology and lung cancer nurse coordinators. Key themes resulting from this study were: (1) competence/skill: referrers needing confidence in the quality and capability of palliative care; (2) care coordination: the need to ensure integrated care with defined lines of responsibility and clear team communication; (3) ease of referral: the need for ready access to a palliative care provider in the lung cancer clinic; and (4) perceptions: concerns about patients losing hope and fears of negative patient reactions. It was

recommended that clinicians receive further education on the roles and benefits of early palliative care, and the best way and time to introduce it with patients. Another perceived barrier was the stigma associated with the word "palliative," a connotation with death. These findings were similar to the 2014 Bakitas et al. study of oncology clinicians that described the challenges of using the word "palliative," and its perceived association with hospice or death. Similarly, the clinicians discussed the challenge of knowing when to introduce palliative care to patients. In overcoming these challenges, clinicians mentioned the importance of standardizing palliative care, introducing the concepts of palliative care early, and using terms such as "supportive," rather than "palliative." Clinicians acknowledge it is possible to overcome the barriers associated with palliative care through education of both clinicians and patients.

Practical suggestions given by clinicians included the need for education on when to refer patients to palliative care and communication workshops on palliative care transitions and breaking bad news to patients. Having palliative care specialists in the clinic was considered helpful to the referral process; this was also mentioned by Bakitas (2014). Overall, the clinicians had a positive experience with palliative care services and its integration in oncology care.

This study by Le et al. (2014) adds to the understanding of the perceived challenges and useful practices of clinicians who care for lung cancer patients. These perspectives included those of multiple disciplines who care specifically for lung cancer patients in three metropolitan-area university hospitals rather than a single site, and used focus group interviews rather than individual interviews alone. Limitations to this study include its location outside the U.S., in Melbourne, Australia, and its setting at a large

university hospital instead of an outpatient community setting, which could make translating its findings to programs without ready access to palliative care difficult. In addition, this study and the one conducted by Bakitas and colleagues in 2014 did not include perspectives of primary care physicians, which are important to understanding the perceived useful practices and challenges to integrating palliative care into oncology care and in implementing PCI interventions.

In implementing palliative care programs focused on the QOL needs of patients and family caregivers, it is imperative to consider clinicians' perspectives of meeting these quality of life needs. The literature shows that spirituality is the most difficult QOL need for clinicians to address. Abbas and Dein (2011) reported a qualitative focus group study aimed at exploring the difficulties encountered by palliative care clinicians working in an inpatient hospice unit when asking their patients about spirituality. Interviews were taped and analyzed through content analysis. Focus groups were used to capitalize on communication between participants and group dynamics to generate data.

Emergent themes included lacking the vocabulary to discuss spiritual issues, personal issues surrounding death and dying, training issues, fear of being unable to resolve spiritual problems, time constraints, and difficulty separating spiritual and religious needs. Researchers concluded that spirituality is not well integrated into palliative care and spiritual issues are often difficult to communicate in words. Spiritual care training is a recommendation mentioned to improve spiritual communication, as well as the use of standard spiritual care tools and spiritual support groups. Several clinicians discussed the possibility of "opting out" of spiritual conversations with patients and being aware of their own limitations. Also, clinicians felt it was important to know when to

refer patients to other members of the interdisciplinary team. This study had limitations in generalizability to other populations due to its small sample size and single-site location.

A better understanding of how clinicians communicate spiritual care in palliative care settings may help them address this vital facet of QOL. It was reported by Abbas and Dein (2011) that "spirituality is often difficult to communicate in words and spiritual issues may be better expressed through poetry, metaphor or music than through spoken or written language" (p. 348). An understanding of the perceived difficulties of spiritual communication and how clinicians provide spiritual care is not revealed in this study. This may help clinicians understand how to address this vital facet of QOL and develop training curricula to meet these needs.

Wittenberg, Ferrell, Goldsmith, and Buller (2015) conducted a cross-sectional survey with 124 clinicians including nurses, social workers, and other attending one of two continuing education courses. Clinicians had on average 10 years or more of clinical experience. The survey measured the frequency and initiation of communication about spirituality and forgiveness with patients/families, the perceived difficulty of communication across topics, and preparation and resources for these discussions. It was reported that the highest level of difficulty in spiritual communication was when talking with the family after the death of a patient, followed by conducting a spiritual history with a patient. Facilitating forgiveness communication between parent and adult child, followed by facilitating forgiveness between partners was most difficult for all participants.

It was recommended by Wittenberg and colleagues (2015) that communication about spirituality for patients and family should occur not only at the end of life, but also

in the early stages of the illness. This study provides guidance on areas of focus in spiritual care trainings for clinicians. Education appears essential in providing tools to navigate culture and religion, and developing comfort and deep listening skills (Wittenberg et al., 2015).

A recent literature review on the education, implementation, and policy barriers to greater integration of palliative care further revealed challenges in the implementation of palliative care. Aldridge et al. (2016) reviewed literature over the past 10 years and identified palliative care as lacking in adequate education/training and the perception of palliative care as end-of-life care. Implementing palliative care was sometimes hampered by an insufficiently trained palliative-medicine workforce and challenges in identifying patients appropriate for palliative care referral. It was therefore recommended to integrate palliative care concurrent with oncology and medical treatments across care settings, to include emergency departments.

In summary, education and communication are recurring themes in the literature regarding the challenges of interdisciplinary clinicians integrating palliative care into practice. Moreover, there is a perceived barrier in addressing the spiritual needs of patients and families. Despite challenges in implementing palliative care, providing palliative care interventions for patients with lung cancer and their family caregivers remain necessary in order to meet their QOL needs. Although these interventions continue to move upstream, their implementation and dissemination into real-world community settings remains an ongoing challenge. From a macro perspective, it is important for the culture of palliative care to continue to change and evolve. This includes the education of interdisciplinary teams on the impact of PCIs on the quality of

life needs patients and FCGs, in addition to providing them with specific skills, such as communication in the area of spirituality.

Implications for Future Research

A gap exists in palliative care intervention literature on incorporating the perspectives of interdisciplinary teams to enhance components of intervention studies prior to implementation. Feedback and buy-in from front-line clinicians involved in the care of lung cancer patients and FCGs in community settings may assist in the implementation and maintenance of PCIs. Focus group research with interdisciplinary teams of clinicians has been used in palliative care studies to enhance communication among team members and improve awareness of participants' individual feelings towards a topic. Conducting focus group research with palliative care and oncology clinicians prior to implementing PCIs may assist in the validation of intervention components and enhance its maintenance into clinical practice.

Conceptual Framework: RE-AIM Model

The National Institutes of Health (NIH) addressed the vast gap between current knowledge and practice in the area of dissemination and implementation of research. It has been reported that the benefits of evidence-based research are frequently not implemented into practice in a timely manner (Glasgow, Chambers, Khuoury, Kaplan, & Hunter, 2012), and there is little evidence that new knowledge is being translated into typical clinical or community practice (Almedia & Brito, 2014). By contrast, the identified framework for this study is focused on the translation of intervention research into practice using the RE-AIM model, a conceptual framework used to evaluate the effectiveness of translating intervention research into practice. RE-AIM is used as an

evaluation on an individual organizational level, or both.

Glasgow, Vogt, and Boles (1999) proposed that the RE-AIM model be used for evaluating public health interventions that assess the five dimensions of this model. The authors warn that failure to adequately evaluate translation programs in all five dimensions could lead to wasted resources, discontinuities between stages of research, and failure to improve public health. Therefore, it is important to assess and evaluate interventions on both the individual and organizational levels. At the individual level, reach and effectiveness are assessed based on individuals who participate and are chosen to receive a health benefit from a program. Effectiveness is assessing changes in the primary outcome, potential negative outcomes, and quality of life. Adoption and implementation are assessed based upon the delivery setting or delivery staff level. Adoption is defined in terms of settings or delivery staff that would implement and sustain an intervention. Implementation is the degree to which the intervention is delivered as planned and the expenses associated with the intervention. Maintenance is defined as the degree to which an effect is sustained at the individual level at least 6 months post the program. It is also defined as an intervention being sustained after the formal research funding is complete.

A systematic review of nursing intervention studies on patients and family members reviewed nursing interventions that focused on patients with chronic disease, such as cancer, schizophrenia, or Alzheimer's disease, and their family members. Most interventions were targeted at patient and family members with an emphasis on the family member's role in the intervention. The main focus in the studies reviewed used dimensions of the RE-AIM model (Mattilia, Leino, Paavilaninen, & Astedt-Kurki, 2009).

Almeida and Brito (2014) suggested that the RE-AIM framework be used in nursing for planning and evaluating health programs that reach a large representative sample of the target population with effective strategies that are easily adopted and implemented, and sustained over time in different settings.

The theoretical framework of RE-AIM has implications for intervention research in hospice and palliative care (Demiris, Oliver, Capurro, &Wittenberg-Lyles, 2013). Demiris (2013) applied the RE-AIM model to case study examples for the use of qualitative research methods on palliative care implementations. This study specifically focused on the use of qualitative methods to understanding staff participation and assessing organizational readiness in the Adoption phase of planning an intervention study. Adoption is further defined by Demiris and colleagues (2013), as "how feasible it is for the program to be adopted in the real-world settings and whether it can be adopted by low resource settings" (p. 168). Furthermore, assessing the success and failure factors at organizations before implementation can help gauge needs and ensure clinician buy-in (Demiris et al., 2013).

Implications of RE-AIM Model

The RE-AIM Model provides a framework for dissemination and testing of the proposed PCI and its dissemination into practice at study sites as usual care and was used to evaluate Aim 1 of the interdisciplinary PCI: To Adopt a Palliative Care Intervention (PCI) tested in a NCI-funded Program Project (P01) for dissemination to other oncology settings. Elements of the RE-AIM framework has been embraced for this project, contributing to the adoption phase of the model to develop organizational support in delivering the intervention (see Figure 2). Understanding the perceptions of palliative

care and oncology clinicians' in preparing for PCI implementation may assist in the

adoption phase on an organizational level.
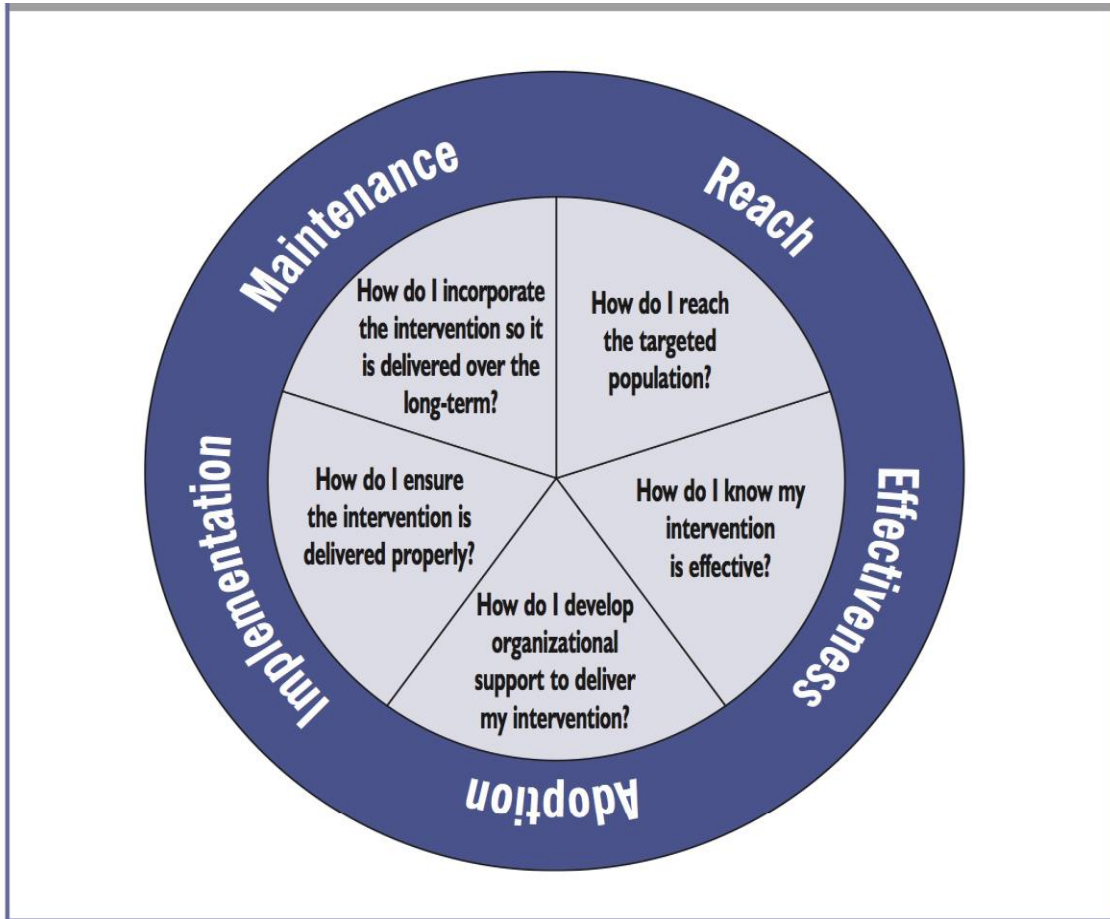
Figure 2. Elements of the RE-AIM Framework (Belza, Toobert, & Gasgow, 2013).

RESEARCH METHODOLOGY

Overview of the Study Design

This research contributed to an ongoing two-phased intervention study funded by the National Institute of Nursing Research (NINR), part of the National Institutes of Health (NIH). The ongoing study was conducted to test the dissemination of a palliative care intervention (PCI) for non-small cell lung cancer (NSCLC) patients and their primary family caregivers. During phase one, a baseline for standard palliative care was established at each site. Phase two was the intervention of the structured PCI. This qualitative research study was embedded in the PCI study and conducted at the end of phase one, prior to implementation of the PCI.

The purpose of this research was to inform a PCI for lung cancer patients and their FCGs prior to implementation by eliciting the perspectives of palliative care and oncology clinicians (e.g., physicians, nurses, social workers, and chaplains) on addressing lung cancer patients' and FCGs' QOL needs through qualitative methods (focus group and key informant interviews). These recommendations were used in the Adoption component of the RE-AIM model (Glasgow, Vogt, & Boles, 1999) for palliative care and hospice intervention studies. Recommendations were elicited to gauge organizational support and assess positive and negative factors before the intervention began. Ultimately, this approach was taken to maximize the likelihood for translation and long-term adoption of the PCI. (Demiris et al., 2014).

This research allowed investigators to better understand standard palliative care for lung cancer patients and FCGs prior to implementation at each site, to include useful

practices, challenges, and perceived needs of palliative care clinicians as they prepared to

support patients and FCGs across quality of life dimensions. See Figure 3 for an

illustration of the PCI study as it incorporated this qualitative study, which could enhance

the adoption of the intervention into clinical practice.

Phase I: Establishing a baseline for standard palliative care

Refine PCI

Phase II: Implementation of a structured PCI

Patient Identification/ Recruitment

PC Nurse or staff works with clinicians & care managers to identify~**30** stage 2-4 lung cancer cases per site.
-Consent patient and caregiver to participate in the assessment
- Facilitate data collection

-PC Nurse or staff identifies all stage 2-4 lung cancer cases in clinic.
-Enroll ~ 40 patients and caregiver for the PCI
-Consent patient and caregiver to participate in the PCI intervention

Data analysis, Data review; Adapt PCI as needed in collaboration with clinicians.

Assessment

Surveys to be completed
-Patient completes a battery of surveys about quality of life, symptom burden and distress
-Caregiver completes a battery of surveys about quality of life, caregiver burden, satisfaction, preparedness

Surveys to be completed
-Patient completes a battery of surveys about quality of life, symptom burden and distress
-Caregiver completes a battery of surveys about quality of life, caregiver burden, satisfaction, preparedness

Intervention

Focus group and key-informant interviews
-Feedback from clinicians.
-Perspectives on addressing patient and family caregiver QOL needs through palliative care.
-Perspectives on adopting and implementing PCI

Palliative Care Intervention
-Comprehensive patient and caregiver QOL assessment (surveys per above)
-RN works with interdisciplinary care team, patient and caregiver to develop a comprehensive care plan
-RN provides tailored education & skills training to patients and caregivers
  Patient: 2 sessions to cover: 1) Physical & psychological and 2) social & spiritual issues phone F/U

Figure 3. Translation of a lung cancer palliative care intervention

Research Aims and Questions of Study

The three specific research aims and questions were as follows:

Aim 1: Identify clinicians' perspectives on how to address patient and FCG QOL

dimensions (physical, psychological, social, and spiritual needs) through palliative care.

Research question 1--How do clinicians' address QOL dimensions of patients

and FCGs with lung cancer through palliative care?

Aim 2: Identify clinicians' perspectives on challenges in addressing patient and FCG

QOL dimensions (physical, psychological, social, and spiritual needs) through palliative

care services.

Research question 2--What are clinicians' perspectives on the challenges of

addressing patient and FCG QOL dimensions (physical, psychological, social, and

spiritual needs) through palliative care?

Aim 3: Identity needs of palliative care clinicians in order to support patients and FCGs

across QOL dimensions.

Research question 3a--What are the needs of palliative care clinicians' in

supporting patient and FCG across QOL dimensions.

Research question 3b--What are clinicians' perspectives on adopting

and implementing the PCI?

Population and Sample

This study targeted palliative care and oncology clinicians. Purposive sampling

was used to represent a range of disciplines to include nurses, physicians, social workers,

chaplains, and nurse administrators to capture the varied experiences of the team

members. The population for this study included clinicians working at three selected

outpatient oncology settings, and the eligibility criteria were: (a) employment at one of the three selected facilities, (b) licensing in the profession, and (c) having provided care to a lung cancer patient/s.

Research Procedures

Recruitment

Approximately 25 participants were invited to participate in one of three focus group interviews. Clinicians were initially contacted through the organization's email system by the primary principal investigator of the intervention study. The email document described the purpose of the study and that participation was voluntary. Potential participants were asked to email or call the primary researcher of this study if interested in participating. The need for participants at a focus group was announced by the research team at an education session for the palliative care clinicians who had agreed to take part in the PCI study. The investigator of this study was present and briefly outlined her involvement and the purpose of the focus group research. A final email announcement was sent 1 week prior to the first focus group meeting. Recruitment for individual phone interviews was conducted after the completion of the three focus groups to invite clinicians who were unable to attend focus groups. Approximately 10 emails were sent with an information sheet describing the study and that participation was voluntary. Potential participants were asked to email or call the primary researcher of this study if interested in participating in a phone interview.

Consent Process

The Institutional Review Board (IRB) of Loma Linda University deemed this study to be of minimal risk to participants. As an alternative to written consent, an

information sheet was distributed to participants (See Appendix A). Content included on this sheet was the purpose and procedures of the study, and information regarding confidentiality. After having read the information, clinicians understood that their participation in the study was strictly voluntary; that only the study team would have access to the recording of the focus groups; that any names would be de-identified in transcription of the recordings and future publications; and that choosing to participate or not to participate in the study would not affect their employment.

Protection of Human Subjects and Ethical Issues

Ethical approval was given from the Institutional Review Board (IRB) from the three selected facilities and deferred IRB approval was obtained from this University's IRB. Permission to access and communicate with clinicians was obtained from research administrators at the selected facilities. Participation in this study was explained as voluntary. Information sheets were reviewed with participants prior to beginning the focus groups and individual phone interviews.

Focus Group Participation

After receiving IRB approval, one focus group interview was conducted at each of the three research sites. A total of 14 clinicians participated in the three focus groups was (*n=14*), all of whom were members of an interdisciplinary palliative care team; approximately 4-6 participants were present at each session. Group sessions were held in a private, comfortable room at each designated facility and lasted approximately 1 hour. The focus group guide was influenced by the Focus Group Research Methods in Program Evaluation (Krueger & Casey, 2015b, p.13). During the interview, discussions were generated by means of open-ended questions (e.g., what are the strengths of your

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palliative care team in meeting the quality of life needs of lung cancer patients and family caregivers? What are the challenges in meeting patient and family caregiver quality of life needs? What strategies have you used to overcome these barriers? How might this structured palliative care intervention change your current workflow?). The semi-structured focus group guide addressed both targeted components of quality care provided to lung cancer patients and the supportive needs of clinicians implementing the PCI (See Appendix B, Focus Group Guide). Follow-up questions were based on discussions that elicited the perspectives of the diverse health care team. Participants were encouraged to offer examples from their experiences. Focus groups were audio-recorded and transcribed verbatim.

Focus Group Procedure

The focus groups were conducted by a team consisting of a moderator, co-moderator, and a note-taker, each of whom had a distinct role during the sessions. In addition, at least one of the two principal investigators involved in the PCI study were present at each group session. Their specific assignments are described next.

Moderator

The moderator functions as the primary interviewer. Beyond asking questions, the moderator's task is to facilitate discussion within the interdisciplinary team. The moderator invites reflection and dialogue, is sensitive to different personalities and speaking styles, and strives for all voices to be heard. Given the realities of complex group dynamics, a focus group moderator should have abilities above those of a one-to-one interviewer (Holloway& Wheeler, 2010). Fundamentally, moderators must be skilled in guiding group members towards effective interaction.

Krueger & Casey (2015) also specify that the moderator and co-moderator share the following responsibilities during and after focus group meetings:

1. Establishing rapport with participants.

2. Acting as host (welcoming participants and making them feel comfortable).

3. Delivering an introduction: A welcome, a brief overview that defines the purpose of the group, and establishing ground rules.

4. Keeping the discussion on track and participants engaged and involved.

5. Seeking out both cognitive and affective domains to elicit participants' thoughts and feelings on the topic.

6. Bringing the session to a close and summarizing the responses.

Co-Moderator

The nurse researcher involved in educating and assisting the palliative care clinicians with patient recruitment in the intervention study took the role of co-moderator. As co-moderator, her role was to help keep participants engaged and the discussion on track. The co-moderator was also there to clarify and answer questions about patient and family caregiver recruitment and involvement in the PCI.

Note-Taker

The research associate involved in the PCI study assumed the role of note-taker. The function of the note-taker is to assist in capturing the focus group discussion. This task included keeping track of identifying information such as date, time, and location of focus group interview, types of participants (e.g. nurse, social worker, physician, or chaplain), and notable quotes and key points during the focus group interview. While helpful in reconstructing the audio-recorded sessions and for debriefing the event, notes

are for the researcher's use, to complement the verbatim transcripts from the recorded interview; they do not provide sufficient detail to function as the basis for analysis (Holloway& Wheeler, 2010). The note-taker did not participate in the discussion.

Principal Investigators of PCI

At least one of the two principal investigators of the funded project were present at each focus group session. The role of the principal investigators was primarily to observe and to further clarify questions the participants had concerning the intervention phase of the ongoing study. After each focus group, the moderator, co-moderator, and principal investigators of the PCI discussed what was heard and planned for subsequent focus groups.

Focus Group Approach

The focus group research method is characterized by interactions between the participants from which researchers discover how people think and feel towards a particular issue (Holloway & Wheeler, 2010). Specifically, focus groups have the potential to evoke thoughts and opinions about a topic relevant to health care, treatment evaluations, and illness experiences. In this study, the perceptions of the diverse health care clinicians about the quality of life needs of lung cancer patients and FCGs were elicited by bringing nurses, physicians, social workers, and chaplains together for focus group interviews. This method seeks to encourage a safe environment for self-disclosure through careful participant selection, carefully designed questions by a moderator, and the formation of clear ground rules for participants (Krueger & Casey, 2015a).

Focus groups were chosen as the primary qualitative method for several reasons: One, the PCI involves members of an interdisciplinary team rather than any one

professional group, and the focus group method allows for simultaneous input from all members of the collaborative team; two, it allows for members of an interdisciplinary team to elicit distinctive and similar experiences they may encounter. In the process of hearing others' perspectives, participants may become more aware of their own unique perspective and feel empowered to express similarities as well as differences; three, focus groups provide input from three different research sites, thus allowing for further differentiation of the PCI at an organizational level. The purpose of using focus groups in this research was to enhance collaboration and document interprofessional communication, which could provide insight into the perceptions of the interdisciplinary team.

Critiques of the focus group method have advanced the argument that other members may influence participants, possibly causing participants to change their original responses. Responding to a perceived social desirability, some participants may even make up answers in response to certain questions. This could create a false understanding of the subject discussed and the results would have little credibility. To the degree that certain participants take a dominant role during the discussions, there is a real risk for some voices not to be heard (Krueger & Casey, 2015a). Focus group interviews which involve multiple professions may be affected by a power dynamic in which participants from some disciplines may not feel equally empowered to express their true feelings or opinions towards the topic. It is conceivable that participants' work-relationships with other participants in the focus group could influence what they decide to share or not share. Therefore, focus group interviewers have to be well aware of these pitfalls and able to maneuver through complex group dynamics, which, though real, do

not have to invalidate the process. In fact, these points of critique were considered when creating the focus group guide: by first allowing participants to write down their thoughts after being asked a question, and secondly, asking participants to briefly explain their written responses allows for responses that are uninfluenced by the other group members. Each expressed idea was taken seriously and participants were able to draw on these individual thoughts and then discuss them within the focus group. Thus, potential biases were held in check by thoughtfully and intentionally conducting each focus group.

Key Informant Interviews

Key informant interviews were used as an alternative option for clinicians who were unable to attend one of the three available focus groups. Of the 10 recruitment emails sent to potential participants, non-palliative care clinicians (*n=5*) responded. Key informant interviews were conducted by one researcher in the form of individual phone interviews using open-ended questions generated from the focus group guide.

Demographic Information

A demographic questionnaire was completed by each participant and used to assess sex, racial/ethnic identity, age, discipline, and years of experience in the participant's discipline.

Data Analysis

The process of analyzing qualitative data was conducted through conventional content analysis (Hsieh & Shannon, 2005) in order to systematically examine and discover key concepts. Transcripts were coded using a constant comparison method, and categories, subcategories, and text exemplars were identified and verified with the principal investigator of the PCI study. Findings were organized to address the three aims

of this study. Preliminary and final findings were shared with the PCI principal

investigators to better support lung cancer patients in their palliative care transitions and

to prepare clinicians for the implementation of the palliative care intervention.

Content Analysis Approach

Hsieh and Shannon (2005) highlighted approaches to qualitative content analysis

and its use in health-related studies. Qualitative content analysis is one of many research

methods used to analyze transcribed data. Research using qualitative content analysis

focuses on the characteristics of language as communication, paying attention to the

content or contextual meaning of the text. Specifically, conventional content analysis is

used with a study design which aims to describe a phenomenon (i.e., how clinicians

address QOL needs of lung cancer patients and FCGs). This type of content analysis is

typically appropriate when existing theory or research literature on a phenomenon is

limited. Preconceived categories are avoided; instead, the categories and names for the

categories are allowed to arise from the data. Researchers engage themselves in the data

to allow new insights to emerge, representing inductive category development (Hsieh &

Shannon, 2005).

Discussion of Analysis Approach

The advantage of a discussion and analysis approach was to gain direct

information from participants without imposing preconceived theoretical perspectives.

This allowed flexibility, a valuable technique when dealing with participants of various

backgrounds and experiences, which was anticipated in the interdisciplinary team

participating in this study. Challenges of this analysis, as outlined by Hsieh and Shannon

(2005), run the risk of inaccurately representing the data due to an incomplete

understanding of the context and key categories. Credibility and rigor of this approach was established through peer debriefing with study researchers of the PCI study and constant comparison, feedback, revision, and validation of findings.

Analysis Procedure

Procedures outlined by Hsieh and Shannon (2005) were used and built upon during the data collection and analysis phase. Initial analysis of transcripts was conducted manually and organized using MAXQDA (2016), a computer- based qualitative analysis program. An outline of the method used to analyze data is shown in figure 4.
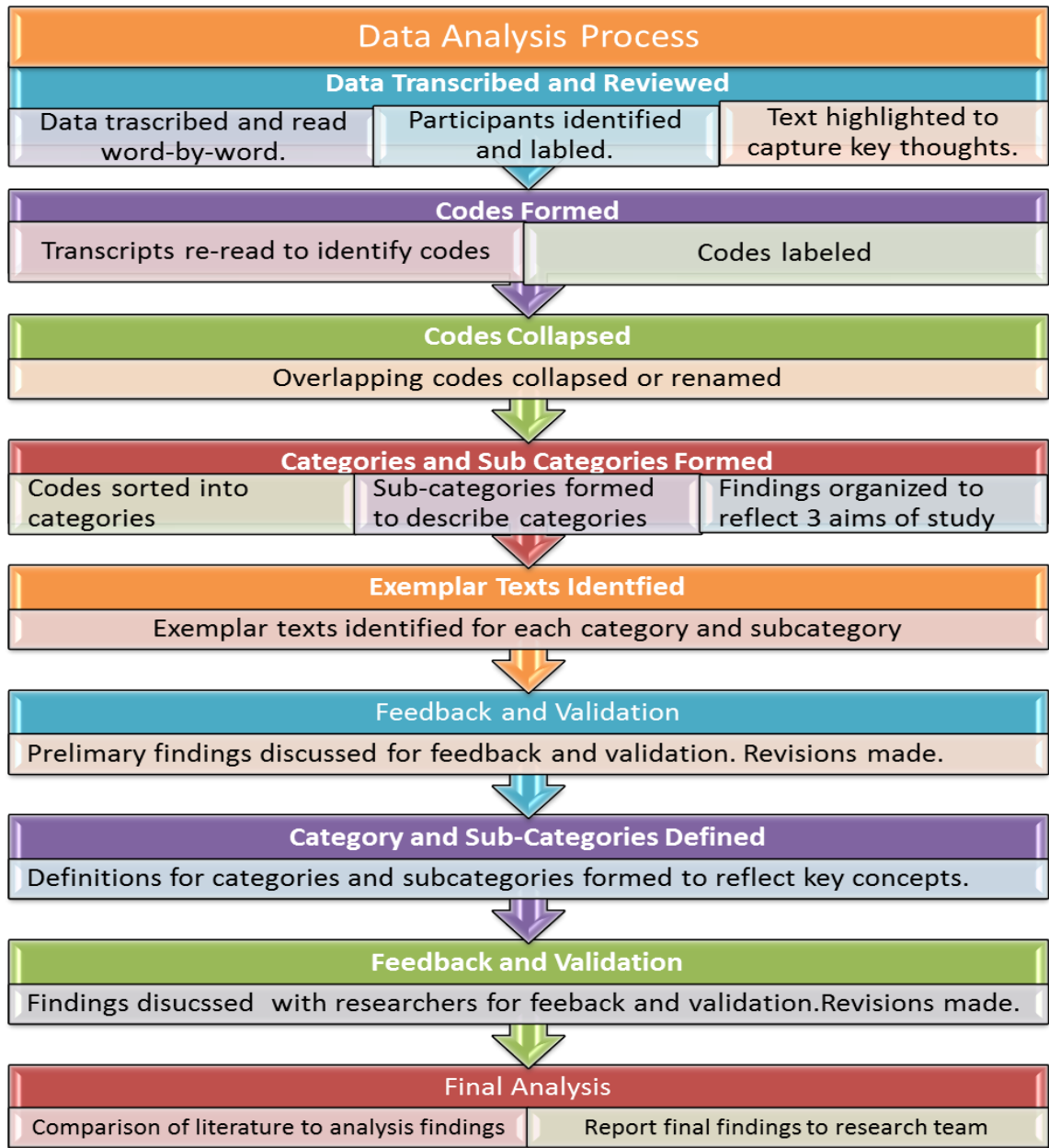
Figure 4. Data Analysis Process

First, data were transcribed and read verbatim by the researcher. Participants in focus groups were identified by profession and labeled for analysis purposes (i.e., nurse1, physician2, social worker). Notes taken during each focus group were used during the review of transcripts. During the initial review, certain key phrases from the transcription

were highlighted that seemed particularly significant. Notes were taken of first impressions and thoughts.

Second, transcripts were re-read to derive codes centered on the responses of participants. Labels for codes were initiated from ideas that emerged and were reflective of more than one key thought. Codes centered on QOL dimensions for patients and family caregivers were an example of initial emerging codes, with overlapping concepts (physical, psychological, social, and spiritual needs).

Overlapping codes with related concepts were collapsed into one code or re-named to meet the description of the text. Codes were then placed into categories which specifically addressed the success and challenges in meeting patient and FCG quality of life needs and the needs of clinicians in adopting a new PCI.

Codes were then sorted into categories based on their relationship and further broken down into subcategories which enlightened the identified category. Each category and subcategory was then acknowledged and organized into tables to reflect the three aims of this study, and exemplar texts were formed for each category and subcategory. Definitions for categories and subcategories were formed to reflect key content described in the text.

Codes, categories, sub-categories, and text exemplars were examined for feedback and validation with two additional researchers (principal investigators of PCI study) during preliminary and final stages of the analysis to improve accuracy and enhance rigor, credibility, and internal validity of the findings. Revisions were made during this process and reported frequently to the PCI research team.

CHAPTER FOUR

RESULTS

Characteristics of the Study Sample

Three focus groups and five individual phone interviews with key informants were conducted. A total of 19 palliative care and oncology clinicians were involved in this study (i.e., physicians, nurse coordinators, nurse administrators, social workers, and chaplains). Although oncology clinicians were invited to focus group sessions only palliative care clinicians attended the focus groups. Participation included 14 clinicians from three interdisciplinary palliative care teams (one palliative care team per site). Clinicians who were unable to attend focus groups were invited to participate in individual phone interviews to elicit additional perspectives. Five clinicians were then added to this study. This included one oncology physician, a thoracic surgeon, two oncology nurses, and one chaplain. All nurses in this study were registered nurses.

Table 1 shows the demographic characteristics of the study sample, which was composed mostly of Caucasian non-Hispanics (47.4%), followed by Asian Pacific Islanders (26.3%), and Latino or Hispanics (21%). A higher percentage of females were represented (63.2%). Mean age and years of experience varied slightly between disciplines with a mean range of 47.5 to 52 years. Mean years of experience per discipline ranged from 8.5 years to 19.8 years.

Table 1. Characteristics of health care clinicians who participated in focus groups and interviews

Study Sample (N=19)		
Variable		%
Focus groups or Phone Interview		
Focus group	14	73.7
*Phone interviews	5	26.3
Sex		
Male	7	38.8
Female	12	63.2
Racial/ Ethnic Identity		
African-American	1	5.3
Asian/ Pacific Islander	5	26.3
Caucasian (non-Hispanic)	9	47.4
Latino or Hispanic	4	21
Discipline		
Physician/Oncology	1	5.3
Physician/Thoracic Surgeon	1	5.3
Physician/Palliative Care	3	15.8
Nurse/Oncology-Coordinator	2	10.5
Nurse/Palliative Care-Clinician	6	31.6
Nurse/Palliative Care-Administrator	2	10.5
Chaplain/ Palliative Care	2	10.5
Social Work/ Palliative Care	2	10.5
	M	*SD*
Mean Age by Discipline		
Nurse	47.5	23.6
Physician	50	24.9
Social Work	52	25.9
Chaplain	51.5	25.6
Mean Years of Experience in Discipline		
Nurse	15.2	24.7
Physician	19.8	32,2
Social Work	18	29.3
Chaplain	8.5	13.8

*Individual phone interviews were conducted with one oncology physician, one thoracic surgeon, three oncology nurses, and one chaplain.
-All nurses in study were registered nurses (RN).

Review of Interview Findings

The overall responses of oncology and palliative care clinicians were accepting of implementing the palliative care intervention. This finding was supported by all three focus group interviews with palliative care teams, as well as by five individual phone interviews with oncology clinicians. Another notable finding was that all three palliative care teams involved in the study were supportive and genuinely appreciative of each member of the team. This observation was evidenced by clinicians speaking highly of their fellow team members during the three focus group interviews, supporting an interdisciplinary team model for patient care.

The analysis of interview transcripts resulted in emergent codes, categories, and subcategories, which were recorded manually and further refined using MAXQDA (2016), a computer-based qualitative analysis program. Categories and subcategories were derived from the data and then organized according to each aim of this study: 1) Identify clinicians' perspectives on how to best address lung cancer patient and family caregiver QOL needs through palliative care services; 2) Identify clinicians' perspectives on challenges in meeting lung cancer patient and family caregiver QOL needs through palliative care services; and 3) Identify needs of clinicians in order to support patient and family caregiver QOL needs through palliative care services and the adoption of a PCI.

Categories for Aim 1 and Aim 2 addressed useful practices and challenges in the following areas: (a) early palliative care; (b) interdisciplinary care planning; (c) symptom management; (d) addressing psychological needs, (e) addressing social needs; and (e) providing culturally respectful care, to include spiritual care. Two major categories derived from Aim 3, identifying the needs of palliative care clinicians in the adoption of a

PCI: 1) clinician education needs and 2) organizational challenges. Five subcategories were identified to support responses, which further described content-focused categories; for example, support in providing spiritual care for patient and family caregivers was a subcategory, which identified clinician educational needs. Emergent categories, subcategories, text exemplars, and definitions of each research aim are summarized in tables 2, 3, and 4 of this chapter. Examples of codes are presented for various subcategories to further support content.

Useful Practices in Addressing Lung Cancer Patient and FCG QOL Needs

Clinicians were first asked about the strengths of palliative care services in addressing lung cancer patients and family caregivers QOL needs (i.e., what do you feel your team does well with meeting the QOL needs of patients with lung cancer?). During focus group sessions, clinicians were given a table that organized the four QOL dimensions into four quadrants (See Appendix). Prior to beginning the discussion, each participant was asked to fill in each QOL quadrant, listing "three things that you feel your palliative care team does particularly well in improving patients and family caregivers needs addressing their physical, psychological, social, and spiritual well-being." This method allowed participants to reflect on each dimension and develop individual perspectives prior to focus group discussion. Participants involved in phone interviews were asked the same open-ended questions, allowing for individual discussion of each dimension and simultaneously contributing to patient and FCG quality of life needs. After individually identifying current strengths on paper, each participant shared their responses with the group. Individual contributions triggered group discussions which identified both areas of agreement and differences. Participant interaction was also

stimulated by interview questions which probed different aspects of the topic using open-ended questions.

Early Palliative Care

Early palliative care for lung cancer patients was defined as beginning at stage II or shortly after, or before oncology treatment began. Introducing palliative care early in the trajectory of illness for lung cancer patients was done to address and improve QOL. Practices used by clinicians included normalizing the referral process to decrease the stigma of palliative care, having a working relationship between oncology and palliative care, facilitating buy-in from clinicians and patients who recognize the value of palliative care, and being proactive in the referral process. Normalizing the referral process to decrease the stigma of palliative care was defined as presenting services to the patient in a way that decreased their fears and cleared up any misunderstandings about palliative care. Clinicians explained two interventions used to normalize the referral process: referring all patients when they are first diagnosed (i.e. *"I really like what we've done, we've taken the stigma away by basically, everybody gets referred, which I think is a huge, huge step."* Nurse) and using the word "support" or "support team" to define palliative care:

> I definitely use different words based on if I get a client that's really concerned that we're giving up. Then I use the words "support team"… I'm not trying to give up the palliative word, but it gets them to answer the phone…. (Nurse).

Having a working relationship with the oncology and palliative care teams was described as an important of initiating palliative care early in the patient's disease trajectory. Establishing rapport between the palliative care and oncology teams and physically "embedding" or "integrating" the palliative care and oncology departments

enhanced the working relationship and facilitated early referrals of patients to palliative care. Buy-in from both clinicians and patients was seen as playing a role in the successful implementation of early palliative care. Clinicians reported that being proactive in identifying patients who may benefit from palliative care services eased the transition of patients from oncology care alone to adding palliative care to their treatment regimen.

Interdisciplinary Team Planning

Interdisciplinary team planning was described as an essential element in addressing patient and family caregiver QOL needs. Interdisciplinary team planning is defined as palliative care teams and oncology teams working together to meet the patient's quality of life needs and care planning, to include an individualized treatment plan which draws on the expertise of each discipline and specialty. This was well illustrated by a chaplain's response during one of the focus group sessions:

> Giving them that support and using the interdisciplinary model… If there is a psychosocial issue, we have a social worker there to sort of jump in and see if we can pick that apart, and the team allows that…I will use the term 'dance'. If there is a spiritual thing that comes up, I am there. The doctor and the nursing team are great at assessing the physical part. (Chaplain)

Clinicians discussed the importance of interdisciplinary team meetings in preparing a comprehensive plan of care. In addition, including family in care planning provides an opportunity to participate and ask questions of the interdisciplinary team. Attention to family dynamics is important in understanding how to best incorporate the family member into the plan of care. An oncology clinician gave an example of how family is involved in care planning:

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Having the discussion…what's going on with the patient, what the workup needs to be, and what the plans are, what are the options…risk/benefit discussion…I give them the opportunity to ask questions and participate. We try to feel out the dynamic between the patient and who else is there with them. (Physician)

Symptom Management

Participants in all three focus groups sessions and five interviews agreed that palliative care services successfully addressed the physical needs of patients through symptom management, including pain management. Hence, "symptom management" was an emergent category from the texts. Clinicians defined symptom management as addressing physical symptoms of patients related to disease process or treatment. Clinicians emphasized two ways in which they provided symptom management: providing patients with direct access to clinicians (i.e., "The follow up with accessibility…we reinforce as much as we can to give us a call if something doesn't feel well." Nurse); and anticipating patient needs and planning for immediate response (i.e., "Maybe they don't have any symptoms today but we know what it potentially will look like, so getting them kind of prepped for that." Physician). These two aspects were viewed as key elements in managing patient symptoms.

Addressing Psychological Needs

Addressing the psychological needs of patients with lung cancer was defined as focusing on patient and family mental well-being or any related distress associated with the illness. Psychological needs associated with illness were well supported in patients with lung cancer and their family caregiver, and emerged in virtually all interviews. Responses in which specific psychological needs of patients and family were discussed were placed in this subcategory. Clinicians who recognized the importance of meeting a

patient's psychological needs described emotional responses by patients and caregivers,

as seen in the following focus group discussion:

Nurse: When they come in, they are in shock, a lot of emotions, fear and uncertainty.
Physician: Maybe, you know, they are grieving; you expect them to be anxious, for the
patient who has a new diagnosis of cancer.

Providing education on psychological symptoms such as anxiety, grief, and

depression and resetting the patient's expectations are two ways of responding to

patients' and FCGs' psychological distress. Resetting expectations in the goals for

treatment and life after a diagnosis of lung cancer was highlighted in the following

response of a palliative care physician:

> Also in terms of a psychological intervention, resetting their expectations
> whenever they are diagnosed with advance disease and are referred to palliative
> care, the expectation is that they are going to be dead next week…so sometimes
> bringing that out into the open that that is what many patients think and no, that is
> not likely to happen. And come on, let's get going, you have a life to live. And it
> helps reset their whole expectations about their lives and their treatment and their
> goals for…'what am I going to do with myself now? (Physician)

Addressing Social Needs

Addressing the social needs of patients and family caregivers was defined as

identifying and connecting patients and family to financial resources and fostering

relationships including family, clinician, and peer support. Psychological and social

needs were sometimes addressed together as psychosocial needs. While the role of the

social worker appeared particularly important in this matter—especially in situations

where professional intervention is warranted—all clinicians identified addressing social

needs as an important role. Relationship building in which clinicians offer social support

by "being there" and getting to know the patient is vital in building trust and

communication with the patient and family. This was stressed as a key factor by

clinicians. Providing financial support, in-home support, and transportation for patients and FCGs are aspects of care coordination that helped meet their social needs. Lastly, offering cancer-focused support groups for patients and counseling FCGs with the resources needed to support them were other means of supporting social needs.

Addressing Spiritual Needs

Clinicians encountered spirituality in the context of seeing patients in distress and suffering (i.e. "you used the term 'suffering' and I think that probably captures better the spiritual dimension of the illness." Physician). Clinicians can ask patients what usually helps them get through hard times. When patients express that their faith helps them with difficult life circumstances, clinicians can encourage patients to draw on their spirituality to facilitate coping, to foster acceptance of their disease, and find meaning and hope in the context of their religious beliefs.

Clinicians reported that they addressed spiritual needs by assessing them using a formal assessment tool or by asking patients questions about their spirituality or spiritual background. Enquiring about patients' beliefs sometimes leads to a meaningful conversation that can gives clinicians a way to provide culturally respectful spiritual care without imposing clinicians' beliefs on the patient. As an example of a formal assessment, clinicians cited a psychosocial tool, a formal questionnaire that incorporates questions that probe into patients' spiritual well-being. Clinicians explained that the social worker at each site conducts these more-targeted psychosocial assessments for patients referred for social or psychological needs. Other clinicians (e.g. chaplains, physicians, and nurses) involved in this study gave examples of standard informal questions they use to assess patients' spirituality as it pertained to coping with their

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illness. An example of standard informal questions used by clinicians was: "What helps you get through your day? What helps you kind of cope with all of this? Some people say faith is important." (Physician). A chaplain involved is this study stated "asking what is your religious background opens up the conversation." (Chaplain)

Besides actively assessing spiritual needs in an attempt to provide culturally respectful spiritual care, clinicians said they sometimes allowed patients to initiate a spiritual conversation. Building on an established relationship of trust, they seek to listen to the patient and work with their religious beliefs.

In addition, interdisciplinary team support is perceived as very helpful--drawing upon the assistance of a team member such as a chaplain or social worker. In providing culturally respectful care, clinicians explain they intentionally use language congruent with patients' beliefs and their view of God or other higher power. This practice also helped with clinicians' personal comfort with religions they do not identify with, as reflected in the following statement:

> I have standard, neutral prayer phrases that I've used before that work really well with me, and with families, even if it's something that's a religion outside of what I'm comfortable with, I make it very neutral kind of prayer statements. (Social Worker)

More often, clinicians identified interventions other than prayer, such as being there and listening to the patient. Other interventions included meditation, music, and distracting them, as described by an oncology nurse: "Meditate…Listen to music you like, just to get their heads out of the disease" (Nurse).

The support of the interdisciplinary team was important in addressing patient and family caregiver spiritual needs. Referrals for spiritual support were most often made to the social worker or chaplain, especially when the clinician was not comfortable with

addressing the spiritual dimension or felt it was outside of their scope of practice, such as in the following example: "Pressing psychological issues or spiritual, I refer them to the social worker because I'm not comfortable talking to them about spiritual and religious issues." (Nurse). Other clinicians, such as the oncologist, referred patients to the social worker and nurse to help address their spiritual needs: "I don't ask them directly what is your faith and spirituality but my case manager, social worker, and the charge nurse does."

Chaplains were not official members of the palliative care interdisciplinary teams at the three outpatient sites. However, staff at one site explained they were fortunate to have a chaplain who extended services to their outpatient oncology clinic, such as in the following statement by a palliative care nurse: "Our chaplains are unofficially part of the group…When we see patients and families, she really knows what questions to pinpoint and ask." (Nurse). This chaplain was also present at the focus group session with the palliative care team and was supportive of using an interdisciplinary team model, with the chaplain playing a significant role in addressing the spiritual dimension.

It was observed during this focus group session, the only focus group that involved a chaplain, that conversations concerning the spiritual needs of the patient and family were referred to or addressed by the chaplain. The involvement of the chaplain at this focus group was noticeably different from the sites without chaplains on the interdisciplinary team.

Summary of Useful Practices in Meeting Patient and FCG QOL Needs

Participants from each site expressed positive aspects of their current palliative care structure in meeting patient and family caregiver needs prior to implementing phase

II of the PCI study. Categories and subcategories emerged which described how team members worked together to meet patient and family QOL needs (see Table 2). Buy-in and support from the palliative care team and referring clinicians was a significant element in referring lung cancer patients early in the trajectory of illness. Clear communication about the plan of care between the oncology and palliative care groups was seen as important to successful care. Interdisciplinary team planning which incorporated care planning was also viewed as a vital component to meeting the quality of life needs of patients and caregivers.

Addressing each dimension of quality of life was discussed--physical, psychological, social, and spiritual. Anticipating needs and keeping patients and family informed were considered vital in symptom management. Relationship building was discussed throughout each focus group and individual interview. Attention to spiritual needs was seen as important in helping patients and family cope and find meaning in illness. Specifically, assessing patients' spiritual needs by asking questions concerning their spirituality was necessary in providing culturally sensitive spiritual care without imposing their personal beliefs on the patient. Clinicians often explained addressing spirituality as taking the support role, as well as consulting with members of the interdisciplinary team such as a chaplain or social worker.

When the strengths of palliative care in meeting each QOL dimensions were discussed, meeting patients' spiritual needs was perceived as more difficult by clinicians than meeting other quality of life dimensions.

Table 2. Aim 1 Emergent Categories: Clinicians' perspectives on how to address patient and family caregiver QOL dimensions.

Categories/Description	Sub-categories: Definition	Sub-category: Text exemplar
Early palliative care for lung cancer patients was defined as starting palliative care at stage II or shortly after or before treatment.	**Normalizing the referral process to decrease "stigma" of palliative care:** Relating palliative care to patients in a way that decreases fears and misunderstandings associated with palliative care (i.e., the clinician giving up on the patient or services being only for the hospice/dying patient). **Having a working relationship between oncology and palliative care teams**: Having a rapport between the palliative care and oncology teams. Having the palliative care and oncology departments physically "embedded" or "integrated" assists with the working relationship, communication, and early referrals of patients to palliative care. **Buy-in:** The support of palliative care by clinicians and patients who recognize the value of palliative care **Being proactive**: Identifying patients who may benefit from palliative care services and actively reaching out to patients and clinicians.'	**Normalizing the referral process to decrease "stigma" of palliative care:** <u>Referring all patients:</u> "I really like what we've done, we've taken the stigma away by basically, everybody gets referred, which I think is a huge, huge step." (Nurse) **Having a working relationship between oncology and palliative care teams**: "That's one of the main areas we have, a partnership in place with oncology where we were getting the threes and fours, and we learned twos would be included since the study started." (Nurse) **Buy-in: "**When the doctor is the one that's referring, there is a buy-in from the patient." (Nurse) **Being proactive:** "Proactively…not just waiting for things to happen, but actually reaching out and prioritizing who are the high need patients." (Social Worker)

Interdisciplinary planning: Palliative care, oncology, and other clinicians working together to meet QOL needs and plan care for the patient.	Interdisciplinary team meetings: Meeting as an interdisciplinary or "multi-disciplinary" team to plan care for the patient.	Interdisciplinary team meetings: "So, I think that is the most important part of what we do is, sitting down with almost every patient, as a team." (Social Worker)
	Including family in care planning: Including family in the discussion and planning for the patient.	Including family in care planning: "We're having the discussion with family about what's going on with the patient, what the workup needs to be, and what the plans are…" (nurse)
Symptom management: Addressing physical symptoms of patients with lung cancer related to disease process or treatment.	Having direct accessibility to clinicians: Clinicians being available to patients to answer questions, address needs, and follow up with the patient.	Having direct accessibility to clinicians: "I think having a number for them to call Monday through Friday, regarding any questions that they have. Whether symptom- management or just general questions." (Nurse).
	Anticipating needs and immediate response: Clinicians anticipating the patients' needs and educating on what to expect regarding symptoms. Providing a fast response and plan of action.	Anticipating needs and immediate response: "Maybe they don't have any symptoms today but we know what it potentially will look like, so getting them kind of prepped for that." (Physician).
Addressing psychological needs Addressing patient and family mental well-being or any related distress associated with illness.	Recognizing psychological needs: Identifying psychological distress that may be associated with the patients' illness and recognizing it as a need that should be addressed. Examples of psychological distress are grief, uncertainty, anger, resentment, isolation, and anxiety. Educating on psychological symptoms:	Recognizing psychological needs: "Maybe, you know, they are grieving you expect them to be anxious, for the patient who, has a new diagnosis of cancer." (Physician) Educating on psychological symptoms:

	Providing support and education to keep the patient and family informed on symptoms such as anxiety, grief and depression. **Resetting expectations:** Helping patients reset their goals for treatment and their lives after diagnosis.	"A lot of it is education some of…and also just ways to reduce anxiety. I focus a lot on that with these particular patients." (Nurse) **Resetting expectations:** "Also in terms of a psychological intervention, resetting their expectations. Whenever they get diagnosed with advance disease and get referred to palliative, the expectation is that they're going to be dead next week… And it helps reset their whole expectations about their lives and their treatment and their goals…" (Physician)
Addressing social needs: Addressing patient and family caregiver social needs by identifying and connecting them to financial resources and fostering relationships.	**Relationship building:** Clinicians offering social support by "being there" and getting to know the patient. **Care coordination:** Providing financial support, in-home support and transportation for patients and family caregivers. **Support groups and counseling:** Offering cancer focused support groups and counseling for patients and family caregivers.	**Relationship building:** "We start the foundation of a relationship with them." (Physician) **Care coordination:** "We specifically ask about financial support, transportation needs…some in-home services if needed…" (Physician) **Support groups and counseling**: We have a lot of cancer-focused support groups." (Nurse)

Addressing spiritual needs Addressing patient and family caregiver spirituality related to illness. Spirituality can be used to assist with coping, acceptance, and finding meaning and hope in the context of religious beliefs. Spirituality may be associated with "distress" and "suffering," or it may have a "positive" impact on the patients' illness experience	**Assessing spiritual needs**: The assessment of spiritual needs through a formal assessment or asking patients questions concerning their spirituality or spiritual background.	**Assessing spiritual needs**: "Part of our psycho-social assessment in every consult does have the spirituality included, and sometimes it comes up very naturally." (Social Worker) "What helps you get through your day? What helps you kind of cope with all of this?" Some people say faith is important." (Physician)
	Providing culturally respectful spiritual care: Meeting spiritual needs in an open way.	**Providing culturally respectful spiritual care:** "I can remember having a Muslim family come and get me to pray with them and just kind of modifying it to where it's not going to be offensive to what their beliefs are. **But they trusted me**, so that nice, you know." (Nurse)
	Clinician provided spiritual support: Interventions clinicians provide in order to support patients spiritually.	**Clinician provided spiritual interventions:** "Meditate…Listen to music you like, just to get their heads out of the disease and what's going on with that. Refocus them a little bit." (Nurse)
	Interdisciplinary team support: Addressing spiritual needs through the assistance of a member of the interdisciplinary team such as a chaplain, social worker, nurse or another member of the team.	**Interdisciplinary team support:** "Pressing psychological issues or spiritual, I refer them to the social worker because I'm not comfortable talking to them about spiritual and religious issues." (Nurse)

Challenges Meeting Lung Cancer Patient and FCG QOL Needs

Perceived challenges faced in care delivery and QOL needs of lung cancer patients and FCGs in introducing palliative care, interdisciplinary care planning, addressing social needs, and providing culturally respectful care to include spiritual care.

Challenges in the Introduction of Early Palliative Care

While starting palliative care early in the disease trajectory was seen as an essential component of meeting patient and family caregiver QOL needs, the study also challenges in introducing and referring lung cancer patients to services. Differences were found across sites about when to refer patients to palliative care. Further, there were no specific criteria used for referring patients.

One of the challenges discussed by clinicians was introducing patients to palliative care services (i.e., "The challenges that we really have is introducing them to service." Nurse). This involved the referring clinician, patient, and family's beliefs about palliative care. Challenges in introducing palliative care were related to a perceived stigma about palliative care, resulting in hesitancy to take part in palliative care services. The stigma was mainly related to misunderstanding or lack of knowledge about palliative care. Specifically, patients feared a palliative care referral meant clinicians had "given up" on them. Clinicians found themselves facing a mixture of misperceptions (i.e. palliative care equaled hospice; palliative care was for dying patients) and misinformation (i.e. palliative care as an inscrutable, undefined "black box"). There was further discussion on the need for education on palliative care services for patients, families, and clinicians (e.g. internal medicine and general medicine specialties):

> **Nurse 1:** On the education side, we're still a black box I think. We're getting out there to educate with internal medicine with all the sub-specialties.

Nurse 2: I agree that with the stigma around the black box….”

The challenge of the patient, family, or clinician not being ready for palliative care services, was discussed with a palliative care team:

> **Nurse 1:** Aside from the word 'palliative,' they're just not ready…they want time to think about it and, and they want it to be aggressive.
> **Nurse 2:** That's a big one. Not ready. They're not ready.
> **Physician:** But then when are they ready? If you don't start from the beginning, when do you step in?
> **Social Worker:** That's worse, and then they are in hospice in a week or two.

Identified explanations associated with "not being ready" included: The patient, family, or clinician wanting more time to make decisions or continue with current treatment, patients living longer with lung cancer, and patients not experiencing symptoms. Patients living longer with lung cancer are due to advancements in medications and treatment that prolong the progression of the disease. With patients remaining in the early stages of the disease, physicians are holding off on palliative care referrals until the cancer has progressed or the patient becomes symptomatic. This concept was expressed in the following response by a palliative care nurse:

> There are so many more different medications now. Even for lung cancer patients…even the doctors are saying that all these patients we thought were end stage, are really not end stage. End stage meaning, less than a year to left to live, and they're living a lot longer. So, I think because of that, a lot of the doctors are holding off on referring the patients. (Nurse)

An oncology nurse explained that introducing patients to palliative care who were not experiencing symptoms during the early stages of lung cancer was a challenge, such as a patient with stage II lung cancer (i.e., "Or they just say, 'I'm not ready for it yet.' Because for stage II, most of them are asymptomatic." Nurse). However, introducing palliative care late in the trajectory of the illness caused a delay in supporting patient and FCG quality of life needs along with treatment. As described by a social worker in the

focus group exchange above: "That's worse, and then they are in hospice in a week or two (Social worker). Clinicians perceived this as a challenge particularly when the palliative care team was consulted at late stages of the patients' illness or as a quick fix for pain control when other interventions had failed.

Challenges in Interdisciplinary Care Planning

Interdisciplinary care planning was seen by clinicians as an important component of addressing patient and FCG QOL needs. However, when encountering obstacles in interdisciplinary communication, such as the division of care planning goals and inconsistency in interdisciplinary team meetings, challenges did arise. Division in care planning was described as a disconnect between palliative care and other clinicians. A working relationship with the oncology team was seen as vital in communicating and understanding the goals of the patients' care:

> I feel like sometimes there's a disconnect, for me personally, between the palliative care, what the plan is and what's going on with the patient, and the medical side of it, the treatment side…. I feel like maybe somebody, somehow, a connection between those two teams. Because they work together, but they kind of work separately. (Nurse)

Differences in team meetings were identified between the sites and seen as challenges. These differences, including meeting schedules, frequency, and tone were mostly found among non-palliative care members. That said each team at all three sites met at least once per day to discuss patient needs.

Challenges in Addressing Social Needs

Challenges in addressing patient and family caregiver social needs were discussed in the focus groups and individual interviews, specifically in referrals to financial resources and support groups. Although clinicians acknowledge patient and caregiver

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support groups as helpful in meeting social needs, the lack of these support groups was

seen as a problem, as noted by a palliative care social worker:

> We don't, at this point, have any support groups, that's something we're hoping to start…it's just a hard thing for patients to find and they're looking for them. (Social worker)

Challenges in addressing patient and family financial needs during treatment were also a

concern of an oncology-staff nurse, but were not mentioned in focus group sessions with

the palliative care team.

> Well we have to on practically a daily basis explains financial issues with the patients because I deal a lot with the oral drugs that have a big price tag along with them for the Medicare population. And I've had to deal with patients who've lost their coverage in the middle of treatment that I've had to help them with that because we don't have a specific person dedicated to the financial, some of the financial concerns. (Nurse)

This challenge, although not reported as a challenge of palliative care services, sheds

light on the difficulties lung cancer patients face and the financial support they require

across the spectrum of medical care. A lack of dedicated staff available to discuss

patients' financial concerns could attest to access to resources and the barriers clinicians

face while providing financial guidance.

Challenges in providing culturally respectful care

A major concern of both palliative care and oncology clinicians were challenges

in addressing patient and family caregiver spiritual needs in an open, non-threatening

manner, and advocating for the patient. The QOL dimension of spirituality was viewed as

more difficult to address compared to the physical dimension ("Even asking us to identify

it is difficult... we're so often doing the physical." Nurse). How to ask about spirituality,

feeling uncomfortable with spiritual issues, and prioritizing spirituality in the plan of care

were three identified concerns. Clinicians were concerned about not knowing what

questions to ask, or whether asking questions about spirituality was appropriate within their clinical role (e.g. "I don't know that I can actually ask people about their spirituality… in an unbiased fashion." Physician). While some clinicians used informal questions to probe their patients' spiritual needs, questions about spirituality outside of the patients' religious affiliation was perceived as a challenge for many (e.g. "It's usually just seeing if they're religiously affiliated, but not anything beyond that, which is already in their chart." Nurse). Lack of comfort with spiritual issues was mentioned by many of the clinicians (e.g. "I think it's just an area that we're just not as comfortable with because we haven't really been touching on that." Nurse).

Challenges in addressing spirituality were also related to prioritizing spirituality into the plan of care. Clinicians explained that spirituality was often addressed last or not all (e.g. "There is still so much other information to go over with the patient, there is not time to talk about spirituality" Physician; "I have to explain the disease process…I don't have the time to talk about God." Nurse).

Lastly, challenges in providing culturally respectful care included clinicians' responsibility for advocating for the patient's wishes while also assessing the cultural norms and dynamics of the patient's family. The following texts were derived from two separate focus group discussions and used as examples to describe this challenge:

Nurse: It triggers feelings within us, because we want to be the patient's best advocate, and what does that look like?

Nurse: I think some cultures don't trust our information. They think we're keeping some of the information away from them, that we're keeping them away from the hospital. They sometimes they just feel comfortable in the hospitals and I feel like we are the barrier who have to keep them from getting that full care in, at the end of life. Even though it may not help, but they just feel like it's their right.

Summary of Challenges in Meeting Lung Cancer Patient and FCG QOL Needs

Introducing palliative care, planning interdisciplinary care, addressing social needs, and providing culturally respectful care were perceived as direct challenges in meeting lung cancer patient and family caregiver QOL needs through palliative care services. The stigma associated with palliative care was seen as a major challenge in introducing palliative care. Clinicians felt that an understanding of palliative care and the types of services offered was vital for the patient, family caregiver, and healthcare clinician. The readiness of patients and referring clinicians to discuss palliative care also played a role in referring patients to palliative care. Communication with the interdisciplinary teams or other teams involved in the patients' care was also a challenge, especially when discussing the goals of care. Palliative care specialists felt a working relationship with the oncology team was vital in the communication and understanding of the patient's care goals.

Addressing psychological and social needs was often a challenge due to the availability of resources, such as the lack of support groups for patients and family caregivers. Both palliative care and oncology clinicians felt addressing patient and family caregiver spiritual needs in an open, non-threatening manner was important, as well as advocating for the patient while honoring the cultural needs and dynamics of the family. (See Table 3 for summary of emergent categories, subcategories, and text exemplars).

Table 3. Aim 2 Emergent Categories: Clinicians' perspectives on the challenges in addressing patient and family caregiver QOL dimensions.

Categories/ Definition	Subcategories/Definition	Sub-category/Text Exemplar
Challenges in the introduction of palliative care Challenges in introducing and referring patients to palliative care- related to referring clinician, patient and family beliefs, readiness and goals	**Stigma of palliative care:** "Push-back or "holding off" on palliative care referrals due to fears, misunderstandings, or lack in knowledge associated with palliative care (i.e. the clinician giving up on the patient, services being only for the hospice/dying patient, not knowing what palliative care is). **Readiness:** Push back or holding off of clinician' or patients' due to them "not being ready." This may be due to many factors. Factors related to readiness were identified and coded. Codes identified included: Wanting more time, living longer with lung cancer, not having symptoms (asymptomatic).	**Stigma of palliative care:** "A lot of the doctors are holding off on referring the patients to us because, sometimes the patients will think, "well if you refer me to palliative care, does that mean you're giving up on me?" So, because of that stigma, uh, the doctors, I think, are holding off." (Nurse) **Readiness:** "That's a big one. Not ready. They're not ready." (RN). "But then when are they ready? If you don't start from the beginning, when do you step in?" (Physician) "That's worse than they are in hospice in a week or two." (Social Worker)
Challenges in interdisciplinary care planning: Challenges in interdisciplinary care planning were related to division amongst the palliative care team and variance in interdisciplinary team meetings.	**Division in care planning:** A "disconnect" between palliative care and clinicians caring for the patient. **Variance in interdisciplinary team meetings:** to include frequency of meetings and disciplines included.	**Division in care planning:** "I feel like sometimes there's a disconnect, for me personally, between the palliative care, what the plan is and what's going on with the patient. (Nurse) **Variance in interdisciplinary team meetings:** "It's not formal. You do the team part based on what each of the members say…and you read through the chart" (Nurse)

Challenges in addressing social needs: Challenges in addressing patient and family caregiver social needs by identify and connecting them to financial resources and support groups	Lack of support groups: Challenges in providing social support though support groups to patient and families.	Lack of support groups: "We don't, at this point, (have) any support groups, that's something we're hoping to start…it's just a hard thing for patients to find and they're looking for them." (Social Worker)
	Financial concerns: Challenges addressing patient or family financial needs during treatment.	Financial Concerns: "I've had to deal with patients who've lost their coverage in the middle of treatment that I've had to help them with that because we don't have a specific person dedicated to some of the financial concerns." (Nurse)
Challenges in providing culturally respectful care: Challenges in meeting patient and family caregiver needs related to barriers such as meeting spiritual needs and providing cultural sensitive and ethical care.	Challenges in providing culturally respectful spiritual care: Challenges in addressing patient and family caregiver spiritual needs in an open approach. Advocating for the patient: Challenges in advocating the patients' wishes while taking into consideration cultural norms and family dynamics.	Challenges in providing culturally respectful spiritual care: "So even asking to identify it. We're so often doing the physical." (Nurse) Advocating for the patient: "Even in the consult, in the outpatient setting, she deferred to the son, whatever the son wanted to do, you know, even though she was kind of leaning more towards no treatment. I try to encourage them to write it out, an Advance Directive." (Nurse)

<center>**Clinicians' Perceived Supportive Needs**</center>

Clinicians were asked about their needs regarding palliative care issues to better meet the needs of patients and their family caregivers. Researchers also asked clinicians about their needs and concerns in adopting the new PCI into their current practice. Clinicians discussed the educational needs of non-palliative care clinicians to enhance buy-in and increase early palliative care referrals, and in addressing the spiritual needs of patient and family caregivers. Organizational challenges were identified, with similarities and differences noted between each site. Staffing constraints and workload, time constraints, and the work environment were considerations discussed within the organization (See Table 4 for a summary of emergent categories).

Education Needs

Spiritual well-being is one aspect of a palliative care intervention, both in measuring the well-being of patients and caregivers, and providing clinicians with education about the spiritual dimension in patient care. Support and education in providing spiritual counseling for patients and family caregivers was acknowledged as a concern for many clinicians, particularly in the palliative care teams involved in the PCI. Many welcomed the idea of receiving training and support in the areas of spirituality (i.e. "I would welcome help in that area. If we can recognize it I guess is the problem" Nurse; "We need proper training to address it" Nurse).

Palliative care education was discussed as an intervention to increase organizational buy-in and palliative care referrals for lung cancer patients, especially for non-palliative care clinicians. Again, palliative care was seen as "a black box," described by a palliative care nurse in a focus group session: "On the education side, we're still a

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black box I think. We're getting out there to educate with internal medicine with all the subspecialties. I would say, organizationally, even getting buy-in to educate, staff" (Nurse).

Organizational Challenges

The lack of adequate staffing was seen as interfering with care and follow up of patients' needs, including their psychosocial and spiritual needs. These concerns arose at one site and from multiple disciplines. Social workers also reported challenges with patient's psychological and social follow-up. Clinicians strongly suggested this challenge was related to not having enough social workers to follow-up with patients after a psychological assessment, or after offering the patient outside resources and support. This challenge fell under the category of organizational challenges and was exemplified by a social worker and nurse administrator in two separate focus groups:

> **Social Worker:** As one social worker…it's just a limitation, is that I can only do what I can do…. I'd love to have more time to do follow up phone calls to see how people are doing after I've seen them in clinic.
> **Nurse:** Our challenge with us on the social medicine piece is that we don't have enough bandwidth…. we've just added another social worker to assist with that battle. Because, we're addressing social needs right then and there. But then, follow up is lacking.

Clinicians stressed challenges in addressing spirituality when a chaplain was not part of the palliative care team. Chaplain support was seen as an organizational challenge, with two of the sites lacking a chaplain involved in their palliative care teams: "It would be great to have, maybe a chaplain available because I think most of us share privately that we feel we're limited because we don't have the proper training to maybe address it." (Nurse)

Needs in Adopting the PCI

When discussing the needs of clinicians in adopting the PCI, time constraints were a concern, especially in teaching and care planning for the patient and family caregiver: "The biggest is time constraints… the teaching sessions will take time and preparation and creating a plan for each patient, so I know it's going to take time, and we are quite stretched as we are" (Nurse). The outpatient clinic environment was discussed, specifically the desire to make the environment more comfortable for patients and family caregivers. The clinic's day-to-day administrative functions and its physical setup were seen as making the setting less private and comfortable for patients. One physician described the need for a more comfortable environment for patients: "We are a long way to changing the environment that the patients are in and to make it more comfortable for them." It was also mentioned that having the right environment played a part in discussing spirituality with the patient:

> You kind of have to have, you know, the right environment to do that in, and so… That is definitely something that we could work on. When I say environment, it's just because there's so much going on…so many people, usually, and when is the right time? (Nurse)

Summary of Clinicians' Perceived Supportive Needs

In general, clinicians' responses were related to educational and organizational challenges. Education for non-palliative care clinicians on the principles of palliative care and palliative care resources was discussed as a means of encouraging early palliative care referrals. Educational needs were also identified in the area of spirituality, specifically in how to start conversations about spirituality and feeling comfortable discussing spirituality with patients and FCGs. Organizational challenges were seen in possible changes to their normal workflow, such as having time to incorporate the PCI

into their everyday practice. The busy outpatient environment was also seen as a challenge to in-depth education and spiritual conversations. That said, the clinicians were open to receiving education on spiritual conversations and training on the delivery of spiritual education to help the patient and family caregivers cope with their illness, one component of the PCI.

Table 4. Aim 3. Emergent categories: Clinicians' perceived needs in order to support patient and FCGS across QOL dimensions and in adopting the PCI.

Categories	Sub-category and Text Exemplar
Education Needs Training and education needs of clinicians in meeting patient and family caregiver QOL needs and adopting the PCI.	**Support in providing spiritual support for patients and family caregivers:** "I would welcome help in that area. If we can recognize it I guess is the problem" (Nurse). "Need proper training to address it." (Nurse) **Non-palliative care clinician education on palliative care services to increase organizational buy-in and palliative care referrals:** "On the education side, we're still a black box I think. We're getting out there to educate with internal medicine with all the sub-specialties. I would say, organizationally, even getting buy-in to educate staff." (Nurse)
Organizational Challenges Challenges in meeting patient and family caregiver QOL and adopting the PCI related to constraints or workflow of the organization.	**Staffing constraints and workload:** "Our challenge with us on the social medicine piece is that we don't have enough bandwidth…. we've just added another social worker to assist with that battle. Cause we're addressing social needs right then and there. But then, follow up is lacking." (Nurse)**.** "It would be great to have, maybe a chaplain available because I think most of us share privately we feel we're limited because we don't have the proper training to maybe address it." (Nurse) **Time constraints**: "The biggest is time constraints… the teaching sessions will take time and preparation and creating a plan for each patient, so I know it's going to take time, and we are quite stretched as we are." (Nurse) **Environment: "**When I say environment, I mean there's less opportunity to talk about spirituality. It is just the way inpatient is set up. There just so much going on and so many people." (Nurse)
Outcome of focus group towards adoption of a new PCI for lung cancer patients and family caregivers	**Buy-in from clinicians:** "The way I would say it is that the palliative care intervention is excellent. It should be done." (Physician) **Opportunity for interdisciplinary team collaboration:** "It's good to take a minute to just, see where we're at, you know... and what's working and what isn't, it's a helpful dialogue." (Chaplain)

Summary of Chapter Four

One perceived positive outcome of the focus group sessions was giving the participants the opportunity for interdisciplinary collaboration (It's good to take a minute to just, see where we're at, you know... and what's working and what isn't, it's a helpful, It's a helpful dialogue." (Chaplain). Both the focus groups and individual interviews allowed for clarification of the PCI, potentially increasing the likelihood of buy-in and adoption of the PCI.

The clinicians' perspectives were particularly valued when beginning the intervention phase. Results were reported to the research team to inform the PCI components to better meet the needs of the recipients and the clinicians. How clinicians addressed quality of life issues during the Care-Phase I was aligned with the three components of the PCI: a comprehensive baseline QOL assessment of patients and FCGs, a personalized palliative care plan, and interdisciplinary care meetings.

Meeting with the clinicians prior to the intervention aided in an understanding of each site's standard of care and the successes and challenges faced by the team and organization. The interdisciplinary teams showed a willingness to begin the phase II intervention and were also provided an opportunity to voice their concerns and collaborate with the research team. In reviewing the perceived challenges of the palliative care and oncology clinicians, it is important to recognize the challenges and support needs which arose during the implementation phase to ensure the intervention was delivered properly.

CHAPTER FIVE

DISCUSSION

Introduction of Discussion

The primary purpose of this study was to explore palliative care and oncology clinicians' perspectives on the perceived facilitators and challenges to implementing a Lung Cancer-Palliative Care Intervention (PCI). A secondary purpose is to maximize the likelihood of the effective adoption of a PCI into clinical practice through the use of the RE-AIM model for intervention research (Glasgow, Vogt, & Boles, 1999). The PCI—a nurse-led intervention—involves the early integration of palliative care alongside oncology care, focusing on improving the quality of life (QOL) of non-small cell lung cancer (NSCLC) patients and family caregivers (FCGs). The three specific aims of this study were to (a) identify clinicians' perspectives on how to best address QOL dimensions (physical, psychological, social, and spiritual needs) of lung cancer patients and family caregivers through palliative care services; (b) identify clinicians' perspectives on challenges in addressing patient and family caregiver QOL dimensions (physical, psychological, social, and spiritual needs) through palliative care services; and (c) Identity needs of palliative care clinicians in order to support patients and FCGs across QOL dimensions.

This study was unique because it was embedded in an ongoing study on a palliative care intervention. Participants of this study were clinicians who were actively involved in the recruitment, retention, and data collection of patients and family caregivers into the PCI. Secondary, this study elicited input from clinicians prior to implementation of the PCI. Other studies have reported on clinicians' perspectives post-

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PCI implementation for lung cancer patients and family caregivers to improve future delivery of the intervention (Back et al., 2014; Bakitas et al., 2013; & Le et al., 2014). However, eliciting input from clinicians prior to implementation allowed the research team to gain a richer understanding of the perceived challenges and successes related to palliative care at each study site.

Clinicians shared their perspectives about the useful practices and challenges in integrating early palliative care with standard oncology care as an element in meeting patients' and family caregivers' QOL needs. Challenges were related to the stigma associated with palliative care, referral practices of clinicians, and education needs. Other facilitators and challenges centered on addressing dimensions of quality of life (physical, psychological, social, and spiritual needs) for patients and family caregivers, with spirituality identified as a difficult dimension to address. These perspectives contributed to an ongoing discussion of the education or training clinicians need to adequately address spirituality with patients and caregivers. Findings on specific education needs and organizational challenges allowed investigators to adjust to the existing workflow and perceived challenges in adopting the three components of the PCI: (a) attention to the comprehensive patient and family caregiver quality of life dimensions (physical, psychological, social, and spiritual needs); (b) support for interdisciplinary team input in the plan of care; and (c) patient and family caregiver education.

This chapter will discuss findings for each of the above areas and compare results to empirical research which highlights similarities and differences along with suggestions for practice. Lastly, strengths and limitations of the study methodology will be discussed.

<center>**Discussion of Findings**</center>

<center>***Integrating Early Palliative Care into Standard Oncology Care***</center>

This study provided insight into the perspectives of experienced palliative care and oncology clinicians on the helpful practices and challenges of integrating early palliative care alongside standard oncology care, including identifying a time frame that expert palliative care and oncology clinicians define as "early." The PCI included patients with an early diagnosis of stage II, NSCLC. Clinicians concurrently described "early" as shortly after or before beginning the first session of chemotherapy, during the initial start of treatment, and at stage II of a lung cancer diagnosis. A discussion of the optimum timing for palliative care referrals and defining "early" versus "late" palliative care has been reported throughout the empirical literature (Bakitas, 2015; Temel et al., 2010; Temel et al., 2011; Ferrell et al., 2015); however, these discussions did not produce clear cut guidelines about optimum timing. Likewise, clinicians participating in this study did not have a clear consensus of a specific criterion for referring lung cancer patients to palliative care services. Hence, the question of "*How early is early*" recently addressed by the American Society of Clinical Oncology (ASCO) in January 2017, in which Ferrell and colleagues, (2017) recommended optimal timing of palliative care referrals for advanced cancer patients as within 6 weeks after diagnosis.

Initiating palliative care early in the trajectory of illness has been reported to improve the QOL and survival of both cancer patients and their family caregivers (Nipp et al., 2015). Similar to these findings, there was a unanimous agreement of clinicians that initiating palliative care early in the trajectory was important to improving patient QOL. However, this was not always successful at the three study sites. Clinicians further

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discussed the effective practices and challenges to initiating early palliative care alongside oncology care for lung cancer patients.

Useful Practices and Challenges in Early Palliative Care

The introductory findings on early palliative care for lung cancer patients will be compared to a study by Le and colleagues (2014) that explored perceptions of 28 lung cancer clinicians on the acceptability of early integration of palliative care in patients with incurable lung cancer. The study (Le et al., 2014) was similar to the current study in that it used focus group and key informant interviews and a multi-site and interdisciplinary approach. However, Le and colleagues were limited to three large university hospitals with limited access to outpatient settings, and also focused predominately on the perspectives of oncology clinicians (Le et al., 2014). The current study added the perspectives of both oncology and palliative care clinicians in three outpatient settings.

Useful practices identified in the results included the importance of the referring clinicians' confidence in the quality of the palliative care provided (Le et al., 2014). The findings by Le and colleagues about clinicians' confidence in the quality of palliative care matched our study findings, specifically that referrals were provided earlier when the referring oncologist and the patient each recognized the value of palliative care. In addition, clinicians highlighted the need for cultivating buy-in for palliative care services from both clinicians and patients, with clinicians perceiving that the value they placed on palliative care services affected patient and family caregivers' buy-in about the services.

A major challenge with regard to introducing palliative care was the concern that it carries a "stigma," i.e., palliative care being perceived as synonymous with the

clinician "giving up" on the patient, or that services are only for the hospice/dying patient. This was presented as one reason why clinicians sometimes hesitated to provide early referrals to palliative care services. To decrease this challenge, some clinicians have begun de-stigmatizing palliative care by routinely referring all patients to the service, suggesting it is a normal part of the treatment process. In addition, some clinicians substitute the term "support services" for "palliative care," to further de-stigmatize the service. Using different terminology for palliative care was also recognized in the literature (Bakitas et al., 2013; Bakitas et al., 2014; & Coyle, 2015).

While early referrals may be one way of "normalizing" referrals to palliative care services, the idea of referring all patients, as mentioned by clinicians in this study and that of Bakitas et al. (2013), raised concerns about having adequate time and trained palliative care personnel available to meet the demand (Aldridge et al., 2016). One way to fill this need may be to integrate palliative care into standard practice. Coyle (2015) stressed that it is vital for oncology healthcare providers to have a general working knowledge of palliative care and integrate it into oncology practice, making it less likely that a patient's first exposure to palliative care being a referral. Rather, oncology specialists could find appropriate ways to inform patients about palliative care resources available throughout the trajectory of their illness.

Attention to QOL Needs of Patients and Family Caregivers

Attention to the quality of life needs of patients and their family caregivers is a major component of an interdisciplinary PCI, specifically incorporating education, support, and an interdisciplinary plan of care across QOL dimensions (physical, psychological, social, and spiritual). Overall, this study's findings on clinicians'

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perspectives on the practices and challenges of addressing QOL needs were similar to other studies in the literature (Back et al., 2014; Bakitas et al., 2013; Le et al., Abbas & Dein, 2011). This confirmed findings of a previous study on the importance of treating the "whole patient," including meeting all QOL needs (Bakitas et al., 2013), with researchers finding that spirituality was the most difficult dimension to address (Abbas & Dein, 2011; Wittenberg et al., 2015). This dissertation study added a distinct element that explored the perceived cultural challenges in meeting the quality of life needs of patients and FCGs at study sites.

Useful Practice and Challenges in Meeting QOL Needs

Addressing Physical Needs

Clinicians have acknowledged that meeting the physical needs of patients includes symptom management. In fact, symptom management, encompassing pain control, was discussed across all interviews as a core component of palliative care for lung cancer patients. These findings were comparable to a 2014 study by Back and colleagues that explored the perceptions of experienced palliative care teams on their roles in providing early palliative care in outpatient settings. Managing symptoms was seen as leading to patients' improved functioning and as a bridge to other discussions such as emotional issues. Clinicians in this study reported that first addressing symptom management helped build rapport and made it easier for patients to share their emotional and spiritual concerns, increasing trust between the provider, the patient, and their family. Clinicians then viewed their role as supporting the social needs of the patient and family caregiver.

Addressing Social Needs

The practice of addressing the social needs of patients and family caregivers by connecting them to financial resources and emotional support was described as care coordination by the clinicians interviewed for this study and in the current literature (Aldridge et al., 2016; Luszcynskas, 2012). Clinicians participating in this study further defined the practice as "relationship building," in which they offered social support by "being there," getting to know the patient and building trust and communication. While some clinicians felt that providing social support was part of the social workers' role, especially when professional intervention was needed, all clinicians discussed the importance of providing emotional support for their patients.

A challenge of addressing patient and FCG social needs was related to the resources available at each site; one example was the lack of support groups. Though Aldridge (2016) discussed the importance of peer support, no study on the lack of support groups was found in the literature, and indeed was only mentioned as a problem at one of the three sites. However, it is notable that PCI researchers recognized the social and economic resources available to patients and FCGs at each site prior to beginning the intervention.

Addressing Psychological Needs

Addressing psychological needs was defined by clinicians in this study as addressing patient and family mental well-being or any related distress associated with illness. Perspectives of clinicians were that both patients and family caregivers experience psychological distress. They further described their experiences with patients and family members who exhibited forms of grief, uncertainty, anger, resentment,

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isolation, and anxiety. Likewise, Liao et al. (2010) listed depression and anxiety as common types of psychological needs experienced by lung cancer patients. Psychological distress also affects has a large impact on the family caregivers of lung cancer patients (Akechi et al., 2006). Clinicians cited the importance of recognizing when a patient was exhibiting these symptoms, providing education on symptoms, and anticipating future needs for psychological support. These practices were useful in facilitating patient's coping and decreasing the anxiety of not knowing what to expect. These findings are comparable to those of Le et al. (2014) who described the roles of palliative care clinicians in helping facilitate patient's emotional coping, acceptance, and planning.

Meeting the psychological needs of patients and FCGs was aided by resetting goals and expectations for treatment as the patient's prognosis changed. These changes were described in the literature as "transitions" by Maguire and colleagues (2013). During times of transition the need to provide both psychological and spiritual support for patients is especially high. Transitions occur most often during four critical points: diagnosis, completion of treatment, disease progression, and terminal care (Maguire et al., 2013). It was noted that although clinicians discussed the importance of supporting patients psychologically, social workers were most often consulted for a more in-depth clinical assessment of these needs and asked to provide outside resources and referrals to support the patient and FCGs. Likewise, it was expressed that psychological follow-up with patients was lacking after they were provided with community resources and referrals. Clinicians attributed this to an organizational challenge of inadequate social work staff to follow patients throughout their treatment.

In summary, the literature suggests that psychological follow-up and targeted

psychological interventions are often deficient in clinical practice (Northouse et al., 2012). Although a systematic assessment of patient and caregiver psychological needs is advised in clinical care, it is unknown how often this occurs in real-world settings.

Culturally Respectful Care

Exploring the perceived differences within each site was valuable to the PCI researchers in meeting the specific needs of patients and FCGs. Therefore, the clinicians' perspectives about their roles in meeting QOL needs centered on a mutual understanding of cultural norms and respect for patients and families. This helped build trusting relationships between clinicians, patients, and caregivers. Likewise, Carpenter and Berry (2016) recommended that "having a respect for the patient and family members' hopes and goals for what they want to achieve during the illness is essential" (p.440). Conflicts arose when the goals of clinicians and patients were in conflict. This was expressed particularly in the areas of decision-making and communication between the patient and family, and the family and clinician. Likewise, Mazanec and Panke (2016) warn that the "three most common sources of cultural conflict are between the patient and family, among the healthcare team members, and among the healthcare team patient and family" (p.423).

Culturally Respectful Spiritual Care

One of the major needs discussed by clinicians was in providing culturally respectful spiritual care, defined by the clinicians as meeting the patients' spiritual needs in an open way. This was practiced by inquiring about the patients' beliefs and not imposing the clinicians' personal beliefs on the patient. Initiatives clinicians used in providing culturally respectful spiritual care included allowing the patient to initiate the

conversation, going with the patients' belief, listening, and building trust with the patient.

Clinicians' challenges in providing culturally respectful spiritual care were in assessing spiritual needs, not having enough time, and feeling uncomfortable discussing spiritual issues. Likewise, it was reported that one of most difficult tasks was conducting a spiritual history with a patient, or asking about their spiritual needs (Wittenberg, Ferrell, Goldsmith, & Buller, 2015). Additionally, conducting a spiritual assessment beyond asking the patient their religious preference was not always perceived as a part of the clinicians' role; rather, that role belonged to the chaplain or social worker. However, a useful practice mentioned by clinicians in overcoming this challenge was interdisciplinary team support, especially when they were uncomfortable discussing spirituality. This may be viewed as a supportive measure but can also be viewed as a challenge. For example, in this study clinicians mentioned not asking patients about their spirituality, instead referring them to the nurse, social worker, or another discipline to address. Although not directly discussed in this study, Abbas and Dein (2011) found that several clinicians discussed the option of not having spiritual conversations with patients, the importance of being aware of their own limitations, and knowing when to refer the patient to other members of the interdisciplinary team. However, it is possible that other members of the team might also be uncomfortable or lack competence in providing spiritual care.

Other challenges in assessing a patient's spiritual needs were not knowing which questions to ask, if they were allowed to ask about spirituality or religion in their clinical environment, and the scope of their clinical role. Similarly, Abbas and Dein (2011) reported the results of a qualitative focus group study, which explored the difficulties

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encountered by palliative care clinicians in an inpatient hospice unit when asking about their patients' spirituality. Themes that emerged included lacking vocabulary on spiritual issues, personal issues surrounding death and dying, training issues, fear of being unable to resolve spiritual problems, and time constraints. Further, Abbas and Dean (2011) concluded that spirituality is not well integrated into palliative care and spiritual issues are often difficult to communicate in words.

Implications for the PCI

This study was valuable in complementing Aim 1 of the PCI study: *To adopt a palliative care intervention (PCI) tested in a NCI-funded Program Project for dissemination to other oncology settings.* Findings were shared with the investigators during the early stages of the PCI. Investigators also heard firsthand during the focus groups held at each site the specific successes and challenges perceived by the clinicians. In response to the challenges discussed in this study, support from PCI investigators was established. For example, clinicians discussed a challenge in meeting lung cancer patient and family caregiver QOL, specifically that the greatest need was support in providing spiritual care. Since the PCI was a nurse-led intervention, palliative care nurses were expected to educate and support the patient and family caregiver spiritually. Though spiritual care content is included in the written materials, being comfortable reviewing this content with the patient and family was anticipated as a challenge. In addition, two of the sites lacked a trained spiritual clinician, such as a chaplain. Hence, the study nurses and investigators were able to support the palliative care nurse in providing this content as well as addressing other QOL needs through education and role-play.

Time was a major concern of clinicians. Researchers were able to acknowledge this concern and provide appropriate follow-up and support in understanding the research tools and making PCI implementation better fit the clinicians' workflow. In addition, the researchers recognized the specific organizational needs at each site; for example, the communication challenges between referring clinicians and the need for education on palliative care services. It was acknowledged that this finding may play a role in the recruitment and retention of participants into palliative care services and specifically into the PCI study. Hence, in future studies, and as the dissemination of this PCI continues, recognizing these challenges early may help investigators offer support tools necessary to referring clinicians, addressing education needs, and facilitating organizational buy-in.

Additionally, this study explored clinicians' perspectives on the challenges and successes in addressing the quality of life needs of lung cancer patients and family caregivers. These perspectives may be helpful in comparing and validating future QOL education teaching materials developed to meet the needs of lung cancer patients.

Study Limitations and Strengths

This study used focus group and key informant interviews with palliative care and oncology clinicians to prepare for phase II of a PCI study/intervention conducted in three outpatient settings. Approximately 25 participants were invited to participate in focus group interviews. Clinicians were initially contacted through their organization's email system by the primary principal investigator of the intervention study, who was employed by the healthcare system at the three sites. Therefore, one strength of this study was that it was embedded in an ongoing, funded PCI study in which palliative care team members at each site were already invested and participating. Although participation in this study was

voluntary, it was encouraged by palliative care team nurse administrators. Prior to focus group recruitment and in preparation of the PCI implementation, principal investigators had begun education sessions and research meetings with members of the palliative care teams in phase I of the study. In addition, this researcher met the PCI research team and palliative care nurses involved in this study prior to recruitment. It is believed that contacting clinicians who were already participating in the study prior to recruitment fostered buy-in and increased the likelihood of their participation in the focus group studies. The clinicians were also provided with food during their usual break or mealtimes, making it easier for them to take part. The palliative care clinicians who took part in the focus group responded within 2 weeks of the primary recruitment email. Although it was convenient for this study to be embedded in a funded research project, recruitment and involvement of clinicians may not be easily transferable to other outpatient settings without this advantage. Additionally, PCI research team members were present at each focus group meeting to validate findings and clarify PCI questions of clinicians. Although this was supportive of the integrity and trustworthiness of the study, it is possible that their presence may have affected the verbalized perspectives of the clinicians involved in the focus groups.

While oncology clinicians were invited to participate in focus groups, few participated, which limited the perspectives of non-palliative care clinicians ($N=5$). Having both oncology and palliative care members involved in the focus groups may have led to further discussion informing the PCI and the challenges of integrating palliative care into oncology care.

Nevertheless, the sample size *(N=19)* was representative of the interdisciplinary palliative care team members at each site and a good representation of the total workforce involved in this intervention. This included at least one palliative care physician, at least two palliative care nurses, and the palliative care nurse administrator at each of the three sites. However, since a chaplain was not directly involved on the palliative care team at each site, only one chaplain participated in the focus groups. Further, to get a more in-depth perspective of trained spiritual care workers, a chaplain involved with inpatient palliative care was recruited for an individual phone interview. This perspective was useful in exploring the practices and challenges of meeting the QOL needs of lung cancer patients and family caregivers with attention to spiritual needs; however, this chaplain was not directly involved with the outpatient palliative care team or with the PCI. The perspectives of social workers was lacking at one site; however, the role and perspectives of the social workers at the two sites were robust and viewed as a good representation of this discipline in preparation for the PCI by the research team.

The aim of this study was to explore the perspectives of clinicians in meeting the QOL needs of both lung cancer patients and FCGs; however, the focus was predominately on the patient. While similar perspectives were discussed for the FCGs, these practices and challenges were difficult to pinpoint during the analysis phase. The findings of this study may be most transferable to outpatient oncology and palliative care sites.

Evaluation of Trustworthiness and Integrity of Study

Guba and Lincoln's (1994) framework (as cited in Polit & Beck, 2012) was used to evaluate the trustworthiness and integrity of this qualitative research study. This

framework uses practical strategies to enhance credibility throughout different phases of a qualitative study (e.g. data generation, coding, analysis, and reporting results). Specifically, the framework provides criteria to evaluate the credibility, dependability, confirmability, transferability, and authenticity at each phase. These criteria will be discussed in the context of a descriptive qualitative study using conventional content analysis (Hsieh & Shannon, 2005).

Credibility

Credibility refers to the confidence and accuracy of the study findings; in this study, credibility was established by following distinct descriptions of conventional content analysis. Prolonged engagement with nurses participating in the study post-data collection helped ensure that the data accurately represented study participants. This was done through phone meetings with the research team and palliative care nurses in preparation to launch the intervention phase at each site, and during the early implementation stages of the PCI. During these calls, the research team documented the challenges and successes of meeting QOL needs, recruiting participants at each PCI site, and validating the needs of clinicians in successfully adopting the intervention.

Dependability

Dependability refers to the stability of data over time and conditions. This study's dependability was established through careful documentation of findings and decision making with multiple researchers. Confirmation of findings was conducted during the analysis phase using the methods of conventional content analysis of review, feedback, validation, and revision. In addition, findings were compared to related studies for similarities, which confirmed stability of results in different settings overtime.

Confirmability

Confirmability refers to corroborating study results by two or more individuals not related to the study. This is done to ensure that the data represent the perspectives of the participants rather than the researchers (Polit & Beck, 2012). Confirmability of this research was established by the presence of at least two nurse-researchers at each focus group, eliciting the insights of those who heard the perspectives of the clinicians firsthand. Debriefing after each focus group played a major role in maintaining rigor within the data collection phase of this study.

Transferability

Transferability is the extent to which qualitative findings can be transferred to or have applicability in other settings or groups. In 2012, Polit and Beck noted the importance of providing sufficient descriptive data that other researchers can use to evaluate the applicability of the data to other contexts. These criteria were used to explain the study methodology in detail. With its multi-site, multi-discipline, and multi-researcher design, the study ensured objectivity of findings and a broader perspective of possible transferability into other sites and populations.

Authenticity

Authenticity refers to the degree to which researchers fairly and faithfully depict a variety of realities. Authenticity expresses feeling and tone and participants' lives as they are lived, and provides readers with insights into the sensitive nature of the issues being described (Polit & Beck, 2012). Authenticity was established throughout data collection, analysis, and while writing up the findings of the study. For example, during analysis of the interview data, the researcher was diligent in making sure that categories emerged

directly from the transcripts, allowing category definitions to flow directly from the words and meanings described by the clinicians.

Implications for Palliative Care Intervention Studies

This research focused on the adoption phase of the RE-AIM model. In line with the RE-AIM model, the following components, implementation and maintenance, should be evaluated in successfully translating the PCI into clinical practice. Further, a follow-up investigation with clinicians during and post PCI implementation at each site may be helpful in recognizing the successes and challenges of applying the components of the PCI. This follow-up may also assist in the maintenance of the PCI at each site long-term. Input from non-palliative care clinicians who care for patients with lung cancer, such as oncologists and primary care physicians, may provide a broader perspective of how to best address the quality of life needs of patients and family caregivers. For example, there may be implications for a future qualitative study exploring patients' and family caregivers' challenges and successes with the PCI. Additionally, eliciting the perspectives of an ethnically diverse group of patients and family caregivers across different disease stages may increase the likelihood of the PCI reaching a larger group of patients and family caregivers. Lastly, there are potential implications for a replication of this study to improve the impact and dissemination of this particular PCI, and other PCIs, into clinical practice. The perspectives of clinicians may vary as they are translated to other outpatient settings and encounter different organizational challenges.

Implications for Palliative Care Research and Nursing Practice

The PCI study from which this study was drawn involved both nurse researchers and experienced palliative care nurses. Hence, it represented a supportive forum in the

connection of palliative research to clinical nursing practice. Furthermore, this was a nurse-led intervention in which nurses implemented a new structured palliative care intervention which included patient and family caregiver education sessions, comprehensive assessments of patients' and FCGs' quality of life needs, and interdisciplinary team input in a plan of care. In addition, nurses were involved with research procedures such as recruitment, chart reviews, and completion of structured data collection tools. Although these nurses were highly trained in palliative care, they did not have previous experience in research and required support at each phase of the study, including the preparation of the PCI intervention and during the implementation phase. In response to these foreseen needs, the research team continued to meet with the palliative care nurses at each site to consult on challenges in recruitment and in the adoption of the three elements of the PCI. Further, the nurse-researchers supported the practice nurses by providing training and education in research methods, and the practice nurses provided insight into the real-world needs and experiences of lung cancer patients and their family caregivers within outpatient settings.

Implications for Palliative Care Nursing Education

This study elicited the perspectives of highly trained and experienced interdisciplinary clinicians on the subject of palliative care. Although these perspectives involved the disciplines of nursing, social work, medicine, and chaplaincy, it may be especially useful in the integration of palliative care into nursing education. Implications for nursing education lie in clearly defining palliative care to decrease stigma and to promote the early integration of palliative care into oncology care. Training in the general concepts of palliative care should include an assessment of QOL needs of cancer patients,

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with attention to symptom management, and psychological, social support, and spiritual needs. This general assessment should be done prior to consulting specialized palliative care services, leaving a more in-depth comprehensive assessment of the patient in need of palliative care services. It may be useful to identify signs to help non-palliative care nurses and clinicians know when to consult palliative care teams (Ferrell et al., 2017). The perspectives on the useful practices and challenges of early integration of palliative care into oncology care lends insight on the significance of educating patients, FCGs, and clinicians to eliminate the "black box," or what is unknown, about palliative care services. Further, the need for interdisciplinary collaboration and care planning was found to be important; therefore, it is vital that nurses be educated on the value of working with other disciplines to meet the quality of life needs of cancer patients.

Implications for Spiritual Care Education

This study has implications for education in the assessment of patients' spiritual care needs and in providing culturally sensitive spiritual care. Clinicians expressed the importance of not imposing their own spirituality on the patient but rather allowing for an open dialogue for spiritual conversations with the patient as the focus. However, many clinicians discussed being uncomfortable in assessing patients' spiritual needs or initiating spiritual conversations. The PCI provided training for nurses and written education for the patient and family caregiver; this also provided the nurse with a structured template for addressing the spiritual needs of patients and FCGs. Providing written education may be helpful in guiding nurses through difficult conversations and in assessing patients' spiritual needs. This study shed light on the absence of spiritual assessment tools in these settings and that many nurses do not assess spirituality beyond

the patient's religious preference because they do not know what to ask. Therefore, including education about the differences and implications of religion and spirituality may be useful, along with structured assessment tools. Several clinicians reported that discussing spirituality was difficult due to lack of time, prioritizing the patient's care, and the outpatient environment; specifically the business functions and lack of privacy in the outpatient clinics made it difficult to have such sensitive conversations. It may therefore be useful to further explore how to best address spiritual needs in an outpatient environment. Lastly, this study has implications for the integration of spirituality into routine palliative care. It was noted that trained chaplains were not readily available at most of these sites and throughout the healthcare system. This makes it even more important for nurses to have a general knowledge of spiritual assessments and how to support and refer patients in their spiritual journey as it relates to their illness and coping.

Conclusions

This study provides insight into the way experienced clinicians approach the quality of life needs of lung cancer patients and their family caregivers. This was a multi-site study involving several disciplines (e.g. nurse, physician, social work, and chaplain) and specialties (palliative care, oncology, and thoracic surgery) involved in the care of lung cancer patients and FCGs. This study is unique because it translates the perspectives of clinicians involved in an ongoing PCI study into community-based settings and describes the real-world challenges of integrating palliative care into patient treatment. Clinicians' perspectives were captured through focus group and individual interviews. These perspectives reflected an overall buy-in of the PCI and provided researchers with

the educational needs and organizational challenges at each site prior to implementing the

PCI.

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APPENDIX A

FOCUS GROUP RECRUITMENT EMAIL

Translation of a Lung Cancer Palliative Care Intervention

Dear Colleagues,

We'd like to invite you to participate in a 1-hour focus group discussion as part of our preparation to implement a structured palliative care intervention for Kaiser Permanente members with non-small cell lung cancer and their family caregivers.

As you may already know, Kaiser Permanente has been collaborating with City of Hope on this research project since late 2014. We have gathered the baseline data we need and are now moving into phase 2 of the project and would like to hear from you!

Given the valuable insights you have in working with patients and their loved ones, we hope you'd consider sharing your perspectives to help us refine the intervention and maximize its impact on patients and their families. Please see the attached information sheet for additional details.

The focus groups will be held on <DATE1> and DATE2> from <TIME1> until <TIME2> at <PLACE>.

If you are unable to attend the focus group or prefer to participate in individual interviews with us, we are happy to accommodate your schedule.

Ms. Shaunna Siler, a doctoral nursing student from Loma Linda University will be conducting these focus groups/interviews as part of her dissertation with assistance from me and Dr. Betty Ferrell. Please contact Ms. Siler directly if you are interested in participating: ssiler@llu.edu or 703-398-7657.

Sincerely,

Huong Q. Nguyen, PhD, RN
Research Scientist
Kaiser Permanente Southern California

FOCUS GROUP GUIDE

Clinician Group

Welcome and Introduction

[Introduce Project, Team Members, and Clinicians]

You have been invited to this focus group because you are a knowledgeable member of this interdisciplinary team and we value your expertise. We appreciate you being here and thank you in advance for your participation.

We are here to learn from you about your experiences in caring for patients with lung cancer and their family caregivers. Specifically, we are interested in learning how you address the needs of patients and families through the use of palliative care and barriers to providing optimal palliative care. The research team will use the results from our discussion today to inform the refinement of a palliative care intervention to meet the needs of your patients.

The information you provide today is confidential and will not be shared beyond the research team. As in professional practice, you will want to remember to keep everything you hear in this room confidential. We are recording this session so that we can listen carefully to your experiences and suggestions even after this session is over.

Questions and Probes

First, we want to learn from you about your positive experiences of addressing patient and family needs. This includes their physical, psychological, social, and spiritual needs.

1. Prompts to "strengths":
Let's talk about the <u>strengths</u> of palliative care.

a. Take this piece of paper and write down three things that you feel your palliative care team does particularly well in improving patients' and family caregivers' needs- please address their physical, psychological, social and spiritual well-being.

b. OK. Let's go around the table and each of you tell me what you wrote down and give me a one-sentence description of each item. (Facilitator to list each item on a flip chart. If an item is mentioned more than one time, put a check mark next to it for each additional time it is mentioned.) (Pick the one with the most check marks).

c. A number of you said X was a strength. Talk more about that. Discuss two or three items as time allows.

2. Prompts to Barriers/Weakness:
Now let's talk about what needs improvement. Let's use the same process.

a. Using the same piece of paper, write down three things you find particularly difficult in improving patients' and family caregivers' needs- again, please address their physical, psychological, social and spiritual well-being.

b. OK. Let's go around the table and each of you tell me what you wrote down and give me a one-sentence description of each item. (List each item on a flip chart. If an item is mentioned more than one time, put a check mark next to it for each additional time it is mentioned.) (Pick the one with the most check marks)

c. A number of you said X could be improved. Please talk more about that.

Probes to be used as needed
      - What strategies have you used to overcome these barriers?
      - How successful were you in overcoming these barriers?
      - What did you learn?

3. **Prompts to Minority/Cultural Needs.**
We are also interested in tailoring a palliative care intervention to meet your patient population. We are interested to explore the cultural barriers and needs of your patients and families.

a. Think of an encounter that you found particularly difficult or unique in providing culturally sensitive palliative care to patients with lung cancer. Please tell us about this encounter and what you found to be difficult or unique.

Probes to be used as needed:
- Are there any cultural barriers that you see in the population that you serve?
- Are there any noticeable trends seen in the populations that you serve?
- Describe your response to their needs.
- How confident were you in your ability to meet their needs?

4. **Prompts to Clinician Needs.**
We are interested in *your* needs as clinicians and how the palliative care intervention should be structured to best serve you as you care for patients and families with lung cancer.

a. What are your concerns regarding implementation of the palliative care intervention?

Probes to be used as needed
- How might this structured palliative care intervention change your current workflow?
- Discuss areas of training that may help prepare you to be more effective in providing palliative care.
- In what areas and *how* can communication be improved amongst your interdisciplinary team?
- What have you learned from Phase I with patient and caregiver recruitment that might be helpful to inform Phase II?

Concluding Remarks

On behalf of the entire project team, we thank you for participating in today's focus group. We are very grateful for your willingness to share your experiences and to help us learn better practices in providing palliative care for patients and their family caregivers with lung cancer. This information will be used to inform the adoption of the palliative care intervention to best meet the needs of patients and their caregivers.

APPENDIX C

PARTICIPANT INFORMATION SHEET

KAISER FOUNDATION HOSPITALS
SOUTHERN CALIFORNIA PERMANENTE MEDICAL GROUP
STUDY # _____

INFORMATION SHEET
Translation of a Lung Cancer Palliative Care Intervention for Clinical Practice
(Provider Focus Group Interviews)

SPONSOR: National Institute of Nursing Research
INVESTIGATOR: Huong Q. Nguyen, PhD, RN
                    100 South Los Robles Avenue, 2nd Floor
                    Pasadena, CA 91101
TELEPHONE: (626) 564-3935

You are being invited to be in a research study. The purpose of this informational sheet is to provide you with information about this study:

➢ The purpose of this study is to conduct focus groups at Kaiser medical centers to gain the perspectives of palliative care clinicians (e.g., physicians, nurses, social workers, and chaplains) regarding non-small cell lung cancer (NSCLC) patients' and family caregivers' quality of life needs to inform the adaptation and refinement of a palliative care intervention (PCI).

➢ Participation in this study is entirely voluntary. You may choose not to be in this study. You may leave this study at any time. Your decision to participate will <u>not</u> affect your employment at KPSC. If you choose to take part in this study, your participation will take approximately 1 hour.

➢ If you agree to participate, you will meet with a member of the research team and discuss palliative care services for patients with lung cancer that you may be involved in at your medical center. The interview will be in the form of focus groups with other palliative care and oncology clinicians or one-on one interviews. The interviews will be audio-recorded, and all information will be kept strictly confidential. You may share only what you feel comfortable in sharing, and you can refuse to answer questions or stop your participation at any time.

➢ There are minimal risks if you participate in this study. Some of the questions may be considered sensitive, may be difficult to answer, or may cause you to feel uncomfortable. You may refuse to answer any questions. There is no guarantee that you will directly benefit from participating in this study.

➢ The information we collect from our focus group meetings including audio-recordings will be shared only with the research team and will be kept strictly confidential. Any published results will not include your name or other identifying information.

If you have any questions about this study please contact:

Huong Nguyen, PhD, RN, Principal Investigator
626-564-3935; huong.q2.nguyen@kp.org

If you have any questions about your rights as a research subject, please contact:

Armida Ayala, PhD, Director
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APPENDIX D

QUALITY OF LIFE DIMENSIONS

Palliative Care Focus Groups

Quality of Life Dimensions

Physical	Psychological
Social	Spiritual

Elements of the Palliative Care Intervention include:

1. Attention to the comprehensive patient and family caregiver quality of life dimensions (physical, psychological, social, and spiritual needs).
2. Support for interdisciplinary team input in the plan of care.
3. Patient and Family Caregiver Education.