The Role of Nurse Navigators in Diagnostic Phase of Adult Patients with Lung Cancer

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Health Sciences

in

Community Health

University of Ontario Institute of Technology

July 2nd, 2013

Abstract

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Cancer is a major concern in today's health care field, especially in Canadian adults. The diagnostic phase is a clinical process that involves mapping the patient journey, identifying and prioritizing the symptoms, and corresponding the symptoms with relevant treatment. Oncology nurse navigators are professional nurses who educate and advocate for, and navigate the cancer patient throughout his/her entire cancer treatment. Although nurse navigation is recognized by many provinces as a key element of an integrated system of cancer care, it is not yet delivered in a standardized way across Canada. The significance of this study is that it will contribute to evidence that if a connection is found between positive patient experience and the role of nurse navigators, this will allow for a more standardized delivery of nurse navigator programs across Canada. The phenomenological study of the role of oncology nurse navigators within the diagnostic phase was undertaken to understand the impact it had on patient experience, particularly lung cancer patients. Carried out in one of Ontario's largest cancer centres, Durham Regional Cancer Centre (DRCC) at Lakeridge Health, this study involved interviewing four patients and a focus group with four nurse navigators who were employed at DRCC. A newly designed Bi-Dimensional Framework (Fillion *et al.*, 2012), which focuses on continuity of care and patient empowerment, was used to guide conceptualization of the study, data analysis, and interpretation of results. Through the use of thematic analysis, transcripts were analyzed. The resulting interpretation of the role of the nurse navigators on patient experience is that of patient-focused cancer care; conduct needs assessment, care planning, shared decision-making; easily accessible, identify and eliminate barriers; patient advocate, educational support; personalized symptom management education; and resource navigation. Together these themes identify core

areas of practice which can be used as a foundation to develop and maintain the skills to practice in the oncology field, in order to develop the nurse navigator's role to its full potential.

Acknowledgements

First and foremost, acknowledgement goes to the participants of my study. To the nurse navigators, thank you for your willingness to take part in my study during your busy daily schedules. Your enthusiasm and thought-provoking responses and discussion has greatly benefited the outcomes of my research. To the clients who participated, thank you for staying back or coming in early before appointments to provide your thoughts and reflections. I cannot express how motivated I have become after having met you and learning about your personal experiences, not only as patients but also as individuals. My time with you all was a great pleasure. I hope I have represented you well.

To my supervisor, Dr. Manon Lemonde, I cannot fully explain my gratitude. Your motivation, coupled with your extensive knowledge on research methods, were invaluable throughout this entire process, especially in my most frantic moments. I am so thankful for your critical insights and feedback, as well as challenging me to defend my study, even before the actual oral defense. Because of this, I was able to figure things out on my own and truly appreciate the purpose of my study. I especially want to thank you for ensuring we had a comforting relationship, thus allowing me to seek your guidance and support without a hesitation in mind.

To my committee, Dr. Angela Cooper Brathwaite and Dr. Paul Yielder- thank you for taking interest in my work and guiding me in productive directions. I highly respect and appreciate the knowledge you have bestowed upon me. Angela, words cannot express my gratefulness towards your in-depth review of my data analysis as well my drafts. I admire the time and effort you have put in ensuring I was on the right track. I am grateful to you, Paul, for reminding me of the value of paying attention to the writing styles. Your expertise in research methodologies within health research has greatly benefited towards the details of my study. I specifically want to thank you for your calm and patient energy, and your ability to lighten up academia.

To my mom and dad, I thank you from the bottom of my heart for supporting me and motivating me, especially during my lowest moments. From driving me through snow storms to get to the interviews on time, to listening to my research ideas, I am truly grateful beyond words for having such parents as you. Finally, thank you to all my friends who were there to proofread my entire dissertation, as well as adapt to my emotional breakdowns and supporting me. I am incredibly fortunate to have all of you during this entire process.

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Chapter I

Introduction

Cancer, a terrifying and life-altering disease, is a major concern in today's healthcare field. In 2013, it is estimated that there will be 187, 600 new cases of cancer and 75, 500 cancer deaths in Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Cancer is a process, a chain of events that begin at the molecular level in the human body and persist through changes that the patients and healthcare providers must undergo to deal with the personal and medical effects of this disease. The diagnostic phase of cancer, from suspicion to diagnosis, is a time characterized by countless number of tests and treatments, high levels of uncertainty, and patient anxiety (Psooy, Schreuer, Borgaonkarm, & Caines, 2004). The lengthy waits create anxiety among patients, may delay treatment and increase the possibility of disease progression, which in turn leads to poor patient outcomes (Christensen, Harvald, Jendresen, Aggestrup, & Petterson, 1997). Navigating through the healthcare system and knowing what services are accessible can be very challenging during a restless time when patients are making major life decisions.

Background

There is a diversity of current and emerging roles to guide and improve a patient's journey through the cancer care continuum. The concept of nurse navigation in cancer emerged from the discovery of the challenges patients and their families face in a complex healthcare system. The healthcare system is very complex and the patients must interact with many healthcare professionals within and across multiple health services and sectors. Furthermore, contemporary cancer treatment consists of several treatments over an extended period of time. These experiences certainly place cancer patients at risk for increased psychosocial morbidity, as well as disintegrated care (Bultz & Carlson, 2005).

Since its inception, a key belief of nursing practice is patient-centered care (PCC) (Registered Nurses Association of Ontario, 2002). There have been many attempts to define the attributes of PCC. According to National Research Corporation (NRC) Picker (2013), an organization dedicated to conducting research on patient experience within the healthcare industry, PCC, as required by the patients, can be defined by the following keywords: respect for patient's values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; and transition and continuity. Different initiatives and attributes are required to meet all these needs. Facilitating continuity of care and promoting patient empowerment are significant attributes of PCC (Fillion *et al.*, 2012). Registered nurses, haven taken leadership roles such as nurse navigators, case managers, and telehealth nurses, etc., are in the key position to facilitate continuity of care and promote patient empowerment.

Evolution of the navigation concept

This section will be solely dedicated to describing the history and evolution of the role of navigation, particularly the development of an oncology nurse navigation program within North America.

Navigation was first developed in the 1900s in the United States to improve access to care for patients who faced barriers or poor health service related to racial marginality and poverty (Hede, 2006). Significant challenges and barriers faced by low-income people in accessing timely and effective screening, diagnosis, and treatment led to the first navigation program at the Harlem Hospital Center in New York in 1990, which was guided by Dr. Harold Freeman (Centre to Reduce Cancer Health Disparities, 2003). While the initial American pilot navigation programs focused on underserved and poor populations, the early navigation programs in Canada generally targeted people living with cancer.

During the early 2000s, oncology nurse-led clinical case management and navigator models were implemented nationally (Farber, Deschamps, & Cameron, 2002) as a standard of care and a potential solution to attending to informational and psychosocial needs of cancer patients. One of the early professional models of cancer navigation in Canada was implemented in Nova Scotia in 2001 as a patient-centred, outcome-focused care management approach set in place to aid patients, their families, healthcare professionals, and health leaders in dealing more effectively with cancer and the cancer system. Significant findings from the evaluation of this program identified that patient navigation was viewed as an imperative source of support for patients and families dealing with emotional distress, informational needs and logistical challenges related to cancer diagnosis. It was recognized that cancer patient navigation had significantly improved the quality of cancer care, as well as promoted collaboration and communication among healthcare professionals, resulting in more efficient care (Cancer Care Nova Scotia, 2004). Simultaneously, Quebec also implemented nurse navigators in oncology (infirmières pivots en oncologie) where the nurse navigator accompanies patients and families from diagnosis and onwards (de Serres & Beauchesne, 2000).

Preliminary studies in both Canada and the United States have shown that patients who have access to navigation are more likely to: understand their treatment plans; cope better with their illnesses; understand the barriers they face; access the services they need; and be better prepared for consultations and treatments (Fillion *et al.*, 2006; Freeman, 2006; Hohenadel *et al.*, 2007).

Professional navigators in oncology

In Canada, professional navigation within the oncology field is practiced by healthcare providers, usually nurses (Pedersen & Hack, 2010). Professional nurse navigators assist the patients and their families at many points along the cancer journey, providing a single point of contact and bridging the patients and their families to the interdisciplinary healthcare team, the cancer centre, and community services (Cook *et al*., 2013).

While advances in cancer treatment have saved millions of lives throughout the decade, patients and their families now often face far more complex treatment decisions and follow-up options than they did in the past. Thus, patient navigation is seen as one possible solution to the problem- to navigate the patients through the cancer continuum. However, in Canada, the principal areas of practice for oncology nurse navigators (ONN) have not been described. Determining the core areas of practice needed to develop and maintain the skills to practice in the oncology field is a crucial step in developing the nurse navigator role to its full potential, which can ultimately optimize patient outcomes.

Study Goal, Structure and Summary

Cancer Care Ontario (CCO) implemented a pilot project to introduce the role of patient navigators in the early stage of the cancer journey so as to help patients find their way through the diagnostic process. The first year of the project introduced seven registered nurses into the role of patient navigator in seven Diagnostic Assessment Programs (DAPs) across Ontario. The seven project locations include: Grand River Regional Cancer Centre (Kitchener-Waterloo), Hotel Dieu Hospital (Kingston), Royal Victoria Hospital (Barrie), St. Joseph's Hamilton & Niagara Health System, Thunder Bay Regional Health Sciences Centre, Toronto General Hospital (University Health Network), and R.S. McLaughlin Durham Regional Cancer Centre

(Oshawa). The objectives of the patient navigation pilot project were to develop and implement a cancer patient navigation training course for nurses in conjugation with the deSouza Institute (dedicated to improving cancer care for Ontarians by supporting excellence in oncology nursing across the province); to introduce trained patient navigators into DAPs throughout Ontario; and to evaluate the impact of patient navigators in the diagnostic phase of cancer care (such as patient experience with the diagnostic phase, and provider experience with the diagnostic process and impact of patient navigator) (CCO, 2010).

The role of a nurse navigator has been introduced widely as a means to improve coordination and continuity of care and enhance patient and family empowerment. Although nurse navigation is recognized by many provinces as a key element of an integrated system of cancer care, this navigation process is not yet delivered in a standardized way across Canada (CCO, 2009). Little evidence exists pertaining to the effectiveness of the role of the nurse navigator on patient’s experience as a whole, in supporting the implementation of a nurse navigator position for patients with cancer. It is critical to determine the core areas of practice needed to be developed and maintained to practice in the oncology field. Knowledge and skills are necessary to develop the nurse navigator role to its full potential, which can optimize patient outcomes and satisfaction. Therefore, the conceptual goal of this study was to explore the role of nurse navigators on the overall patient experience of adult cancer patients during the diagnostic phase using a Bi-Dimensional Framework, which focuses on continuity of care and patient empowerment. The significance of this study was to determine the effectiveness of the nurse navigation program as implemented in the cancer centre with respect to patients’ experiences based on the specific roles of the nurse navigators. On a larger scale, this research project will contribute to evidence of the connection found between positive patient experience in the diagnostic phase and the role of oncology nurse navigators during this journey. This will allow hospitals and the Canadian healthcare system to implement more oncology nurse navigator programs to enhance cancer care provided to the patients and their families. This study will further provide evidence of the core areas of practice that are needed to acquire and maintain the skills to practice in the oncology field, in order to develop the nurse navigator role to its full potential, which can optimize patient's outcomes. Furthermore, the evidence will also allow for the nurse navigator program to be delivered in a more standardized way across Ontario and Canada, thus resolving any health disparities to accessibility of this healthcare approach.

The R.S. McLaughlin Durham Regional Cancer Centre (DRCC), a Cancer Care Ontario partner, within Lakeridge Health was chosen for this study. The DAP within the DRCC is an outpatient oncology program dedicated to providing patients' continuum of care during the diagnosis phase of cancer. For the purpose of the study, the nurse navigation program within the diagnostic assessment phase focusing specifically on lung cancer was chosen. The particular program is targeted to determine the diagnosis of the cancer, the cancer stage, and providing support services.

In the initial stage of the study, a comprehensive literature review was conducted to clarify what the roles of the nurse navigators are and how the roles impact the patients with cancer. After the literature review was completed and a conceptual framework for cancer navigation was identified, focusing on the clinical and organizational functions of the navigator role, this program was assessed in practice by a group of male and female adults aged 60 years and above. Specifically, a phenomenological design (to be further discussed in Chapter 3) was used to describe: the role of a nurse navigator at a cancer centre in (a) improving continuity of care for the patients (consisting of its components: informational continuity; management continuity;

relational continuity), and (b) enhancing patient and family empowerment (consisting of its components: active coping; self-management; supportive services). By describing the roles of the nurse navigators, it helped answer the following research question:

- How does the role of a nurse navigator in the diagnostic phase influence the overall experience of adult lung cancer patients?

This study entails qualitative research as it seeks to describe the experience of the lung cancer patients with respect to continuity of care and patient empowerment following a nurse navigator program within the diagnostic phase. This will be explained in the following chapter.

The goal of this study was to document the lived experiences of adult lung cancer patients within the diagnostic phase based on the care given by their nurse navigators. This study also documents the views and perspectives of the nurse navigators working within the diagnostic assessment program and how they feel their cancer care affects their patients' experience. It is expected that this approach will initiate determining the core areas of practice that are needed to develop and maintain the skills and abilities of a nurse navigator so as to optimize the role.

To summarize, Chapter 1 was concerned with the background information and the need for a navigation program within the oncology field, and the impact of professional nurse navigators on patient experience. It is now important to further define the nurse navigator role, its application and current relevance as represented in the literature. Therefore, Chapter 2 will build upon the concepts presented in Chapter 1 by providing the most recent review of supporting literature. Chapter 3 will explain the study's method which provides details about the sample, data collection, and analysis used. Chapter 4 will present the findings. Chapter 5 will review and discuss the findings to relevant theory. Chapter 6 will conclude the study by explaining the study strengths and limitations, as well as provide implications for practice, education and research.

Chapter II

Literature Review

As mentioned in Chapter 1, the need for professional navigators- healthcare providers with knowledge and skills to guide and support the patients and their families within the cancer care continuum- is vital. However, the topic of nurses as professional navigators is relatively new and therefore future research is needed to provide evidence of the impact of oncology nurse navigators on patient's experience. Thus, this literature review is structured with respect to the discussion of the empirical and theoretical literature pertaining to the roles of the nurse navigators within the cancer field. The efficacy of oncology nurse navigators seems to be a consistent topic within the literature. Therefore, the empirical themes found in the literature relating to the efficacy of ONNs include: improving screen rates; improving adherence to diagnostic services after detection of abnormality; improving cancer treatment; improving co-ordination of care; and patient assessment and support. The theoretical literature explains the need for an integrative framework that could improve the efficacy of cancer navigation programs based on the limitations found in the empirical literature. Hence, the theoretical literature will focus on the Bi-Dimensional Framework which supported this study. Additionally, this framework guided the development of this study and enabled me to link my findings to the body of nursing knowledge.

The literature search and review process provides the necessary background information to situate this research project within the available evidence. The literature has further provided the required framework to guide this research. The following sections will be discussed in this chapter:

1. *Search strategy and selection criteria*: description of what the criteria were for the literature search and how the articles were selected for the literature review.
2. *Nurse navigator definition*: definition of what a nurse navigator is and what the roles consist of.
3. *Efficacy of nurse navigators*: description of how the roles of the nurse navigators impact patient outcomes.
4. *Challenges encountered with nurse navigation program*: description of the challenges faced with nurse navigation programs.
5. *Summary*: review the gaps and inconsistencies of the literature review, and discuss the goals of the study.
6. *Bi-Dimensional Framework*: an overview of the newly designed Bi-Dimensional Framework and its relevance to this study.

Search Strategy and Selection Criteria

Databases searched were Medline, CINHAL, and PsychInfo to review and gather all the articles related to nurse navigators. The specific keywords that were used to retrieve the articles were “nurse OR patient navigator”, “role of nurse navigator”, and “nurse OR patient navigator AND diagnostic phase.” The literature search included studies which were conducted within North America. This demographic connection proved to be very useful and reliable because cancer care and services offered vary from country to country. Furthermore, the articles used in this literature review had studies conducted within the years 1990-2012. This time period inclusion is critical to consider because 1990 was when the first nurse navigation program was established in the United States, and this can be used to compare with the nurse navigation program offered today. This time period can also identify gaps between nurse navigation services throughout the years.

The literature search in identifying scholarly articles needed for the review was based on a two-step selection process. The initial literature search was done using database searches mentioned above, which resulted in a total of 56 articles from peer-reviewed journals and grey literature. Duplicate studies from the database were then removed. The second step included reviewing of the abstracts of the 45 articles that were identified in step one (after the removal of duplicate studies) based on the inclusion/exclusion criteria. The inclusion/exclusion criteria consisted of the following: written in English only; literature published from 1990-2012; nurse navigator programs within any areas of cancer; a sample population of adults aged 18 years and above. As a result of the inclusion/exclusion criteria, a total of 36 articles were retained for data extraction and analysis.

Nurse Navigator Definition

Before determining how the roles of nurse navigators impact a cancer patient's experience, it is important to understand who nurse navigators are and what their roles consist of. Various definitions have been suggested to describe "nurse navigator". However, these definitions could be divided into three models used to describe navigators: Active Co-ordination, Facilitating, and Shared/ Tacit (Canadian Breast Cancer Research Initiative, 2002).

Active Co-ordination Model

The Active Co-ordination Mode describes the nurse navigator as mainly filling a direct, proactive co-ordinator role. This model describes the *functional* definition of a nurse navigator where "(nurse navigator) is intended to facilitate a patient's access to services and resources, and improve continuity and coordination of care” (BC Cancer Agency, 2005). The role focuses on activities such as arranging and making appointments for the patient, completing and transmitting forms, and contacting and working directly with referring physicians. The roles also include facilitating access and improving continuity of care (BC Cancer Agency, 2005).

Facilitation Model

In the Facilitation Model, the nurse navigator has a more psychosocial role in patient care. This model describes the patient-centered definition of a nurse navigator where “individualized assistance is offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care” (Association of Oncology Social Work, 2001). This role emphasizes empowering the patient while acting as a resource or consultant. The nurse navigator is more focused on educating and informing the patient, and assisting them in decision-making and co-ordination of services. The roles also include providing proactive guidance and direction (Psooy *et al*. 2004), as well as advocacy and coordination (Battaglia, Roloff, Posner, & Freund, 2007).

Shared or Tacit Model

Thirdly, the Shared or Tacit Model involves the sharing of functions across a team of individuals or healthcare professions, such as oncology nurse navigators working with referring physicians, and/or social workers to maximize the effective co-ordination of care. Furthermore, nurse navigators also have the necessary cancer-related knowledge and expertise about the cancer care system to support other health professionals, such as physicians (Cancer Care Nova Scotia, 2004).

Lay navigators versus professional navigators

To understand the role of nurse navigators, it is important to make a distinction between lay navigators and professional navigators. While both groups of navigators share similar goals to direct patients and their families through the healthcare system and help them overcome barriers, lay navigators do not require formal clinical training (The Center for Health Affairs, 2012). Professional navigators, on the other hand, are generally healthcare professionals such as nurses or social workers who take on additional navigation responsibilities. In Canada, majority of the navigators are nurses (Walkinshaw, 2011).

The studies from this literature review focused on professional navigators, rather than lay navigators. It is also vital to note that the term “patient navigator” is interchangeably used to refer to professional navigators.

Educational requirements for ONNs

Apart from the roles of a licenced nurse, the ONN needs to develop competencies to integrate the roles of a healthcare promoter, educator, counselor, care coordinator, case manager, researcher, and patient advocate. Hence, educational programs for preparing ONNs must ensure that professional nurse navigators are equipped with the necessary knowledge so as to fulfill their roles competently and ethically. ONNs are professional in nature (in comparison to lay-navigators, who are more non-clinicians) and have more in-depth knowledge and expertise on cancer-related interventions. They are more likely to be resource-intensive, and offer the highest level of service and support for patients. Professional requirements to become a nurse navigator include a bachelor’s degree in either health or social sciences with experience in clinical social work and knowledge of local community resources, and/or with experience in quality improvement (Schwaderer & Itano, 2007). Due to the fact that there are rapid scientific and technological advances in cancer care, nurses must maintain current and highly specialized knowledge to provide care. Oncology nursing certification, Certified in Oncology Nursing Canada (CON (C)), is required for nurses to gain specialized knowledge and experience needed for competent performances.

Efficacy of Oncology Nurse Navigators

The purpose of this integrative review is to explore the presence of the oncology nurse as a navigator on measurable patient outcomes. It is important to note the literature review is based on the keywords used in the literature search relating to the ‘role of nurse navigator’ and within the ‘diagnostic phase’. Evidence showed that navigators act as care coordinators and provide the necessary information in a comprehendible way, so as to prepare their patients for decision-making and making the diagnostic process more effective and efficient. The efficacy of nurse navigators indicates the capacity of beneficial change with respect to patient outcomes based on their roles within the diagnostic phase. Based on the literature review, efficacy of nurse navigators can be categorized under the following themes: improving screen rates; improving adherence to diagnostic services after detection of abnormality; improving cancer treatment; improving co-ordination of care; and patient assessment and support.

Improving screening rates

There was evidence of efficacy of nurse navigation in improving screening rates for cancer patients. According to a study by Nash, Azeez, Vlahov, & Schori (2006), professional navigators are significantly effective in decreasing healthcare barriers to colonoscopy screening tests. Although screening tests for colorectal cancer are highly effective at detecting cancer at an early stage and improving survival rate, colorectal screening uptake is low. Factors that contribute to the barriers to colonoscopy screening tests include source of care, racial/ethnic group, educational level, and long wait time for appointments. Nash *et al.* (2006) conducted a retrospective analysis of all colonoscopies performed over an 11-month period, during which professional navigators were hired during the study period to provide continuity for colonoscopy patients. It was determined that immediately after the introduction of the navigators, there was a significant and constant decline in broken appointment rates for screening colonoscopy (from 67% in May, 2003 to 5% in June, 2003). In addition, the rate of screening colonoscopies increased from 56.8 per month to 119 per month. Although, the findings from Nash *et al.*'s study stated the increase in the number of screening colonoscopies was successful due in large part to the influence of the navigators, the implementation of a direct endoscopic referral system and gastrointestinal suite enhancements (utilized for operational efficiency) were also significant factors in contributing to the improvement of screening rates. Since this study showed the combined efforts of nurse navigators with other factors, it is difficult to conclude that the improvements of colonoscopy screening rates were due solely to the services of professional navigators alone. However, Lasser *et al.* (2011) found that professional navigators alone significantly increased completion of colorectal cancer screening (total of 33.6% of patients in the intervention group with a navigator, with a sample size of 425, had been screened compared to 20.0% of control patients with usual care) among ethnically diverse patients. Results of this study indicated the effects the professional navigators' role in improving screening rates. It is interesting to note that although the study by Nash *et al*. (2006) and Lasser *et al.* (2011) both focused on the impact of professional navigators on colorectal screening rates, the results from Nash *et al.*'s study portrayed an immense improvement in screening rate compared to the results from Lasser *et al.*'s study. These results suggest that professional navigation must be combined with other factors, such as a direct endoscopic referral system or educational outreach programs, to increase adherence to screening tests to the maximum level. Another explanation of the finding is that professional navigators must enhance their role of being culturally competent because patients at greatest risk for not being screened include racial minorities (Walsh *et al.*, 2004), and those who are foreign born (Goel *et al.*, 2003). A limitation to these studies was that the majority of them focused on the efficacy of navigators on colorectal patients and not on lung cancer or other cancers.

Improving adherence to diagnostic services after detection of abnormality

Delay in follow-up after the detection of an abnormality is associated with advanced disease stage, increased anxiety rates, and poor survival rates. Several studies (Freeman, Muth, & Kerner, 1995; Battaglia *et al.*, 2007; and Ferrante, Chen, & Kim, 2007) emphasized that the use of patient navigation program had a positive patient experience, as well as an effective diagnostic assessment period. These studies reported the effectiveness of a patient navigator in improving adherence to follow-up visits after the detection of a screening abnormality (of those patients with a navigator, 87.5% completed diagnostic tests after detection of abnormality, compared with 56.6% of the patients without a navigator) (Freeman, 1995); timely follow-up after detection of abnormality (78% had timely follow-up after introduction of navigator versus 64% in preintervention without navigator support) (Battaglia *et al.*, 2007); decreasing anxiety (Ferrante *et al.*, 2007); and increasing satisfaction (Ferrante *et al.*, 2008) of patients who were screened for breast, cervical, prostate, and colorectal cancer. It is important to note that these studies included participants from an urban population. The studies identified that delays in follow-up after cancer screening were related to racial/ethnic disparities in cancer outcomes. Not only did these studies provide evidence of the effectiveness of a patient navigator in improving adherence to diagnostic services after detection of abnormality, but they also identified the importance of a navigator in decreasing barriers related to culture and ethnicity so as to allow for timeliness to diagnostic resolution.

In a Canadian context, Melinshyn & Wintonic (2006) identified supportive care as key function of a nurse navigator that is required to facilitate the diagnostic assessment process after a detection of a breast abnormality. Supportive care is “the provision of necessary services as defined by those living with or affected by cancer, to meet their physical, informational, psychological, social and spiritual needs during the pre-diagnostic, diagnostic, treatment and follow-up phase” (Ontario Cancer Treatment and Research Foundation, 1994, p.15). According to Melinshyn and Wintonic, the process of undergoing diagnostic investigations can cause several stressors such as physical, emotional, spiritual, and psychological nature for patients, which can have a significant impact on delaying diagnostic tests. Similarly, DeGrasse, Hugo and Plotnikoff (1997) explained that the principal supportive care needs of women during the time prior to diagnosis are receiving sympathy from health professionals and acquiring a diagnosis as quickly as possible. Accordingly, the nurse navigators are in the key position to provide health teaching for those individuals who have high levels of anxiety about a particular diagnostic process and minimize the impact of stressors (Melinshyn and Wintonic, 2006). It is important to note that Melinshyn and Wintonic are both oncology nurse navigators, who described their personal experiences and thoughts as an ONN. Although it is not a phenomenological study, the authors did point out the subjective roles they follow in providing effective cancer care, thus allowing for a valid interpretation of the findings. Moreover, these authors pointed out a key function (supportive care) that is used in the present study to determine the impact of the role of the ONN on patient experience using a qualitative approach.

A gap in these studies is the lack of evidence showing improvements in adherence to diagnostic services among patients who have lung cancer. However, the present study aims to address this gap by determining if the role of the ONN impacts timely adherence to diagnostic services for patients with a suspicion of lung cancer.

Improving cancer treatment

The impact of nurse navigators on the timeliness of initiating cancer treatment is diverse. A study by Ell *et al.* (2002) found that there was no significant improvement in the timeliness of commencing breast cancer treatment for patients who received aid from nurse navigators and counselling compared with patients who received no direction and support from nurse navigators. However, another study by Ell, Vourlekis, Lee, & Xie (2007) reported that patients who received nurse navigation and support had faster initiation of breast cancer treatment compared to patients who were randomly assigned to receive usual care. The women (with abnormal mammogram) were randomly assigned to either the intervention group with nurse navigator support, or the control with usual care. Results showed that the intervention group had a significant increase in the rate of adherence to follow-up through diagnosis resolution and faster initiation of breast cancer treatment compared to the women in the control group (90% vs. 66% adherence percentile) (Ell *et al.*, 2007).

A notable study (Freeman & Wasfie, 1989) which initiated the development of the first navigation program in 1990 was called the “Harlem Experience”. In a 22-year period ending in 1986, 606 patients (predominantly African Americans) were treated at the Harlem Hospital Center. Nearly half of the patients with breast cancer were incurable at diagnosis (Stages 3 and 4) and only 6% were in the early stage (Stage 1). The findings stated that the five-year survival rate of these patients was 39% compared to more than 60% in American white women during that time (Freeman & Wasfie, 1989). Shortly after that study was the establishment and implementation of the first navigation program at the Harlem Hospital Center by Dr. Freeman, ‘the father of patient navigation’. In a separate study afterwards by Oluwole *et al.* (2003), 324 breast cancer patients (majority were African American and Hispanic) were diagnosed and treated at the Harlem Hospital between 1995-2000. The findings from this study showed dramatic improvements in initiation of treatments and consequently survival rates. The results also showed that 41% of the patients were in Stages 0 and 1, and only 21% in Stages 3 and 4 (Oluwole *et al.*, 2003). This study concluded that a major factor, which accounted for the dramatically improved results, was due to the navigators who promoted treatment with no delay.

Improving co-ordination of care

A study conducted by Nash *et al*. (2006) observed a healthcare program that consisted of nurse navigation in a hospital-based colonoscopy clinic. This retrospective, quantitative study showed a decrease in the number of missed appointments and an increase in the number of colonoscopies monthly. Furthermore, there is evidence that patients who received navigation had significantly shorter wait times compared to patients without the assistance of navigation in the diagnosis stage of breast assessment (Psooy *et al*. 2004).

There have been various descriptive studies on the effectiveness and impact of nurse navigation from program evaluations across Canada. It has been recognized that healthcare professionals find the assistance of local nurse navigators allows for preparing the patients for appointments more effectively, allows physicians to make more efficient use of their time with their patients, and greater success in working with cancer agencies to effectively book appointments and procedures (Cancer Care Nova Scotia, 2004). Also, nurse navigators are especially beneficial in managing complex cases when patient volumes are high and when multidisciplinary work is needed (Fillion *et al*. 2006). Cancer Care Ontario (2007) reported that there has been a significant reduction in diagnostic wait times and patient anxiety after the implementation of a navigator within diagnostic assessment programs for thoracic (lung), prostate and colorectal cancers.

Patient assessment and support

Complex cases of cancer require more nursing knowledge and expertise in order to provide quality care (College of Nurses of Ontario, 2009). Nurses' knowledge and their ability to amalgamate the necessary information enable them to assess patients who need more support and/or urgent care. It was shown that when nurse navigators interpret clinical information into appropriate language and share this with the patients, this alleviates anxiety and prepares the patients for the diagnostic process and the complex decision-making that lie ahead. Furthermore, their knowledge and experience in cancer treatment, and the awareness of potential side effects increase their ability to navigate patients through the cancer care system (Seek & Hogle, 2007). According to Rees & Bath (2000), it was reported that the most important information needs of cancer patients deals with their diagnosis and treatment options. The presence of a nurse navigator who is responsible for patient care offers both the patients and physicians appropriate information and resources. This in return effectively augments the patient's ability to directly participate in decision-making (Sainio, Eriksson, & Lauri, 2001).

Challenges Encountered with Nurse Navigators

Although results from previous studies (Battaglia et al., 2006; and Ferrante et al., 2007) state that the role of nurse navigators provide proof of improved patient outcomes, there are however challenges encountered with nurse navigators. The Canadian Partnership Against

Cancer (2010) established a guide to implementing navigation, which included the challenges faced by implementation of patient/nurse navigators within hospital settings. The role of a nurse navigator is new and requires training. Without the appropriate training and education, it will be difficult for nurse navigators to interpret clinical information into appropriate language for patients, and thus unable to reduce stress and anxiety, which in turn may result in delaying appropriate treatment. Nurse navigators must have a proactive, rather than a reactive approach to care, which involves teamwork. However, there might be initial resistance to integration of a new role and change in the work culture by oncology nurses. This may lead to initial resistance to collaboration. Furthermore, nurses play host to a high level of compassion fatigue and burnout (Canadian Partnership Against Cancer, 2010).

Summary of Key Findings

Nurse navigators are a solution and an approach to attending to informational and psychosocial needs of the cancer patients to facilitate and advance the diagnostic processes (Melinyshyn & Wintonic, 2006). ONNs collaborate with a patient and his/her family to provide support as they go through the maze of treatments, services and potential barriers throughout the cancer journey. The roles of the ONNs include (but not limited to): reducing barriers to timely access of diagnostic services; initiating and maintaining an ongoing relationship with patient during the diagnostic phase; enhancing the patient’s sense of self-care and self-determination through education and support; facilitating problem solving and decision making; helping the patients understand their diagnosis and available treatment options; discussing symptom management due to treatment and recovery; and conducting comprehensive supportive care needs. For the purpose of this study, an oncology nurse navigator is defined as professional healthcare provider with a strong background in nursing and oncology, who facilitates continuity of care and promotes patient empowerment so as to navigate the patients and their families effectively through the cancer care continuum.

Based on this overall literature review, the results indicated that the role of nurse navigators has a positive influence on patient experience of adult patients living with cancer. There have been confirmations that nurse navigators improve the patient experience by providing information where needed and reducing anxiety and stress levels. Furthermore, evidence showed that navigators act as care coordinators and provide the necessary information in a comprehendible way, so as to prepare their patients for decision-making and making the diagnostic process more effective and efficient. In addition, nurse navigation is designed to reduce health disparities by addressing specific barriers to obtaining timely and quality health care.

However, there is limited published evidence (especially Canadian studies) that showed the impact nurse navigation has during the diagnostic phase of cancer care. Moreover, by reviewing and analyzing the literature, a key gap found was that majority of the studies focusing on cancer care measured patient outcomes (e.g. screening rates, adherence to diagnostic services, etc.) in a quantitative manner, and there is a paucity of qualitative studies. The lived experience of a patient and the roles of the nurse navigator, should be further explored to gain an understanding of the underlying reasons, or the “why” and “how” behind certain behaviours. It further enables more complex aspects of a patient/nurse navigator’s experience to be studied.

This study will fill these gaps in the literature by asking the following question: how does the role of a nurse navigator in the diagnostic phase influence the overall experience of adult lung cancer patients? By using a newly designed Bi-Dimensional Framework developed by Fillion *et al.*, 2012 (which will be discussed in the following section) to guide this phenomenological study, the researcher has uncovered the roles of the nurse navigator and the lived experience of lung cancer patients. Thus, this study has explored the lived experiences of both the patients and the nurse navigators. This is the first qualitative study which captures the roles of nurse navigators in order to understand how they perceived their roles impact continuity of care and patient empowerment. Lastly, this study builds upon the body of knowledge of nurse navigators and lung cancer patients' outcomes, since lung cancer is the leading cause of mortality in cancer. The methodological approach of how this research question is explored will be discussed in the next chapter.

Overview of the Bi-Dimensional Framework

A key gap found during the literature review was the absence of qualitative studies. Quantitative research methodologies dominated the empirical literature, perhaps because the themes within the efficacy of ONNs focus on the operational outcomes. Measurable outcomes of practice, although vital in determining operational efficiency, may not get the attention in this newly developed role. Nursing relations specifically require observation of the behaviours and responses of both the nurse and patient (Arnold & Boggs, 2003, p.10), and are understood as they are lived and reflected upon. Convinced of this, I chose phenomenology as the theoretical perspective for this study. To guide the study methodologically, a newly established Bi-Dimensional Framework was used to determine the lived experience of patients and nurse navigators. This framework sought to acknowledge the qualitative aspect of determining how the role of oncology nurse navigator affects patient's experience by focusing on the bi-dimensional nature of the role: organizational and clinical.

The Bi-Dimensional Framework was established in early 2012 to bring clarity to the roles and functions of professional nurse navigators and suggested relevant outcomes for program evaluations in a Canadian context (Fillion *et al.*, 2012). It assisted the nurse navigators in being more efficient and less challenged in terms of setting priorities and making decisions, while facing demands from the healthcare system and patients. This integrative framework could provide support to the effectiveness of cancer navigation programs, such as the diagnostic assessment program offered at the Durham Regional Cancer Centre at Lakeridge Health. The framework comprised of two-theoretic dimensions of (a) facilitating continuity of care and (b) promoting patient empowerment.

Dimension 1: facilitating continuity of care

The first dimension refers to facilitating continuity of care, which comprises of three related concepts of informational, management, and relational continuity. These three concepts seek to define the organizational functions of the role and when applied they create a coherent and connected experience of care for patients with cancer.

Informational continuity can be defined as the "transmission belt" (Fillion *et al.*, 2012). This is when professional navigators acquire high levels of patient-centered information so as to provide timely and tailored information and advice to the patients, their families, and to other healthcare providers from interdisciplinary teams. The use of diverse communication tools and strategies improve continuity of information and knowledge.

Management continuity is facilitated by conducting comprehensive screening and needs/resources assessment at the beginning and in an ongoing way through the cancer continuum (Fillion *et al.*, 2012). This ensures that the patients are being given efficient and timely support, such as referrals to community services, resources and support systems within the cancer care organization. This concept further corresponds to how the navigators identify lack of resources, find temporary solutions, and report system gaps so as to map the continuum of cancer care, explain treatments and care plans, and decrease barriers to cancer care adherence while minimizing uncertainty for the patients (Fillion *et al.*, 2012).

Finally, relational continuity can be described as maintaining a continuous relationship with the patients and their families throughout the stages of their cancer care experience (Fillion *et al.*, 2012). Professional navigators should be easily accessible, have finely tuned skills in therapeutic conversations, and be able to map the cancer journey. This sustained presence of a professional navigator decreases the distress and increases feelings of confidence for the patients and their families (Fillion *et al.*, 2012).

Dimension 2: promoting patient empowerment

The second dimension refers to promoting patient empowerment, which comprises of three related concepts of active coping, self-management, and supportive care. These three concepts seek to define the clinical functions of the role.

Active coping is defined as assisting patients and their families to actively attain the information, support and referral they need (Fillion *et al.*, 2012). In this concept, the professional navigators should actively provide education and support on coping options to deal with several life changes, facilitate problem solving and decision making around those changes to patients and their families.

Self-management describes the use of various specific efficacy-enhancing techniques by the professional navigators to provide support to the patients while coping with their cancer (Fillion *et al.*, 2012). The use of these techniques can aid the cancer patient to better deal with their health problems and symptom management related to his or her cancer, as well as to accept the illness and regain control regardless of the prognosis. The practice of this concept seeks to provide or facilitate symptom management by assisting and reinforcing the patients in adjusting to and proactively managing their altered health state and symptoms through timely and tailored information and self-care instructions (Fillion *et al.*, 2008).

Lastly, as a third way of reinforcing empowerment, supportive care is utilized to better integrate the clinical functions related toward addressing global distress and patients' unmet needs. Supportive care follows a patient-centered model (Fitch, 2008), and seeks to assist patients and their families with the full range of needs including physical, informational, practical, emotional, psychological, social and spiritual. This is done through helping the patients and their families get access to supportive care by screening, assessing, providing direct care or intervention, and referring (Fillion *et al.*, 2008). In essence, the goal is to provide access to the necessary services, as requested by those living with cancer so as to meet their needs.

Chapter III

Methodology

This chapter outlines the research methodology and procedures used for the study. It maps the process strategically designed and implemented to meet the study's goal. Included are the reasoning and justifications behind each step in the research process. It consists of the following sections:

1. *Study goals and study design*: describes the general overview of approach used to meet the study's goals.

2. *Research setting*: explains where the study participants were recruited from and where the study took place.

3. *Study participants*: describes the sample, sample size, and inclusion/exclusion criteria by which they were chosen.

4. *Ethics and research approval*: describes the process by which this research study went through to obtain ethics approval from all institutions to conduct research with human subjects.

5. *Recruitment strategy*: describes the process taken to recruit the participants for the study.

6. *Data collection*: describes the process taken and methods used to collect the data.

7. *Data analysis*: describes the process used to analyze the study data.

Study Goals and Study Design

This research study examined the following research question:

- How does the role of a nurse navigator in the diagnostic phase influence the overall experience of adult lung cancer patients?

The primary goal of this study was to document the lived experiences of adult lung cancer patients within the diagnostic phase based on the care provided by their nurse navigators. The secondary goal of this study was to document the views and perspectives of the nurse navigators working within the diagnostic assessment program and how they perceive their cancer care affects their patients' experiences. Investigating how the role of a nurse navigator affects patient experience provided results to determine the core areas of practice. The identified core areas of practice can be used as a foundation to acquire and maintain the skills to practice in the oncology field, in order to develop the nurse navigator's role to its full potential. As this study's main goal is to evaluate the effectiveness of the newly implemented ONN role on patient experience at DRCC, it is also intended that these identified core areas of practice will support managers and nurse navigators in evaluating the individual nurse navigator's role. It is hoped too, that these identified areas of practice will help in obtaining and maintaining the structures, processes and educational options needed to support the nurse navigators, especially a new nurse navigator to meet the standard of excellence. This understanding will optimize patient outcomes, and also provide further evidence so as to allow for the nurse navigator program to be delivered in a more standardized way across Ontario.

To achieve the goals, the views of cancer patients and nurse navigators at a diagnostic assessment program within the DRCC at Lakeridge Health were explored using a phenomenological approach. Participants were recruited based on meeting the eligibility criteria. All participants signed the consent form which consists of all the details of the study along with the research ethics board approval from the University of Ontario Institute of Technology and Lakeridge Health before participating.

The overall patient experience was described based on the Bi-Dimensional Framework developed by Fillion *et al.* (2012), consisting of continuity of care and patient empowerment. The goal of the present study was to explore the concept of nurse navigation within the theoretic concepts of continuity of care and patient empowerment to determine the organizational and clinical nature of the role. Continuity of care and patient empowerment were qualitatively described following interviews with the patients and a focus group with the nurse navigators. Data were then analyzed in a categorized scheme.

Research Setting

The research study took place at a community based hospital in Oshawa, Ontario. The R.S. McLaughlin Durham Regional Cancer Centre, a Cancer Care Ontario partner, within Lakeridge Health was chosen for this study. The diagnostic assessment program within the DRCC is an outpatient oncology program dedicated to providing patients continuum of care during the diagnosis phase of cancer. For the purpose of the study, the nurse navigation program within the diagnostic assessment phase focusing specifically on the lung cancer was chosen. The particular program is targeted to determining the diagnosis of the cancer, the cancer stage, and providing support services. This research setting was chosen because the oncology nurse navigation program was newly implemented in 2009 at DRCC, and there was a need to evaluate the program for the effectiveness on patient experience. Furthermore, it is important to note that there have not been any other research studies previously conducted that examined how the role of nurse navigators affect lung cancer patients within the diagnostic phase of cancer care.

Study Participants

Inclusion and exclusion criteria

In order to participate in this research study, potential participants were required to meet certain requirements. The inclusion and exclusion for both the nurse navigators and the patients are outlined below.

Inclusion criteria for patient participants

The patient participants in this study consisted of cancer patients referred to the diagnostic assessment program within the DRCC with a suspicion of lung cancer. Participants were adults above age of 18 years and of either gender. Participants should have had at least two contacts with their nurse navigator (prior to data collection). The number of contacts was justified based on the actual practice, and as well in consultation with a nurse navigator within DRCC at Lakeridge Health (M. McGregor, personal communication, January, 2013).

Exclusion criteria for patient participants

This study did not include non-English speaking, writing, and reading participants. As well, any individuals with pre-existing mental disorders as categorized by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 2000) were excluded from this study as the participants must be fully aware of the services being provided by the nurse navigators and be able to communicate the impact of those services provided.

Inclusion criteria for nurse navigator participants

The nurse navigator participants in this study consisted of nurse navigators providing health care at the DRCC and working in the diagnostic assessment program within the lung cancer department. All participants have completed lung-specific courses as well as hold the designation of CON(C), Certified in Oncology Nursing (Canada).

Sample size

There is no strictly required number of participants for a phenomenological study, but instead the participants must be recruited based on the size of text being generated, the number of observations and interviews that were repeated, time constraints, and the number of researchers involved (Bender, 2009). Crabtree and Miller (1991) recommend that exploratory qualitative studies in primary care research use samples of 6 to 8 respondents. This small sample size makes it possible to explore issues with sufficient depth and flexibility to seek insight that may be overlooked in large sample studies. However, a more recent paper written by Baker and Edwards (2012) on ‘how many qualitative interviews is enough?’ stated that a sample size of 12-20 participants is sufficient for qualitative studies for undergraduate and graduate level theses. “This number gives them experience of planning and structuring interviews, conducting and partially transcribing these, and generating quotes for their papers. More than this number seems to be impractical with their customary time constraints” (Baker & Edwards, 2012). The number of participants therefore is anticipated at the commencement of the study to meet this aim, recognizing that the number may change once the study is under way.

The study sample size (n= 8) was calculated in consultation of the nurse navigators within the DRCC. The admittance rate for lung cancer patients at the DRCC is approximately 35 new patients per month. In conjugation with the literature review, and the restrictions of recruiting participants within a limited population meeting the eligibility criteria mentioned in the inclusion/exclusion section, as well as time restraints for data collection, a sample size of 4 patients was utilized. The number of nurse navigators used in this study was 4 as there are 4 nurse navigators within the DRCC providing lung cancer specific care.

Ethics and Research Approval

Ethics approval was required for this study as it involves human beings as participants. Ethics approval helps protect the welfare, rights, dignity, and safety of these research participants, and was required to protect the researcher's rights to conduct a legitimate investigation. Ethical considerations for this study were met according to the Research Ethics Board (REB) from the University of Ontario Institute of Technology (File 12-012) and Lakeridge Health (File 2012-025). UOIT had undergone an expedited review, based on a full review from Lakeridge Health REB (see **Appendices A** & **B**).

The participants in this study were provided with an informed consent. They were informed that they would be tape-recorded during the interview/focus group, and about who would have access to the data/audio-tapes and where they would be stored. As indicated in the Participant Consent Form, the study did not include any known potential harm, injury or discomfort to the participants. Subjects' participation was voluntary and they were able to withdraw from the study at any time without any consequences to the care they are entitled to receive at DRCC (for the patients) or the employment at DRCC (for the nurse navigators).

Participants were also informed of their right to not answer any of the questions that they feel uncomfortable answering without any consequences (see **Appendices C** & **D**).

Prior to the interview, participants had the opportunity to ask the researcher questions. Then the participants were asked to read and sign the written consent form in order to participate in the study. A copy of the consent form was given to participants for their records.

Confidentiality of information and anonymity of subjects were maintained. The data were entered into a password protected computer, which was only accessible to the researcher. The names, and contact information of the participants did not appear on any forms or on any type of publication. An ID code was used as an identifier, as well as to keep all the names disclosed. All the focus group recordings, consent forms, and personal information collected were kept private in the faculty supervisor's (Dr. Manon Lemonde, PhD, RN, at UOIT) office at UOIT, and only the researchers had access to the data. All recordings and transcriptions will be kept for 5 years after the completion of the research study. After the 5 year period, all data will be destroyed in a proper manner and any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format were destroyed by reformatting, rewriting or deleting. The participants were informed that all the information provided by them will remain confidential and will only be utilized for the purpose of this research.

Recruitment Strategy

The type of sampling used in this study is convenience sample. The nurse navigators were asked to identify patients based on the eligibility criteria using patient records and telephone assessments. This ensures that there is no variability in the care and treatment process. The list of the patients meeting the eligibility criteria was then provided to the receptionist within the diagnostic assessment program along with the letter of invitation to provide to those potential participants (see **Appendix E**). The receptionist also provided the consent forms to those patients and obtained a list of names (and contact information) of those that were interested in participating. A script was written for the receptionist to follow when informing the patients about the study and requesting for their permission to provide their contact information to the primary researcher (see **Appendix F**). Furthermore, since a verbal consent was required by the patients to allow DRCC- Lakeridge Health to provide the primary researcher with their contact information, a patient verbal consent worksheet was created to track the patients that have given verbal consent. The worksheet included the patient's name, notification of whether they provided verbal consent, and the date of the verbal consent (see **Appendix G**). The names of those who agreed to hear more about the study were then passed on to the primary researcher, who contacted the patients and informed them about the study in detail. Following the contact with the patients, those who have agreed to participate in the study were then asked to sign the consent form. Those who did sign the consent form were recruited as part of the sample of the study. These participants were asked to participate in a scheduled interview (interview time was based on the next appointment date at the DRCC).

The primary researcher emailed the nurse navigators working within the diagnostic program at DRCC inquiring about their interest to participate in this study with the letter of invitation (see **Appendix H**). Those who were interested had a chance to inquire of the primary researcher about the study in detail, and were then required to sign the consent form to participate in the focus group.

Data Collection

It is important to note that both observations and interviews are crucial in phenomenological studies because taken for granted habits are “too much part of the participant’s world” (Benner, 1994) to be discussed in interviews alone (Bender, 2009). Observations ensure the actions and interactions themselves give meaning to the behaviours and beliefs of the participants. The original goal of data collection was to incorporate both interviews and observations of the interaction between the nurse navigator and the patients to validate the interviews, however due to time restraints and patient unavailability, the observation portion of data collection had to be withdrawn from the study.

The process taken during the data collection is outlined below accordingly:

1. Brief Introduction: welcoming the participants, providing a brief overview of the interview/focus group and its purpose, and stating the ground rules of the interview/focus group (see **Appendix I**).
2. Consent Form: ensuring the participants understand/agree with everything on the consent form, and signing the consent forms. Two copies (one for the primary researcher, and the other for the participant’s own record) of the consent forms were signed by the participant as well as the primary researcher on the spot.
3. Socio-demographics Form: the participants were asked to fill out a socio-demographics form before the start of the interview/focus group. More details about the form are described below.
4. Conduct the interview/focus group

5. Brief Thank You: all participants were thanked for their participation, and the patient participants were provided with a thank you card with 10 dollars as compensation for their parking expense for the time spent during the interview.

Data were collected after the patients have been assigned to and have had at least two contacts with the nurse navigator at the DRCC (in scheduled meeting rooms). Data were collected through self-administered socio-demographic forms, interviews, and focus group discussions. The following sections will explain this in detail.

Primary method: self-administered socio-demographics forms

Both groups of participants were given a socio-demographics form to complete individually. The forms contain questions such as age, level of education and diagnosis for the patients, and the number of years practiced as a nurse navigator, employment status and the number of years within the diagnostic assessment program for the nurse navigators (see **Appendices J** & **K**). The socio-demographics forms were utilized to determine and describe the characteristics of the sample.

Secondary method: interviews, focus group and audio-recordings

Both the interview and focus group questions were based on the concepts within the Bi-Dimensional Framework (Fillion *et al.*, 2012). Continuity of care was subdivided into three concepts: informational continuity; management continuity; and relational continuity. Patient empowerment was subdivided into three concepts: active coping; self-management; and supportive care (see **Appendices L** & **M**).

Continuity of Care: The Patient Continuity of Care Questionnaire (PCCQ), a standardized questionnaire, was used in developing the interview/focus group questions relating to the continuity of care aspect. The PCCQ was originally developed by Jeff Sisler from the University of Manitoba (n.d.) to evaluate patient perceptions of factors impacting continuity of care. The PCCQ contains six subscales including perceptions of: 1) relationships with providers in hospital, 2) information transfer to patients, 3) relationships with providers in community, 4) management of written forms, 5) management of follow-up and 6) management of communication among providers. These subscales are valuable in identifying problems in continuity of care and for evaluating interventions aimed at improving continuity of care for patients (Hadjistavropoulos, Biem, Sharpe, Bourgault-Fagnou, & Janzen, 2008).

The continuity of care aspect of the questions pertains to how the patients perceive their nurse navigator provide them with timely information (informational continuity), manage their care (management continuity) and maintain an ongoing relationship (relational continuity), and as well how the nurse navigators perceive their roles affect the patients with respect to each concept accordingly.

Certain statements from the PCCQ were chosen and matched with each concept within the continuity of care dimension based on the description provided for each concept by Fillion *et al.* (2012). Subsequently, interview questions were formed based on the two sources.

Figure 1 provides an example of the development of the patient interview question for ‘informational continuity’.

PCCQ (Sisler, n.d.)	**Description of ‘Informational Continuity’** by Fillion *et al.* (2012)	**Formation of patient interview question**
“I was provided with clear information on my diagnosis.”	“Use of information, disease- or person-focused, to make current care appropriate for each individual.”	Did the nurse navigator provide timely and personalized information or advice to you? Please provide an example of a time when this occurred.

Figure 1. Example of the process taken to develop the interview questions.

Patient Empowerment: A detailed description of the concepts within the Bi-Dimensional Framework as portrayed by the authors who developed the framework (Fillion *et al.*, 2012) was used to develop the questions pertaining to the patient empowerment aspect.

The patient empowerment aspect of the questions pertains to how the patients perceive their nurse navigator provide coping options (active coping), provide support in order for them to proactively self-manage their altered health (self-management) and address their needs (supportive care), and as well as how the nurse navigators perceive their roles affect the patients with respect to each concept. Similar process as the interview questions pertaining to continuity of care was taken to develop the interview questions for patient empowerment.

Interviews

All patient participants engaged in a semi-structured interview with open-ended questions, and were interviewed by the primary researcher. These one-to-one conversations with the patients were held in scheduled meeting rooms within the DRCC at Lakeridge Health at the patients’ next available appointments.

In keeping with a phenomenological approach, the interviews were in a conversational manner so as to allow the patients to structure their own narratives thus recalling immediate experiences. As Benner (1994) stated, “There is no one precise story” but instead “multiple stories that are shaped by the particular clearing created by the interview situation” (p.111). The patient interview questions were phrased as concretely, descriptively, and openly as possible, in ordinary language, to elicit a detailed response as possible of the participants’ own experiences and reflections. At the end of each interview, the patient participants were offered the opportunity to add anything they felt was necessary about their relationship with their nurse navigator that may add importance to the study. The general length of the patient interviews lasted for 15-20 minutes.

Focus group

All nurse navigator participants engaged in a semi-structured focus group with open-ended questions, interviewed by the primary researcher. This focus group discussion with the nurse navigators was held in a scheduled meeting room within the DRCC at Lakeridge Health.

A conversational style focus group allowed the nurse navigators to build up on their own responses and promoting a healthy dialogue, as well as enabled the primary researcher to pose follow-up questions and ask questions that probe more deeply (Bender, 2009). This allowed for data saturation ensuring maximum information needed to answer each question was met. At the end of the focus group, the nurse navigator participants were also offered the opportunity to add anything they felt was necessary about their relationship with their patients that may add importance to the study. The focus group lasted for 35 minutes.

Audio recordings

All participants who agreed to an interview/focus group also agreed to have the interviews/focus group audio-recorded, which was then transcribed verbatim into written text. Notes were also taken during the interview/focus group, which included aspects of the participants' communication that stood out (points in the conversation where clarification was needed due to language barriers, poor audibility, or lack of comprehension on certain terms).

Data Analysis

Data analysis was an ongoing process. Before data were analyzed, all interview/focus group audio-recording were transcribed verbatim in written text. The primary researcher transcribed all the interviews so as to be consistent. Each recording was reviewed for audibility on the same day as the interview and transcribed within the following week. Qualitative software packages, such as NVivo, was considered at the beginning to assist with the transcription and analysis of the data, however, such software packages are most useful for qualitative studies with several researchers involved and very large amounts of data (Bender, 2009). Given that this study was a comparatively small qualitative study, Microsoft Word was used to record, store, organize, and retrieve the data. Furthermore, this decision was made in realization that as technically useful as NVivo is for managing data, no computer software can substitute the reading, thinking, and writing required for a comprehensive qualitative data analysis.

All the participants were assigned an ID code so as to keep the information organized, and to protect participants' privacy and confidentiality. This code appears on the transcripts and tapes with each of the interview/focus group recordings. To maintain privacy and confidentiality, any names mentioned in the recordings were removed and replaced with words such as "nurse navigator" or "patient A."

Thematic analysis and coding

In this study, the themes that generated from participants' narratives came together through the iterative process of thematic analysis. The goal of thematic (or content) analysis involves consideration of "meaningful patterns, stances, or concerns" (Benner, 1994) within each text, and creates a new understanding to the phenomenon (Bender, 2009). The entire analysis was addressed through interpretations and the specific parts of analysis were captured and organized in the process of 'coding'. Coding enabled the data to be organized and ensured the interpretations were associated with the research goals.

The process of analysis was guided by the thematic analysis process of Graneheim & Lundman (2004) who described the concepts, procedures and measures needed in order to complete a qualitative content analysis in nursing research. The following points describe the process taken to analyze the data using thematic analysis and coding:

1. Unit of analysis (Graneheim & Lundman, 2004): the entire transcript(s) were read thoroughly several times so as to become familiarized with the data.
2. Focus on analysis: a decision of how to focus on analysis was needed, whether by individual questions or by each concept within the Bi-Dimensional Framework. At the end, data were chosen to be analyzed according to the bi-dimensions (continuity of care and patient empowerment) and concepts within the bi-dimensions (based on the fact that the interview questions were developed within each concept), which in turn became the themes and sub-themes of the data accordingly.

3. Condensed meaning unit (Graneheim & Lundman, 2004): certain phrases or keywords (quotes) were highlighted within the text (within each concept of the transcript).
4. Analysis chart: analysis charts were created (see **Appendices N** & **O**) to organize the data (of the patient interviews and nurse navigator focus group) so as to ease the process of identifying the codes. The chart consisted of the already defined themes (continuity of care and patient empowerment), sub-themes (the concepts within each dimension- e.g. informational continuity within continuity of care), key phrases and words which were identified previously (Step 3), and a column to identify the emerging codes. These charts immensely facilitated the entire analysis process.
5. Identify connections: similarities and relationships between the chosen key phrases and words were identified and combined so as to strengthen data groupings. This process assisted in the categorizing the codes and as well enabled the researcher to create more specific codes.
6. Coding (Graneheim & Lundman, 2004): the process of coding was important for clearly distinguishing sub-themes. A ‘code’ was chosen to give meaning to the underlying data groupings.

Figure 2 illustrates the process taken to develop a code for the theme continuity of care, sub-theme management continuity, focusing on the interview questions for the nurse navigator focus group, *“How do you handle unmet needs of the patients? Do you believe it is important to involve the patients in planning their cancer care? How do you think participation of patient in care benefits the patients and their families?”*

Themes	**Sub-Themes**	**Condensed Meaning Unit**	**Identifying Connections**	**Codes**
Continuity of Care	Management Continuity	- *“it’s more of a working together arrangement than us telling them what they have to do”* - *“sense a loss of power”* - *“empower them to help make a decision that’s appropriate for them and involving them in the care then also will kind of help them to follow through with the plan of care rather than us giving the plan of care and they just have to follow it”* - *“phone assessment prior to the visit, the first visit for the patient, and based on their information needs, their social history, medical history, we target the care plan”* - *“it empowers them and they are more likely to follow through with the plan”*	- *“it’s more of a working together arrangement than us telling them what they have to do”* - *“sense a loss of power”* - *“empower them to help make a decision that’s appropriate for them and involving them in the care then also will kind of help them to follow through with the plan of care rather than us giving the plan of care and they just have to follow it”* - *“it empowers them and they are more likely to follow through with the plan”* --------------------------- - *“phone assessment prior to the visit, the first visit for the patient, and based on their information needs, their social history, medical history, we target the care plan”*	Shared Decision-Making -------------------- Target Unmet Needs

Figure 2. Example of the process taken to develop codes.

Similar approach to analyzing the data of both the interviews and focus group was used. Although the focus group only required analysis of one transcript as a whole, the interview transcripts were analyzed two at a time and then combined as one during the data grouping step to facilitate analyzing large amounts of data. Furthermore, ‘outsider’ checks of the analysis occurred through conversations with the members of the supervisory committee.

Chapter IV

Results

This chapter will review the results from the evaluation of the patient experience based on the roles of the nurse navigators. The qualitative data were collected using patient interviews and nurse navigator focus group. The results of the analyses performed will be reported in the following two sections: (1) results pertaining to the patient interviews and (2) results pertaining to the nurse navigator focus group.

Patient Interviews

This section will consist of the results gathered from the patients, which includes the semi-structured interviews, and the socio-demographics form. The results have been organized into the following sections:

1. *Results of recruitment*: describes how many patient participants were recruited in the study based on the consent and meeting the eligibility criteria.
2. *Demographics of participants*: describes the characteristics of the sample recruited based on the information provided in the socio-demographics form.
3. *Results of the interview*: describes the data gathered from the patients with respect to the Bi-Dimensional Framework: (1) continuity of care; (2) patient empowerment.

Results of recruitment

Patient recruitment and data collection occurred from January, 2013 to the end of April, 2013. This time period was chosen, in discussion with the nurse navigator (McGregor, personal communication, January, 2013), based on the list of patients, as provided by the nurse navigator, who had appointments during this time. A sample of over fifty patients was identified based on meeting the eligibility criteria. Due to time constraints in data collection, patients who resided only in Oshawa were selected. The reason behind this was that the patients who resided near the DRCC, in Oshawa, were more susceptible to coming in to the cancer centre compared to the patients who resided further away. However, these conditions may have caused sampling bias, to be discussed in Chapter VI.

Of the fifteen patients that were eligible to participate in this study, seven patients verbally consented to the receptionist to having the primary researcher call them to inform them about the study in detail. After the initial contact with the seven eligible participants, four agreed to participate in the study. Therefore, a total of four patient participants were recruited to be in the final sample of the study.

Demographics of participants

The demographics of the participants were collected through a self-reported socio-demographics form to determine the characteristics of the sample in the study. The demographic data collection disclosed a participant age range from 58 to 71 years old, with a mean of 64 years. There were two females (50%) and two males (50%). The highest level of education for three participants was high school, whereas the fourth participant chose college diploma as highest level of education earned. Three of the participants were married, and one was divorced. Additionally, three of the participants were of the “Canadian” ethnic origin, and one participant was of the Aboriginal origin. Only one participant was employed, whereas the other three participants were retired. All participants reported to having lung cancer, and have reported “right-lobe removed”. Two of the participants reported they experienced symptoms such as shortness of breath, weight loss, fatigue, and swollen joints during the diagnostic assessment phase. The other two reported no evident symptoms.

Results of the interview

The results from the patient interviews were systematically analyzed based on the concepts of the Bi-Dimensional Framework. These results are discussed in the following sections:

Continuity of care

The overall opinions of how the role of the nurse navigators impacted the patients were positive. Each patient described how his/her nurse navigator was able to co-ordinate care and how the organizational functions of the navigators' roles enabled him/her to have a positive experience during the diagnostic phase.

Informational continuity

All participants agreed that the nurse navigator provided timely and personalized information to them. Participant A mentioned "she was describing to me what was going to happen next (in the diagnostic phase)." Participant B added "she was providing information on a timely basis." When asked to provide specific examples of how the nurse navigator provided personalized information, Participant D said "She explained everything that was going to happen with the surgery. She went through the booklets and explained the type of surgery and what was going to be involved with it and answered my questions."

There was an overall consensus that the nurse navigator was also organized in providing personalized information. Participant A mentioned that "she was taking down notes for me. I didn't know it was for me…but everything was written down for me. To be able to read it again, which was huge." Participant A also mentioned that "she was doing my calendar." Personalized notes and calendars greatly benefited the patients to be on track with all the tests during the diagnostic process.

Moreover, all the participants mentioned that the nurse navigators stayed back after the patient/physician consult to make sure the patients understood the process, symptoms, and answered any questions. Participant C informed that,

"Pretty much right from the start, she was the one that went over everything. She was very patient with me, and no matter what question you ask, she answered the questions and it was a very relaxed atmosphere. So if you had a question, there's no right or wrong question so she would answer them equally and then she went over a few common side effects, but made sure I understood if I had any other little things and made sure I knew them and their meanings."

The perceptions of how the patients felt the information provided to them by their nurse navigator was positive. It is quite clear that the nurse navigators were effective in providing information in a timely and personalized manner. This theme of patient-focused cancer care will be covered in detail in Chapter V.

Management continuity

Managing the cancer patient's care is an integral role of a nurse navigator. The nurse navigators were effective in conducting a needs assessment and comprehensive screening of their patients to ensure that maximum support was provided. By explaining the care and treatment plans to the patients, it was evident that the patients felt more at ease and also decreased any anxiety or uncertainties they may have had previously. Participant A confirmed by stating that "with her explaining each test that was going to happen, it took so much of the tension off. This is an unknown for me anyways, and I was so nervous, not knowing what was going to happen." Participant A continued to explain, "as far as tension and nervousness, the navigator certainly lowered it. Because of her professionalism, she was describing the different tests...there was that sense of empathy." Participant added "she would explain things and then if I had any questions, then she'd answer them in the certain sections…you left there well educated about what was going on with the treatment." One participant mentioned that he had the "reassurance" of what the doctor was prescribing him and what treatments/tests the doctor believed he should do because of the fact that the nurse navigator was there to explain everything and manage his care, so he did not have to worry about it himself. This states that the patients have full trust on the healthcare team due to the fact that they have a 'go-to' professional, their nurse navigator, who they can turn to for support.

Additionally, it was evident from the results that the nurse navigators decreased barriers to cancer care adherence. Participant C indicated a vital point by stating "I felt more comfortable going ahead with my treatment because I understood it better. She (nurse navigator) explained the medical terms to me…she made me feel a lot comfortable in adhering to my cancer treatments." By ensuring certain barriers are addressed and eliminated, such as health literacy barriers, the nurse navigators are able to decrease anxiety and uncertainties and ensure the patients are adhering to their treatments, thus, evidently managing the patients' cancer care effectively.

Relational continuity

As mentioned previously, along with providing co-ordinated care, the nurse navigators maintained a therapeutic relationship with the patients and their families. As one of the participants stated, there was a "professional-personal touch." The nurse navigators played a strong support system for the patients, ensuring an increase in feeling of confidence for the patients and their families. In order to maintain a healthy relationship, the nurse navigators were ensuring they were easily accessible to the patients. Participant A stated that,

“She gave me her business card with her phone number and extension, and more than one occasion, especially on the first time, she stressed any questions, contact me and if she’s not by her desk then leave a voicemail.”

Two of the participants stated that they didn’t need to call the nurse navigators, but knowing that they were easily accessible decreased their anxiety. On the other hand, the other two participants claimed that they did contact the nurse navigators via telephone on several occasions, and were very pleased with the quick service they were provided with. Participant C stated that “she was very helpful over the phone. She explained symptoms that might occur after I have my chemo.” Participant D added that “I called her several times if I had any questions. Because I felt that you can talk to her and I understand that is her job, rather than bothering the doctor. So she did help me.” It is quite clear that the nurse navigators acted as the ‘resource’ for information and the patients felt more comfortable having a relationship with their nurse navigator and getting the appropriate information and responses from them. Furthermore, by maintaining a relationship with their patients and ensuring their needs are met, the nurse navigators are collaborating with the physicians by allowing them to make more efficient use of their time, such as developing a treatment plan.

Although the participants felt the need for a healthy relationship with their nurse navigators, there was a consensus that they did not maintain an “ongoing” relationship with them after the first consult. This will be further discussed in the following chapters.

Patient Empowerment

The overall opinions of how the role of the nurse navigators impacted the patients were positive. All patients described how their nurse navigators were able to empower them so they can actively participate in their health care decision making and how the clinical functions of their nurse navigators' roles enabled them to have a positive experience during their diagnostic phase.

Active coping

The nurse navigators actively provided coping options to their patients so they can deal with the life changes, such as assisting the patients and their families to attain the information and support needed to making vital decisions relating to their health care.

Educational support was the key theme found in the active coping concept. This was supported by the general consensus among the patients in the interviews. They provided educational support to the patients, from explaining general side effects to going over pamphlets to educate the patients about the tests during the diagnostic phase. Participant A stated, "well it was a big cache of information too. She went through some of it with me, especially the tests." Participant B added that, "it was a lot of pamphlets that came. So we went over all those and then she said if there's any concerns or questions then basically mark a few pages and jot a few things down, and then next week we can call and she would call us back." By providing such educational support, the patients felt more at ease to actively cope with their disease and changes that they were going through during this process. Patient C stated, "I'd say it was great to have her talk to me and explain things to me. It certainly made this experience a lot easier."

Self-Management

Self-management proved to be a significant concept in these interviews. All participants felt their nurse navigators effectively took measures to actively ensure that they understood specific efficacy-enhancing techniques to cope with their cancer. Participant C stated, “Now at the beginning she did go through it (booklets) and highlighted some areas and explained each of what that meant.” Participant D added, “Through the booklets, yea, she explained how to manage my symptoms…and if I called her she would explain things to me as well.”

Along with providing general symptom management information at the first consult, the patients felt they had the chance to also inquire of their nurse navigators about personalized self-care instructions whenever they required it. Patient B informed me that, “when I know I have little tiny bumps in my mouth, and she (nurse navigator) explained to me I could either use a baking soda or mouth wash. Then she actually said we’d get you something for that. Then she had prescribed a mouth wash for that for me. So any little things, there’s always something she’ll be there for.”

In addition, the nurse navigators took initiative to explain to the families of the patients how to take care of their loved ones at home. Participant C said, “She told us (informal caregiver-wife, and the patient) how to take care of me, like from keeping from getting a cold, or just like different things that they bring to your attention. Just common sense but right to the chemo, they give you helpful hints, like how to stay healthy, and what to do. Most of it is common sense stuff, but they just bring it to your attention because you’re not really thinking of it all the time. And they always say that if we have any concerns or questions, to call.” All participants agreed that their informal caregivers have all met their nurse navigators and they felt comfortable asking for advice and information on symptom management.

Finally, all the participants stated that their nurse navigators took initiative to inquire of them about their health status and the symptoms they are experiencing during every consult. Participant A stated, “The navigator is always doing my blood pressure, my pulse and my weight, she’s recording that. So that’s all being recorded, so they are tracking me.” To add, the nurse navigators kept track of the patients’ symptoms by asking the patients to fill out a symptom management scaled called the ‘Edmonton Symptom Assessment Scale’ (ESAS), and provided advice/support to the patients on how to manage their altered state and symptoms proactively based on the scales. This will be further discussed in the following chapter.

Supportive Care

Supportive care is a concept that the patients felt was the least important with respect to the roles of their nurse navigators. All participants stated that their nurse navigators did not necessarily provide them with supportive care, such as access to community services. Two of the participants stated that their nurse navigators did not mention any community services to meet their supportive needs. One of the participants stated that he had a social worker come in to meet his supportive care needs instead, “I’ve had a social worker. She had called me, and asked me “Are you concerned? Are you depressed? Do you need anybody to speak to or talk to a minister or a priest?” I said I don’t need anything of that right but if you want to come for one of my treatments and we’ll talk for a few minutes. And then if I do have those, I’d know where to go. She had come to my second treatment and gave me a little pamphlet and card. If I do have any concerns or anything, I know where to go, who to speak to.” However, two of the participants stated that they did not receive any supportive care or referrals to community services because they did not need them, and they were aware that all the contact information for any community services were already addressed within the brochures, which were provided during the first consult. Participant D informed me that, “No, we didn’t talk about that (community services to addresses unmet supportive needs) because I didn’t need it. I think there is information in the booklets…see this is my second cancer so I know. I’ve had lymphoma for 15 years and I’ve been involved with a lot of groups, home care, and a lot of the facilities. So she (nurse navigator) knew my history.”

Nurse Navigator Focus Group

This section will consist of the results gathered from the nurse navigators, which includes the semi-structured focus group, and the socio-demographics form. The results have been organized into the following sections:

1. *Results of recruitment*: describes how many nurse navigator participants were recruited in the study based on the consent and meeting the eligibility criteria.
2. *Demographics of participants*: describes the characteristics of the sample recruited based on the information provided in the socio-demographics form.
3. *Results of the interview*: describes the data gathered from the nurse navigators with respect to the Bi-Dimensional Framework: (1) continuity of care; (2) patient empowerment.

Results of recruitment

Nurse navigator recruitment occurred from December 2012 to January 2013. A total sample of four nurse navigators were identified based on meeting the eligibility criteria. All four nurse navigators were working within the diagnostic assessment program at DRCC, and fortunately all of them consented to participate in the study.

Demographics of participants

The demographics of the participants were collected through a self-reported socio-demographics form to determine the characteristics of the nurse navigators in the study. The demographic data collection disclosed a participant age range from 39 to over 50 years old. All four participants were female. There was a discrepancy in the level of education amongst the nurse navigators. Two of the participants stated that they have a college diploma; one participant stated she has a baccalaureate degree; and the fourth participant reported a Master's degree as the highest level of education earned. The number of years working in oncology also varied significantly (with 4.5 as the minimum and 20 as the highest number of years). The average number of years the ONNs reported they worked within the oncology field was 12.125 years. However, the number of years working within the diagnostic assessment program as a nurse navigator (1.75 years) was relatively consistent. Finally, two of the participants stated that they are full-time nurse navigators, whereas the other two participants reported part-time as their employment status.

Results of the focus group

The results from the nurse navigator focus group were systematically analyzed based on the concepts of the Bi-Dimensional Framework. These results are discussed in the following sections accordingly.

Continuity of care

The overall opinions of how the role of the nurse navigators impacted the patients were positive. Each nurse navigator provided her own opinion on how she assisted her patients with complex health needs navigate the health system, and how she perceived nurse navigators guide and enhance a patient's journey through the care continuum.

Informational continuity

All participants agreed that the nurse navigators were efficient and effective in transferring information and accumulated knowledge to the patient in order to ensure current care is appropriate for the patient. It was evident that having access to and understanding a high level of information about the patients helped with providing a continuum of care. Participant C mentioned, "Having all the tests and access to all that information about that patient and every test they've had as well, we don't have duplication of tests and things that you know that cause the patient more grief I guess. So they don't have to run back and forth for different things and just having the access to look at the results for the tests as well you know, maybe the symptoms are related to what's going on."

Lastly, by having knowledge of patient information and symptoms, the nurse navigators were capable of ensuring patient-focused cancer care. Participant A mentioned, "I think it initially helps us to individualize that care because we can target specific concerns or side effects that patients may have. With the background in oncology, knowledge of the disease process then and that way we can be helpful to the patients."

Participant B added, "I think what Participant A said, more like directing their care based on their symptoms or what they are telling us. So maybe we can skip a few other things that we had planned for that patient with the new information or things that they present, and maybe we can zone in on what's more important to that patient and their diagnosis or treatment based on what that they are telling us. So we might not have to do other tests, we can avoid that stress for that patient and concentrate on something else that will help that patient."

It is quite clear that the nurse navigators were effective in providing personalized cancer care due to having a high-level of knowledge of their patients and having access to information such as the symptoms experienced. This theme of patient-focused cancer care will be covered at greater length in the next chapter.

Management continuity

Results from the focus group confirmed that nurse navigators coordinated and organized their patients' cancer care successfully and thus providing a sense of security and ease for both the patients and their families. In order to ensure a consistent and comprehensive approach to management of cancer, the nurse navigators targeted unmet needs of the patients. Participant D stated, "We try to direct the information we give to the patients based on what their needs are. So we do have phone assessment prior to the visit, the first visit for the patient, and based on their information needs, their social history, medical history, we target the care plan to that individual patient." Conducting a needs assessment in order to manage care was a significant response brought upon by both the patients and the nurse navigators. This theme of conducting needs assessment will be further discussed in the following chapter.

Another theme that was evident in effectively managing the patient's care was shared decision making. The nurse navigators reported that it was vital to involve the patients in planning their care. As Participant C stated, "it is important to involve them (patients) because it will decrease the anxiety of the unknown, what to expect. They may have a history of dealing with somebody in their life that has had cancer, that has had bad experiences either based on how many years it was or where it was, and so you really need to let them know what their plan would involve, you know what it consists of, and they're a part of it. So they need to know it's more of a working together arrangement than us telling them what they have to do." Participant C added, "Also there's a lot of cultural diversity in our location so sometimes getting that health history and finding out how much information they know already and how much information they are interested in receiving, and kind of direct the way things are going to be flowing down the road."

The nurse navigators believed that the patients felt a sense of loss of power during the diagnostic assessment phase. The patients were not aware of what was happening, and what will happen in the future, so the nurse navigators "empowered them to help make a decision that's appropriate for them and involving them in the care…(which) kind of helped them to follow through with the plan of care rather than us giving the plan of care and they just have to follow it. This way it empowers them and they are more likely to follow through with the plan."

Participant B further reported that, "If they're participating in their care, well they're going to be alerting us and finding out more information about as far as maybe there are needs that they're going to be requiring for their care like transportation or they might need home care or they might need in order to come have treatments or anything like that." So by ensuring a shared-decision making approach is followed, the nurse navigators easily targeted any unmet needs affirming that the two key themes are inter-connected.

Relational continuity

The concept relational continuity generated many themes based on the discussion during the focus group. There was a consensus that initiating and maintaining an ongoing relationship created trust between the patients and their nurse navigators. By developing trust, the patients "are more up to giving information or their concerns or be more open and then you can really get to what will help them through their journey." Trust leads to identifying and eliminating barriers, key theme in relational continuity.

Participant A mentioned, "Sometimes I think it helps us to be a little more proactive in identifying the barriers and helping patients and families work through them. They may be something totally unrelated to the disease itself but it may be a social or a mental health issue that prevents the patient from coming to an appointment or following through with investigations that are required to get a diagnosis or having a good rapport with the patient or family is really important to providing that care."

Finally, by having a healthy relationship with the patients, the nurse navigators acted as a patient advocate. The nurse navigators reported that by establishing a trusting relationship with the patients, they were able to gain a lot of insight and information about how the patients were feeling and what they needed. The nurses felt it "helps to advocate for the patient if you have a better rapport with them so that you know where they are" and what their needs and barriers are. Furthermore, the nurse navigator being a patient advocate "helped to communicate better with the doctors" so as to eliminate any communication barriers between other healthcare providers and the patients.

Patient empowerment

The overall opinions of how the role of the nurse navigators impacted the patients were positive. All the nurse navigators explained how they promoted patient empowerment so their patients can take an active role in the decisions made about their own health care. There was also discussion on how the nurse navigators empowered the families of the patients so they can play an integral role in taking care of their loved ones.

Active coping

The nurse navigators actively took steps in providing coping options to their patients to lessen the impact of the stressors in order for them to take control of their lives. The nurse navigators ensured their patients received all the information and support from the first consult so they were prepared to solve any problems that may arise and make decisions concerning their health care. Participant A stated, “I think upfront we provide lots of information to patients about what is happening. We sit in at the consult with the physician so if there are any medical terms or any investigations that they don’t really understand, we continue to be an ongoing resource for that. So that certainly helps out with the decision making.” Participant C added, “You can also just help kind of direct them or lead them in the direction that their care is going so that they can plan for what’s coming.”

There was a consensus that although the condition of the disease remained the same, the nurse navigators played a significant role in identifying the needs of their patients and providing them with coping mechanisms throughout the process. As Participant C mentioned, “I think there are times too when as much as we want to empower patients, there are times when family or the patients call in and they are very frustrated with how slow things are moving or the perception that things are moving very slow. Some things we don’t have any control over, but the more we know about the patient, and the better the relationship, I think the better we can be an advocate for them, and sometimes it’s advocating with the physician you are working with, advocating for the patients with them. Sometimes it’s other hospital departments, sometimes it’s community resources, just to be that voice for the patient, to get them where they need to be. It’s not going to change the course of the disease, but it may help them cope with what they're dealing with at the time."

One of the participants stated that by explaining the treatment plan and providing maximum information on the patient's health status, the participants then decided on the resources, such as community services, they needed in order to cope with the newly gained knowledge. Participant D stated, "…and why they were doing each test, what the benefit of having that test was, and what would happen if they didn't do that test. So because it was so organized and laid out, they felt better."

Another key theme established from this focus group is educational support. This theme was also brought up in the patient interviews within the active coping concept. The nurse navigators all agreed that they acted not only as an educator but as a resource too. Participant B mentioned, "And we provide them with a booklet based on all our programs with all the tests that we could order on the patients. And when we see that patient at consult, we write out each test that they are having done with certain directions. So they have that as a resource. So we provide them with resources too, not just our (telephone) number." The details of the types of resources will be elaborated in the following chapter.

Self-management

The responses of how the nurse navigators provided support to their patients so they can self-manage their altered state proactively lead to the establishment of a major theme within this concept: personalized symptom management.

In order to assess and monitor the symptoms of the patients, the nurse navigators stated they utilized the ESAS. Participant D stated, "We have a sheet that most of our patients would fill out called an ESAS, it's a symptom assessment scale. And it's got eight symptoms that they find patients may encounter like anxiety, depression, appetite, and they need just rate it from 0 being no problems to 10 being problems. Because sometimes patients come in and you ask "how are you?", and they say "fine", but then you look at their ESAS form and bunch of eights and tens written on different findings such as anxiety, shortness of breath. So then you can see that… "so you've circled this for 10, so why are you feeling shortness of breath?" The impact of the ESAS on patient symptom management will be further discussed in the succeeding chapter. Three of the participants stated that the ESAS is very effective in "opening up the line of communication" to understand how the patients are feeling and how they are managing their symptoms.

Participant B added, "When they come to the clinic, we can see if they're struggling with shortness of breath or if they're pale or discoloured, or we might do vital signs, or just based on the…or the talk with the family member that's bringing them in saying "oh my gosh, they can't walk, they've got back pain, they can barely feel their legs". Then that kind of clues you into what they need to let the doctor know that maybe they got like a cord compression or something else is going on. So just communication and that symptom scale." Participant C added that ESAS alone does not effectively assess the patients' symptoms, and that they must have a therapeutic conversation with the patients to understand the symptoms more in depth. This allowed them to provide the appropriate symptom management techniques to the patients and their families.

Identifying patients' needs is also significant when educating the patients of the various specific efficacy-enhancing techniques to cope with their cancer and plan their care accordingly. Participant A stated, "Once you've identified the issues, you're going to be directed and focusing that clinic appointment on those and trying to resolve them or have a plan of action of how we're going to resolve that so that we can continue providing care for that patient." Participant A further added, "Managing their symptoms can improve their overall cancer care experience. If their diet is not the best, they may need a feeding tube. They may need extra support that we would recognize so we can speak to the physician to say that this maybe something that they need. So their diets improve, then their performance status will be better so they can accept treatment for their cancer as well."

Although the responses stated how the nurse navigators actively took steps to manage their patients' symptoms, there was limited data on how they specifically provided education and support so the patients themselves can manage their care/symptoms appropriately at their homes.

Supportive care

The nurse navigators acted like the gateway to resources/community services in order to address and meet the needs of the patients and their families. All participants agreed that they provided a description of the community services that were aimed to helping cancer patients and their families. Participant C stated, "We have lots of resources within the clinic. We have community resources such as homecare, Hearth Place, and sometimes it involves reaching out to other community agencies that are churches or ethnic related communities to help out that patient. Even though we have a defined set of support system in the hospital, there are always opportunities to reach out to the community and see what else is out there that may help us individualize that care for that patient." If patients felt they needed specific services, the nurse navigators provided access to these services either within the hospital or the community outreach programs.

Participant B added that there is a committee set to improve patient experience at the DRCC dedicated to “improving patient experience conference where it’s lead by patients and I think there are a few staff members on there just to initiate it.” The patients were referred to this committee if psychosocial and emotional support is needed.

The nurse navigators felt that providing access to supportive care benefits the patients and their families because “It makes the whole diagnostic phase easier for them. They can hopefully plan easier, organize their time, and have a little bit more control over things.” Participant A added, “It’s a distressing time completely so if they have a little bit of control, it just helps ease that process.”

Participant D concluded by saying, “A lot of people that are diagnosed with cancer, or are looking at being diagnosed with cancer that’s not always their focus. It’s “what am I going to do with my kids or job?” They are not even thinking of what their treatment’s going to be like. Zoning in on that and seeing what their needs are at that moment may not be even cancer related. It could be just knowing that there is help and resources and people that want to kind of make the process easier for them. Also, it does give them a sense of...with community support, knowing that they’re not in it alone. That there are other people that have been in the same or similar situation that they can relate to, and they kind of get comfort in that.”

This aforementioned comment demonstrated the level of empathy that the nurse navigators portrayed in identifying the supportive care needs of the patients so as to reinforce empowerment. It further exhibits how they effectively integrate the clinical functions of their role toward addressing the global distress and patients’ unmet needs.

Summary of Results

In summary, this chapter demonstrated the results of the patient interviews and nurse navigator focus group. The data showed the perceptions of the patients and the nurse navigators on how the role of the nurse navigators impacted patient experience within the diagnostic phase, with respect to continuity of care and patient empowerment. Both sets of participants gave positive responses to the questions relating to each of the concepts within the Bi-Dimensional Framework.

The synthesis of these findings resulted in the identification of a set of core areas of practice for professional nurse navigators. These core areas of practice were defined based on the separate opinions of the patients and the nurse navigators. To be specific, the areas of practice were determined based on how the patients perceived their nurse navigators impacted their experience at the cancer center, and what the nurse navigators felt were important in providing a positive patient experience and how their roles as a nurse navigator impacted the patients and their families, with respect to each of the concepts within the Bi-Dimensional Framework. Figure 3 shows how the professional navigation framework defined by Fillion *et al.* (2012), with its six concepts, corresponds to the core areas of practice identified. The following chapter will explain the core areas of practice and their significance with respect to continuity of care and patient empowerment in detail.

<table>
<tr><td colspan="2">Dimension 1: Continuity of Care</td></tr>
<tr><td>Concepts</td><td>Core Areas of Practice</td></tr>
<tr><td>Informational Continuity</td><td>• Patient-Focused Cancer Care</td></tr>
<tr><td>Management Continuity</td><td>• Conduct Needs Assessment
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<tr><td colspan="2">Dimension 2: Patient Empowerment</td></tr>
<tr><td>Concepts</td><td>Core Areas of Practice</td></tr>
<tr><td>Active Coping</td><td>• Patient Advocate
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Figure 3. Core areas of practice in relation to the Bi-Dimensional Framework.

Chapter V

Discussion

The goal of this study was to determine how the roles of nurse navigators within the diagnostic phase of cancer affect patient experience. Concepts of the Bi-Dimensional Framework (consisting of continuity of care and patient empowerment) developed by Fillion *et al*. (2012) underpinned the study, and guided data analysis and interpretation of the results. This chapter includes the interpretation and analysis of the previously described results. These findings are categorized in accordance with the concepts of the Bi-Dimensional Framework and the identified sub-themes and the core areas of practice, based on the analysis of participant responses from the interviews and focus group.

Continuity of Care

The first dimension corresponding to facilitation of continuity of care includes the three related concepts of informational, management, and relational continuity. The results from this study identified core areas of practice, defined by the three concepts, related to the organizational functions of the nurse navigator role. In combination, these functions profile a comprehensible and interconnected model and experience of care for patients with lung cancer specifically related to the diagnostic phase of the disease continuum. In this section, I will comment on the following themes: patient-focused cancer care; conduct needs assessment; care planning; shared decision-making; easily accessible; and identifying and eliminating barriers.

Informational continuity

The use of information, whether it be disease or patient-centered, to make current care appropriate for each patient is an integral role of the nurse navigator. Nurse navigators need access to and understanding of high levels of information about their patients and their care. With this acquisition of information, the nurse navigators are able to provide *patient-focused cancer care*.

Patient-focused cancer care

Fillion *et al.* (2012) reported that professional navigators play a role in information continuity by acting as a “transmission belt”. This provides personal-tailored information and advice to the patients and is accessible to healthcare providers.

The findings from this study tend to support Fillion *et al.*’s general proposition. In the current study, both patients and nurse navigators reported that by having individual case knowledge of the patient with cancer and their care components, the nurse navigator can easily and effectively provide patient-focused care in a timely and proactive manner. It is timely to restate the scope of the conceptual definition relating patient-focused care and how this concept relates to this study.

There are many models and definitions of patient-centered (or focused) care, however it is critical to examine patient-centered care associated with nursing. PCC, as defined by the Quality and Safety Education for Nurses (QSEN), is “the recognition of the patient as the source of control and full partner in providing compassionate and coordinated care based on respect for patients’ preferences, values, and needs” (QSEN, 2005).

By having knowledge of and access to information relating to the patient, such as symptoms experienced and barriers faced (i.e. communication), nurse navigators are able to identify the patient’s needs and address specific concerns. Therefore, by understanding that patient’s needs/concerns, the nursing team can then provide targeted individualized care. Through the knowledge and exposure of the broad range of symptoms experienced by patients, nurse navigators can synthesise their background in oncology and their understanding of disease processes to provide patient-focused symptom management. In this study, the nurse navigators also found that by having access to new information about the patient, they may be able to discriminate and identify appropriate testing sequences, to better focus on the diagnosis or treatment planning interventions based on the patient’s needs.

Consequently, it seems rather definitive that both nurse navigators and patients contribute valuable information to consolidate and deliver an individualized care plan. Hence, nurse navigators contribute information about the illness, treatment options, and symptom management. The patient contribution offers personalized and subjective information about values, treatment preferences, and needs.

According to the Canadian Association of Nurses in Oncology (CANO), one of the key domains of practices for a specialized oncology nurse involves assisting patients navigate through the healthcare system by understanding its structure, systems and processes, and also by providing the patients with strategies to work within that system (CANO, 2006). The patients from this study confirmed that that their nurse navigators provided timely and personalized information. The nurse navigators ensured that the patients understood what the diagnostic phase entailed: the process, the services, and the options.

In the information technology conundrum, there exists a vast amount of health-related information, and it can be said that booklets and brochures can only aid a patient so much in gaining knowledge, especially during a stressful period. The patients in this study emphasized the importance of having a nurse navigator explain the information within the booklets, as well as medical terms mentioned by the physicians. An anecdotal statement from one patient applauded that nurse navigators are the resource for this information and its interpretation, confirming that in a study by Cook *et al.* (2013), nurse navigators serve as a “conduit of information” between the patient and the other healthcare providers. The findings from Cook *et al.*’s study reinforced the role that nurse navigators perform in relaying and decoding information provided by the physician in “simpler terms” so that the patient gains personal comprehension of the process. Nurse navigators within DRCC attended patient-physician consults, to take notes, as well as aid and advocate translation of the meaning of physician’s information into patient centered literal terms. These notes contained a range of material involving the overall diagnostic assessment plans and the components involving side effects to tests, and symptom management options. This simple, yet effective, approach aids the removal of one of the principal barriers to health literacy. It is widely recognized that health literacy is one of the main challenges to consolidating patient-centered care (Wynia & Osborn, 2010). Hence patients who are not health literate or unable to understand the breadth and scope of their disease and treatment processes, will experience difficulty in accessing care, have poorer understanding of their conditions and low behavioural adherence and compliance with diagnostic services, and also less participation in decision making (Ontario Medical Association, 2010).

It seems therefore that the role of the nurse navigator with respect to continuity of information, such as having access to and understanding a high level of information about the patient, providing timely and tailored information to the patients, utilizing information beyond the medical conditions to include patient values and needs, and acting as the conduit of information between the patient and the healthcare team, ensure that a more patient-focused cancer care approach is followed where the PCC system is “one that considers the individual needs of patients and treats them with respect and dignity” (Ontario Medical Association, 2010).

Management continuity

A core attribute to the nurse navigator role involves following a consistent and coherent method to the management of cancer that is receptive to a patient’s changing needs. By managing the patient’s care, it allows the nurse navigators to *conduct needs assessment* of the patients, ensure effective *care planning*, and allows *shared decision-making* between the patients and healthcare providers.

Conduct needs assessment

The findings from this study emphasized the importance of the nurse navigator’s role in conducting a needs assessment of the patient. The majority of the participants confirmed that the nurse navigator conducts a telephone assessment prior to patient visit to the cancer centre in order to retrieve any medical or symptom-related history of the patient before the first consult with the physician. Additionally, the participants reported that the nurse navigators also conduct a medical and cultural assessment at the commencement of the first consult so as to identify and comprehend the patient’s individual needs.

Medical assessment includes identifying the patient’s medical history, and prominently the symptoms experienced by the patient. In conducting a health assessment, the nurse navigators have the necessary information to develop a care plan which parallels to the patient’s individual medical needs. For example, if a patient portrays certain symptoms such as dyspnea, the nurse navigator can effectively suggest to the physician a prescription of an inhaler, which can facilitate management of dyspnea in accordance with the patient and his/her family's needs and agreement.

Although medical assessment is common within any healthcare setting, cultural assessment is a rather distinctive concept. According to the Registered Nurses Association of Ontario (2007), the basic premise of the cultural assessment is that patients have a right to their cultural beliefs, practices and values, and that these factors should be comprehended, respected, and considered when providing culturally competent care. Cultural beliefs, practices and values also influence patients' behaviours (Cooper Brathwaite & Williams, 2004). The initial phase in conducting a cultural assessment corresponds to the comprehension of the definition of the disease of the patient in terms of the patient's unique culture (Saha, Beach, & Cooper, 2008) so the nurse navigators can provide culturally competent cancer care during the patient-nurse navigator encounter (Registered Nurses Association of Ontario, 2007). Data gathered from this assessment can assist the patient and nurse navigator to develop a mutually acceptable, culturally responsive treatment plan. Although the nurse navigators in this study mentioned the need to retrieving health information pertaining to the cultural diversity amongst their patients, there was not much detail on how they conduct cultural assessments, the types of information retrieved from assessments, and how it benefits the patients and managing their care. Further research is certainly warranted to determine how the nurse navigators target cultural barriers and achieve cultural competency within the cancer centre, given that there are many culturally diverse patients receiving cancer care in Canada.

Additionally, the nurse navigators are continuously conducting needs assessment within the diagnostic assessment phase. The nurse navigators deemed extra services are necessary, and are provided based on continuous assessment of the patient's needs and concerns. For example, dietician referrals are provided based on the assessment of the patients' eating habits.

By conducting needs assessments, the nurse navigators are able to identify and resolve any unmet needs of the patients. The concept of unmet needs refers to the difference between health services deemed necessary to treat a patient and services actually received (Sanmartin, Houle, Tremblay, & Berthelot, 2002). A patient who perceived the need to receive health care services: whether information from a nurse navigator or a therapeutic procedure but has not obtained these services has unmet health care needs. According to a study by Pineault *et al*. (2004), majority of patients wanted to consult a healthcare provider for particular health problems, however, their needs were not met, particularly due to lack of accessibility to healthcare providers. However, the results from this present study demonstrated that patients' needs were met and reinforced the importance of meeting patients' needs. The results from the present study and Pineault *et al.*'s study provide evidence to support the need of healthcare providers, such as nurse navigators, to target unmet needs of the patients.

Care planning

The findings from this study reinforced the role that nurse navigators take initiative to develop an individualized care plan, specific to the diagnostic assessment phase with an understanding that the patient journey differs from one patient to another. It is critical to note that the plan of care is focused on nursing interventions, and not medical interventions.

Prior to developing a personalized care plan, it is crucial for the nurse navigator to conduct a needs assessment. The nursing care plan initiated when the patient was admitted to the hospital, following the initial needs assessment, and a diagnosis was formulated and nursing orders and interventions were developed. The goal of the process was to ensure that nursing care was consistent with the patient's needs and progress towards self-care (which will be discussed subsequently in this chapter). By targeting the unmet needs of the patients, nurse navigators were able to ensure timely matching of unmet needs with services, resources, and support systems within the cancer care organization and the community. The findings from this study supported the many benefits pertaining to care planning with respect to management continuity, including: decreasing uncertainties; decreasing anxiety; and decreasing barriers to cancer care adherence.

The level of uncertainty may increase for patients during the diagnostic phase as it was characterized by numerous tests, followed by the anticipation of the results and diagnosis. A study by Lien *et al.* (2010) concluded that nursing instructions can significantly decrease uncertainty for cancer patients. The results indicated that providing structured nursing instructions based on evidence-based guidelines can promote patient degree of control over their disease and ameliorate patient and family uncertainties (Lien *et al.*, 2010). This study corroborated the results from this study that nurse navigators clarified the care and treatment plans to their patients and families, consequently decreasing any uncertainties the patient may have had previously. The patients felt they became more knowledgeable after having an explanation about the care process, services offered and medical terms compared to when they initially came to the cancer centre with numerous uncertainties and concerns. It seems the nurse navigators portrayed a sense of empathy towards their patients by understanding that the patients were enduring hardship during this time and there were many uncertainties that must be sympathetically resolved. Furthermore, the patients indicated they were reassured about the medical procedures that were authorized by the physician because they felt they can rely on their nurse navigators to explain anything they did not comprehend.

A study by Pineault (2007) found that women awaiting the diagnosis results following abnormal mammogram screening experienced anxiety and fear. Pineault explained that 75% of the participants reported that family and friends did not help decrease anxiety, however support from the healthcare professionals did. Results from the present study contradicted and extended Pineault’s results. The participants from the present study reported that it was important to involve the families of the patients in the care planning process because it decreased anxiety of the unknown. The nurse navigators explained how their patients and their families looked towards each other for support, and the nurse navigators acted as a mediator to provide advice on working together so as to cope with the immediate situation. Additionally, the nurse navigators further explained that if they were able to involve the family members in the care planning, just as much as the patients themselves, it aids the patients in feeling less anxious about the entire process. Hence, it can be concluded that by decreasing the level of uncertainties amongst the patients, the level of anxiety simultaneously decreases.

Several studies (Freeman, 1995; Battaglia et al., 2006; and Ferrante et al., 2007) reported the improvements in both the adherence to follow-up visits after the detection of a screening abnormality, and in the timeliness of obtaining care after diagnosis for patients who were screened for breast, cervical, prostate, and colorectal cancer. However, a noted gap in these studies was the lack of evidence showing improvements in adherence to cancer care services among patients who were suspected of lung cancer. The results from the present study helped to fill that gap by providing evidence of improved adherence to cancer care services with the implementation of oncology nurse navigators. It was evident that the nurse navigators decreased barriers, such as health literacy and communication, which enabled the patients to follow through with the treatment plans. In addition, the nurse navigators explained medical terms with respect to lung cancer as well as the benefits of the diagnostic tests and treatments, which enabled the patients to recognize the importance in adhering to the treatment plans that their physician authorized to have completed.

Shared decision-making

Shared decision-making proved to be a significant area of practice for the nurse navigators. It is essential for enhanced management of care because it is thought to improve health status and patient satisfaction (Golanowski et al., 2007). Thistlethwaite, Evans, Tie, & Heal (2006) describe shared decision making as a process within a patient centered consultation that includes both the patient and healthcare provider discussing cancer care management options and agreeing on cancer care management decisions in partnership (whether treatment options or care planning). While shared decision-making in treatment options is related to medical, or rather physician-intervention and shared decision-making in care planning corresponds to nursing intervention.

The nurse navigators reported that with the diagnosis of cancer, patients often sense a loss of power. To help patients be involved in their care planning, the nurse navigators empowered them to help make a decision that is appropriate for them. Thus, by involving the patients in the care planning process, rather than the nurse navigators informing them on what they must do, the patients became more inclined to commit to the individualized plan.

For an operative shared decision-making between the patient and his/her nurse navigator, appropriate communication techniques must be followed. A study by Stewart (1995) concluded that there are four dimensions of positive communication, which are related to shared decision-making: the provision of clear information; questions from the patient; willingness to share (discuss) decision; and agreement between patient and healthcare provider about the problem and the plan. The current study provided evidence that nurse navigators act as “the resource” when the patients require information about explanation of treatment plans authorized by the physician or community services to meet unmet needs. It was evident the nurse navigators conducted effective needs assessment to meet all the needs of the patients. Confirmations from the patients supported the second and third dimensions of Stewart’s theory. The patients praised the willingness of their nurse navigators to discuss decision plans and resolve any concerns they had. The nurse navigators took initiative to stay back after the patient-physician consult to answer any questions the patients or their families may have and discuss what the physician prescribed in terms of diagnostic tests that need to be done. However, the last dimension of agreement between patient and nurse navigator about the care plan is not clear. Although the nurse navigators did state they have a “working together arrangement” with their patients and noted the importance in shared decision-making, specifications on how the patients are particularly involved in the decision-making of their care planning was not mentioned. Further research should be done to identify the underlying mechanisms of how the nurse navigators provide the opportunity to their patients in shared decision-making, particularly how barriers were eliminated in order to facilitate the patients’ involvement at the maximum level and the outcomes of these actions. It would be interesting to understand shared decision-making between the patients, nurse navigators, and the consulting physicians to get a comprehensive view of the concept.

Despite the nurse navigators stating that shared decision-making is encouraged, the patients claimed the nurse navigators shared maximum information with them about their health status and care. It is important to note that sharing information and sharing decisions are not synonymous, but they are rather separate goals within the consultations process (Elwyn, Edwards, Kinnersley, & Grol, 1999). The nurse navigators sharing information with their patients ensure ‘informed consent’ where the patients are aware of all the risks and benefits of a particular cancer care service and agree to going forward with the healthcare provider’s decisions. Whereas shared-decision making involves the patient in all the stages of the decision-making process, and ensures that with the advice of the nurse navigator, the patient can make a decision on the care options they received. This study has provided some evidence on the components of shared-decision making. However, additional research is warranted to determine how the nurse navigators involve their patients in decision making. It is important to develop shared decision-making models specially designed for the nurse navigators in their several clinical and organizational roles, to ensure effective management of continuity of care.

Relational continuity

Nurse navigators not only have organizational responsibilities, but they also maintain a therapeutic relationship with their patients to ensure continuity of care. The nurse navigators maintain an ongoing relationship with their patients by being *easily accessible*, and accumulate knowledge about the patient as a person to *identify and eliminate barriers*.

Easily accessible

As the key point of contact, the nurse navigators continuously commit to being an easily accessible source of information and support to their patients. Patients and their families have many questions and concerns at all times during the diagnostic phase. From needing information or advice on symptom management to simple scheduling questions, the patients turn to their nurse navigators for the answers. In order to address the concerns of the patients at any time, the nurse navigators made themselves accessible both in person and over the telephone during business hours, from Monday through Friday. Although some of the participants stated they did not have to call their nurse navigators, all of them praised the nurse navigators' initiatives in being accessible over the telephone and they felt they can address any concerns they had in the comfort of their homes. Furthermore, it was reported that the nurse navigators were very efficient in returning the phone calls, stating that being accessible is more than just an administrative responsibility but also showing the compassion and empathy towards the patients' needs.

In fact, the effectiveness of telephone triage is a growing topic of interest in the nursing field. Telephone triage is defined as the interaction between patient and nurse that takes place exclusively by telephone to address health-related problems. In the previous section, the importance of conducting a needs assessment by the nurse navigators via the telephone was discussed. Now we will focus on the importance of telephone interaction for patient education and crisis intervention. Although the patients in the present study did not discuss crisis intervention, they mentioned patient education was discussed with their nurse navigators through telephone conversations. One of the participants claimed she had called her nurse navigator on many occasions to seek advice on symptom management. She reported that her nurse navigator provided education to the best of her abilities, and if the nurse navigator did not know how to address the issues, she would consult with the physician and get back to her on time. By having quick access to information, the patients felt more at ease and had fewer uncertainties. The patients felt the nurse navigators were more accessible than their physicians. The results from this study supports previous studies (Bunn, Geraldine, & Kendall, 2005; Gallagher, Huddart, & Henderson, 1998) by providing evidence of the effectiveness of a telephone triage, by a nurse navigator in increasing patient satisfaction and decreasing patient uncertainty. The nurse navigators explained the importance of being easily accessible in creating a trusting relationship. If the patients felt the nurse navigators are always accessible, a sense of trust and dependability occur. Being accessible to the patients also ensured more open communication as well as information sharing. By sharing the concerns, the nurse navigators were able to identify and eliminate any barriers their patients may be facing.

Identify and eliminate barriers

Developing and maintaining a good rapport with the patients and their families allowed the nurse navigators to be proactive in identifying the barriers the patients and their family members were facing and helped them work through these barriers. There are many barriers to cancer care for patients during the diagnostic phase, including: barriers to information, health literacy, accessibility and mental health issues.

Barriers to information

The patients may feel they receive insufficient amount of information regarding the types of diagnostic testing and the side effects related to the tests from their physician during their consults. The nurse navigators ensure they attend the patient-physician consults and take notes to explain to the patients afterwards. The results from this study showed that eliminating the barriers to information allow the patients to gain knowledge about their diagnosis so they can be better prepared for their treatment. As for the nurse navigators, they have stated there was limited willingness of the patients to give up information, such as symptoms experienced. This created a barrier in trying to determine the appropriate healthcare services for each individual patient. However, the nurse navigators reported they managed to eliminate this barrier by involving the patients and their families in decision making with respect to their care planning. The results indicated that the patients were more willing to share information about their needs and preferences and followed through with the care plan.

Barriers to health literacy

One of the key barriers to patients within the diagnostic phase is health literacy. Most of the patients that come into the cancer centre are not aware of the medical terminologies that the test results show, or even those the physician mentions. The nurse navigators acted as the resource by explaining medical terms to the patients and their families to increase their understanding. Some of the participants also mentioned that the internet has a vast amount of information about health terms but it gets rather complex and confusing for the patients to grasp. They reported the quick access to their nurse navigators provided a comprehensive and personalized explanation of health terms.

Barriers to accessibility

Barriers to accessibility involve both healthcare providers and healthcare services. The responses from the interviews confirmed that the nurse navigators proactively ensured they made themselves available to their patients both in person and over the telephone. For example, the nurse navigators reported that many patients did not know what services, from diagnostic to supportive, are offered or where to go to receive these services. The nurse navigators acted as a “one stop resource” for all their healthcare service needs and they navigated the patients to appropriate services. This will be discussed in further detail in the following section.

Barriers to mental health issues

Individuals who have cancer may experience psychological stress (Artherholt & Fann, 2012). According to Zabalegui *et al.* (2005), psychological stress emerges as anxiety and/or depression and it is mainly related to uncertainty about the cancer diagnosis, side-effects of tests and treatment, lack of social or personal control, progressive physical deterioration, and thoughts of near death. Utsa (2012) further explained that during diagnosis, interactions with the nurses play a valuable role in the provision of support, which has a remarkable importance in dealing with psychological problems common in cancer patients. Results of Utsa's study showed that patients felt nurses (all types of nurses- including nurse navigators) are usually the closest healthcare staff to turn to for psychological support. Therefore, nurse navigators should be aware of the different psychological conditions in order to direct the patients towards social support services or provide counselling in cases where social support services are insufficient. Findings from Utsa's study supported the results of the present study that nurse navigators not only act as counsellors to decrease psychological stress but also act as the resource for community supportive services. For example, the nurse navigators reported they shared information with their patients (whether medical or social) to alleviate their stress. Sharing of information with patients decreases uncertainty, which is a key factor in causing anxiety and depression. Another method of targeting mental health issues is conducting a needs assessment and ensuring the patients are part of the care planning process. Zabalegui *et al.* (2005) reported that lack of personal control is a key factor to psychological stress among cancer patients. The nurse navigators from this study further confirmed Zabalegui *et al.*'s results by stating that they created and maintained a therapeutic relationship with their patients in order to facilitate patient empowerment. Thus, patients can "have a little bit more control over things" and consequently reduced psychological stress. The concept of patient empowerment will be discussed in subsequent paragraphs.

Although the patients felt the need for a healthy relationship with their nurse navigators, they mentioned that they did not maintain an ongoing relationship with their nurse navigators because they did not have many contacts with them. The patients recruited in this study had at least two contacts with their nurse navigators, which included telephone contacts. There was lack of evidence in the literature on the number of contacts between a patient and the nurse navigator to create an effective relationship and a positive patient experience. Thus, the standard of practice within the DRCC was taken into consideration in determining the results of this study, which will be addressed under the limitations of the study.

Patient Empowerment

The second dimension of the framework corresponding to promotion of patient empowerment includes the three related concepts of active coping, self-management, and supportive care. The results from this study identified core areas of practice, defined by the three concepts, related to the clinical functions of the nurse navigator role. In combination, these functions contribute to create an empowered cancer patient. In this section, I will comment on the following themes: patient advocate; educational support; personalized symptom management education; and resource navigation.

Active coping

According to Bulsara, Styles, Ward, & Bulsara (2006), the nurse navigators must support the patients to accept their illness with the use of active coping strategies to regain control. In this study, the participants stated that the nurse navigators took proactive steps to attempt to remove the stressors of the patients during the diagnostic phase by being a *patient advocate* and providing *educational support*, and thus assisting the patients cope with their illness on a larger scale.

Patient advocate

Nurse navigators act like a bridge between the health system and patients. According to Wilcox & Bruce (2010), the main goal of the newly developed role of nurse navigator is to advocate for the patients and their families by coordinating and enhancing care among all interdisciplinary team members. With a nursing background and a comprehensive understanding of oncology components and the diagnostic assessment phase, the nurse navigators are highly competent to act as an advocate for their patients. The nurse navigators from the present study explained that by maintaining a good relationship with the patients and their families, they were able to identify the patients' needs and concerns, which facilitated advocating for them. They described that they advocate for their patients by acting as a communication line between the physician and the patients. Many of the patients would report symptoms experienced, and the nurse navigator took initiative to discuss these symptom related concerns with the physician, not only to bring it out in the open to the other healthcare providers, but to also confirm symptom management techniques. Several times they became the voice for the patients to get them to where they need to be in terms of other hospital departments. However, the results from the current study showed limited evidence of nurse navigators referring the patients to community supportive services so the patients and their families can receive external support. The nurse navigators emphasized that being a patient advocate cannot change the course of the disease but it may help the patients cope with whatever they are dealing with at a certain time during the cancer journey.

Educational support

There are many educational resources that the patients are provided with at the DRCC. The participants stated that during the first consult, patients received numerous resources such as booklets explaining lung cancer (i.e. types of tests, side effects to tests, and symptom management), the diagnostic assessment program and its process, and supportive services. They also received a welcome bag with informational pamphlets, calendars and brochures about the different types of supportive and community services. Some of the patients explained these written resources as “a big cache of information.” Weinman (1990) stated that majority of patients (75%) wanted written information about their illness, as information orally provided is not properly understood by the patients and a great deal is forgotten quite rapidly. Furthermore, Weinman stated that efficacy of booklets about particular medical conditions or treatments also showed consistent improvements in the patients’ knowledge together with positive changes in mood and sometimes in health outcome. However, the results from the present study contradicted the results from Weinman’s study. Patients from this present study praised the effectiveness of having a nurse navigator to explain such information within booklets and brochures. As much as brochures were useful in laying out the information, the patients felt there was a decrease in anxiety and uncertainty when a nurse navigator explained the information to them so they can better comprehend it. This also allowed for a personal interaction with the nurse navigator and the patients. Perhaps the results from Weinman’s study contradicted the present results because his study was conducted in the late 80s/early 90s and the cancer care system has changed immensely since then. Currently, there are diverse diagnostic tests and assessment programs, new medical terms, and access to numerous cancer care services. The cancer patients now are bombarded with endless information and options, and written information is not solely effective in ensuring the patients accurately understand their disease and the health care they are entitled to. Furthermore, written information cannot provide the emotional and social support the patients require during an apprehensive period of their cancer care journey. The patients in the current study stated that by having the nurse navigator as an educational support, they were able to better comprehend certain medical related information. As mentioned previously, health literacy was a key barrier for patients, and nurse navigators proved to be immensely effective in resolving this barrier. Nonetheless, in order for the patients to have a solid educational support, both the nurse navigators and written information such as brochures/pamphlets are needed.

Self-management

Self-management proved to be a key concept in this study. According to Cook et *al*. (2013), nurse navigators facilitate cancer self-management by supporting the patients and their families and reinforcing the patients' abilities to accept the illness and regain control. The participants in the present study mentioned that their nurse navigators helped them cope with social and physical changes, handle the disease and the tests, and cope with loss and distress. However, both the patients and the nurse navigators repeatedly mentioned a core area of practice which assisted the patients in managing their health: *personalized symptom management*.

Personalized symptom management

The results from this current study showed that the nurse navigators not only provided symptom management education, but they also assessed and monitored the symptoms of their patients. First, by providing symptom management education such as timely and tailored self-care instructions or information, the nurse navigators assisted and reinforced the patients in adjusting to and managing their altered health state and symptoms proactively, not reactively. The patients explained that their nurse navigators provided various resources on symptom management and self-care during the first consult. This included information on coping with the residual and relapse warning signs, managing of side effects related to the diagnostic tests, medication compliance, and daily routines. A patient from this study stated that his nurse navigator provided personalized home remedies such as utilizing baking soda or mouth wash for “tiny bumps in (his) mouth.” The patient further added that the nurse navigator took initiative to inquire about the “bumps” at a later visit and prescribed a mouth wash for that specific health problem. Moreover, educating the patients on the importance of being aware of specific symptoms and managing these symptoms can not only decrease anxiety for the patients and their families, but it may also decrease wait times for physician consults. Patients would not be inclined to make unnecessary appointments with their physicians for every symptom experienced but instead they will be well educated on managing their own symptoms at home.

Along with providing self-management education, the nurse navigators also assessed and monitored their patients’ symptoms. By conducting a symptom assessment, the nurse navigators stated they were able to identify any major symptoms that patients were experiencing that may require more attention or that may alter the diagnostic or treatment plan. According to Yarbro, Frogge, & Goodman (2004), when poorly managed, symptoms can affect the treatment of cancer and daily functioning and quality of life of persons with cancer. For example, by monitoring a persistent chronic cough of the patient, the nurse navigator can inform the physician if the cough becomes worse, which then may lead to additional X-ray computed tomography (CT scans) to detect any acute and chronic changes in the lung parenchyma. Thus, it is imperative for nurse navigators to help their patients deal with symptoms that can adversely affect both the quantity and quality of their lives. The symptom assessment at the beginning of each consult allowed the nurse navigators to understand if and how the patients were managing their symptoms. With an insight of such information, the nurse navigators were able to direct symptom management counselling based on the individual patient’s behaviour. Yarbro *et al.* (2004) stated that cancer patients rarely report their symptoms to a healthcare professional. The results from the current study contradicted Yarbro *et al.*'s results. The patients felt they were comfortable to discuss their concerns, including symptoms experienced, to their nurse navigators because the nurse navigators constantly made themselves accessible to their patients in order to provide information and support in a timely and personalized manner. The nurse navigators reported they utilized a symptom assessment scale called the ESAS to assess the symptoms experienced by the patients. The ESAS is a valid and reliable assessment tool used to facilitate the assessment of nine common symptoms experienced by cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. The severity of each symptom is rated from 0 to 10; with 0 meaning that the symptom is absent and 10 meaning that it is the worst possible severity. It is the patient's opinion of the severity of the symptoms that is the gold standard for symptom assessment (Cancer Care Ontario, 2005). This symptom assessment tool distinguishes individual attributes of a symptom (Yarbro *et al.*, 2004). According to Yarbro *et al.* (2004), symptom assessment tools can greatly enhance the healthcare provider's understanding of a symptom experience. The nurse navigators in the current study reported that the ESAS was very effective in "opening up the line of communication" in order to comprehend how the patients are feeling and how they are managing their symptoms. However, it is important to remember that symptoms are subjective experiences and can be very difficult to assess with the use of just assessment tools. The nurse navigators in the present study confirmed this by explaining that along with the ESAS, they must have a therapeutic conversation with their patients to understand the symptoms in depth. For example, a patient may have circled '9' for pain within the ESAS, however the nurse navigators must inquire about the type of pain, the frequency of pain, and whether the pain is associated with specific medical condition or prescription, or due to certain daily routines. By identifying the reason behind the severity of the symptoms, the nurse navigators directed their care accordingly, whether by providing education on symptom management or informing the physician so as to take a more serious action.

Supportive care

Lastly, the final concept which explains how the nurse navigator's role impacted patient experience is supportive care. Although this concept is just as significant as the other concepts within the Bi-Dimensional Framework, the results from the current study provided very limited evidence. The reason was due to the fact that most of the patients felt their nurse navigators did not provide access to supportive care services nor was there a need to access such services. Some of the patients stated that they had family support so they did not find the need to access community related supportive care. While others stated that they were already aware of the supportive services that are being provided as they had previously used them because they, or their family members, had previous experience with cancer. However, all the participants agreed that the booklets and brochures that were provided to them by their nurse navigators at the first consult contained information about supportive services and community outreach programs. Perhaps the evidence on how the nurse navigators provided supportive care to their patients was limited because the sample size was rather small. This will be addressed within the limitations section of the final chapter. Nonetheless, the nurse navigators did state that they provided *resource navigation* to effectively meet the supportive care needs of the patients and their families.

Resource navigation

The nurse navigators emphasized that with their functions of screening, assessment and evaluation, they were improving access to supportive care for cancer patients and their families.

In order to meet the physical, emotional, psychosocial, and spiritual needs of the patients, the nurse navigators reported that they provided access to community services such as homecare, Hearth Place, and other community agencies (i.e. churches or ethnic related agencies) to meet the social and cultural needs of the patients. Hearth Place, a known community supportive service for the patients coming into to the DRCC, is a cancer support centre that offers peer support, information, a resource centre, wellness programs, and an ongoing lecture and discussion series (Hearth Place, 2013). By providing access to such community services, the nurse navigators were able to empower the patients and their families to take control of their disease and include themselves on a larger scale, by being involved in their community. Furthermore, the nurse navigators stated that there is a volunteer based committee dedicated to improving patient experience within the DRCC. This committee is a patient-focused support group led by the patients and several staff members acting as facilitators. The patients were referred to this committee to meet the emotional and psychosocial needs.

The nurse navigators listed the benefits to conducting a supportive care needs and providing access to services to meet those needs of the patients. They stated that providing supportive care made the diagnostic phase easier for the patients as they had more opportunities to plan their care, organize their time, and take control of their lives and the disease itself. Moreover, they explained that the patients felt supported by others from the community. Knowing that there were other patients who were experiencing similar situations or undergoing the same type of treatment for similar cancers allowed them to reach out to each other for support and comfort.

By observing the previous concepts, it can be extrapolated that certain needs, such as informational and emotional, are met by the nurse navigators. Perhaps that may be a reason why the patients felt there was no need to access external supportive care from the community. Another reason why the patients might not have needed community resources can possibly be explained with the following statement: “At the time of early diagnosis, preparedness might lead to a medical decision and practical preparations for the circumstances of post-surgery. After treatment, preparedness might involve finding a supportive community to help ease transition back to work and discovery of a new normality” (BC Cancer Agency, 2005). Essentially, the patients seek to find support and comfort within their community supportive services after treatment. Since this present study focused on cancer patients during the diagnostic assessment phase, the patients might not have found supportive care through community resources a priority.

Chapter VI

Conclusion

The strengths and limitations of this study, and its implications together inform thinking about future directions for practice, education and research in the area of the effectiveness of a nurse navigator's role in providing positive patient experience, specifically focusing on cancer patients within the diagnostic phase. In concluding this dissertation, specific strengths, limitations and implications are highlighted in this study which strengthen the understanding of the nurse navigator roles. The roles are continuously developing and therefore always dependent on regular collaboration and communication if to be comprehended in practice and community health.

Strengths

This study's strengths reside in the methodological choices used. It is vital to realize that these methodological approaches were not chosen as a pure coincidence, but rather to address the gaps found in the literature review. That being said, I believe this study successfully filled these gaps since they became the strengths of this study. This section focuses on the three main strengths of this study: qualitative methods; small sample size; and Bi-Dimensional Framework.

Qualitative methods

As mentioned earlier, previous literature consisted mostly of studies that followed quantitative methods. Although quantitative methods offer concrete data to certain aspects of the efficacy of an ONN on patient outcomes, such as the quantitative results on screening rates, I believe nursing practice requires a more qualitative approach to provide a broader understanding of the actual relationship between the ONN and the patient. For example, the study by Ferrante *et al.* (2007) reported that immediately after the introduction of nurse navigators, the patients in the intervention group had shorter times to diagnostic resolution, lower mean anxiety scores, and higher mean satisfaction scores compared to the control group without a nurse navigator. However, the reason behind the results should be focused to identify the key functions of the ONN that enabled the patients to have low anxiety or high satisfaction scores. I believe recognition should be given to the individuals in the process, not just the observable effect of ‘intervention’ upon a ‘patient’. This study conveyed a richness and intensity of detail pertaining to the interconnected relationship between an ONN and her patients, while bringing clarity to the ONN roles. Phenomenology provides a broader understanding of the patient experience based on the role of nurse navigators because it involved both groups coming together to reflect and provide their lived experiences.

Some of the findings supported what is already known about nurse navigators such as improving adherence to diagnostic services (Ferrante *et al.*, 2007; Melinshyn & Wintonic, 2006), decreasing anxiety (Cancer Care Ontario, 2009), and improving co-ordination of care (Nash *et al.*, 2006). Although these studies were quantitative in nature, the present study added a broader understanding and perspective of the nurse navigator’s roles. For example, the findings of the current study suggested that nurse navigators took initiative to actively provide support (emotional and educational) to the patients during the diagnostic phase, whether it was staying after the physician-patient consult to address any concerns or conducting a needs assessment. Thus, decreasing anxiety and uncertainties for the patients, allowing them to adhere to the diagnostic tests ordered by the physician.

The present study also added new evidence to the body of nursing knowledge such as the core areas of practice for oncology nurse navigators. The use of qualitative methods to collect data allowed me to determine the core areas of practice based on how the patients perceived their nurse navigators impacted their experience and what the nurse navigators felt were important in providing a positive patient experience and how their roles as a nurse navigator impacted the patients and their families.

Lastly, I believe utilizing interviews as a means of qualitative data collection method allowed the participants, particularly the patients, to acknowledge the importance of the role of the nurse navigator within the cancer setting. At the end of each interview, the participants praised the support their ONNs provided, thus creating a sense of appreciation to the profession.

Small sample size

The small sample size was both a strength and a limitation to this study. The limitations of the small sample size will be discussed in the subsequent section.

Although the sample size was small, it enabled the primary researcher to carry out in-depth interviews, particularly with the nurse navigators, which generated new findings about the role of the oncology nurse navigators. Certainly a larger number of nurse navigators would have meant more interview data which would add to the amount of descriptive detail and possibly create a broader variation in experiences. However, the likelihood of interpretations drawn from the results does not rely on the number of participants alone (Bender, 2009). The four nurse navigators in this study expressed their experiences in individual ways and provided diverse observation opportunities. In fact, the data provided reliability and credibility since all four nurse navigators (the entire navigator team) within the lung cancer diagnostic assessment program at DRCC participated in this study, so we were able to gain a comprehensive view of the chosen location of study. Additionally, there was corroboration among nurse navigators' experiences, which strengthens the study findings. Equally, by having such small sample size for a focus group, it was possible to cluster experiences and concerns that echoed across the group into meaningful thematic categories, and further explore issues with sufficient depth and flexibility to seek insight that may be overlooked in large sample studies.

Bi-Dimensional Framework

The framework's strength resides in its comprehensiveness because of the fact that the framework distinguishes the bi-dimensional nature of the nurse navigator role simultaneously: continuity of care and patient empowerment. Moreover, the Bi-Dimensional Framework provided valuable theoretic foundations to better distinguish and comprehend the lived experience of the patients and the nurse navigators.

Due to the fact that the Bi-Dimensional Framework is comprehensive, it was used to guide conceptualization of this study, data analysis, and interpretation of results. Furthermore, the Bi-Dimensional Framework contributed to filling the gaps reported in previous literature, such as the need for identifying patient-centered outcomes to establish evidence-based areas of practice that can be used to clarify the role, function, and desired outcomes. The continuity of care dimension allowed for the identification of the core areas of practice related to the organizational functions of the nurse navigator role. While the patient empowerment dimension allowed for the identification of the core areas of practice related to the clinical functions of the role.

Limitations

Recognizing the challenges and limitations of this study provides good starting points for future research questions. The limitations are not signified as what was done wrong in conducting the study, but instead the drawbacks to the methodological choices made and those unexpected shortcomings of a research project involving human beings. The limitations are categorized according to the methodological choices regarding the sample size and English-speaking participants, the location of the study, the standard of practice and triangulation.

The patient sample size (n=4) was rather small due to time constraints with data collection, as well as potential participants' willingness to participate in the study. For this reason, the ability to conduct a comprehensive analysis was compromised. Furthermore, these findings cannot be generalized to the broader community. For example, the evidence on how the nurse navigators provide supportive care to their patients was limited because of the fact that the sample size was particularly small. Perhaps the four patients that participated in the interview genuinely did not require access to supportive care services (for the reasons they mentioned: having family/friend support and having previous experience with cancer care) and thus not seeing the importance of the nurse navigator's role in facilitating their supportive care needs. Nonetheless, the results from these interviews did provide valid information for the Durham Regional Cancer Centre at Lakeridge Health. This evaluation of the patients' as well as the nurse navigators' perceptions can provide evidence of patient outcomes to the DRCC based on the nurse navigator role.

Only English-speaking participants were included in this study. Although this inclusion criterion was made for sound pragmatic reasons, this may have created a limitation as it excluded a large number of potential participants. By excluding those patients who could not speak English, or have a minimum knowledge of spoken and written English, the various patient-nurse navigator relationships, particularly from explicitly different cultural perspectives, were not identified. The roles of the nurse navigators with respect to continuity of care (i.e. providing information) and patient empowerment (i.e. providing coping strategies) requires a certain amount of communication between the patient and his/her nurse navigator. For example, if a patient from an ethnic minority who cannot speak English was to come in for cancer care, how would the nurse navigators assist that particular patient in navigating through the cancer care continuum? It is rather important to determine how the nurse navigators target cultural and language barriers and achieve cultural competency within the cancer centre, considering the fact that there are many culturally diverse patients receiving cancer care, especially in Canada. While this does not detract from the interpretations of the study, it does raise questions of language and cultural barriers in nursing care and in research.

Furthermore, by choosing patients who resided only in Oshawa and had appointments from February, 2013 to the end of April 2013, created a limitation to this study. Although this was to facilitate the data collection process, these conditions may have caused sampling bias. It results in a non-random sample population in which all patients were not equally likely to have been selected. Just like the limitation of a small patient sample size, this sampling bias also undermines the external validity of the study, where the results of this study cannot be generalized to the broader cancer patient population.

Additionally, by selecting patients who had at least two contacts with their nurse navigators (as previously mentioned, judgement based on the standard of practice and in consultation with a nurse navigator at DRCC), we were not able to identify how the nurse navigators maintained an ongoing relationship with their patients and their families. The patients believed they did not have many contacts with their nurse navigators and thus providing a lack of evidence on the relational continuity aspect of the nurse navigator role.

Finally, the lack of triangulation by using at least two qualitative methods to collect data on participants created a limitation to this study. The initial methodology included observation as a method of data collection so to examine the interaction between the nurse navigators and patients. However, due to time constraints, the observational aspect was removed from the study. Although the findings contain reflections of the lived experience of the patients and nurse navigators, it failed to capture the naturalistic behaviour of the interaction. I firmly believe our study failed to benefit from the knowledge of the behaviours, emotions and relationship, so as to validate the qualitative data retrieved from the interviews and focus group.

Reflection on these limitations has been incorporated into the considerations of the implications of the ideas about the nurse navigator's role on patient experience presented in this dissertation. These implications are discussed below.

Implications

"Learning to make good clinical judgments and be a good practitioner requires ongoing experiential learning, reflection, and dialogue with patients and families" (Benner, Hooper-Kyriakidis, Stannard, 1999, p.17). The implications of this study are divided into two main categories: enhancing practice and developing research, which are discussed in light of the perspective of valuing experiential learning. Phenomenological studies may hold many extensive implications depending on how the readers interpret the findings, however, in keeping with the entire study's framework, the implications presented below focus on the detail of a few specific ideas.

Enhancing practice

Ample guidelines and practice standards already exist for oncology nurses that provide expert direction for best practices. With respect to oncology nurses within a Canadian setting, CANO is a leading organization that supports Canadian nurses to promote and develop excellence in oncology nursing practice. The seven domains of practice for the oncology nurse, as outlined by the CANO foundation document (2006), validate the core areas of practice identified in this study. However, to date, in Canada, the core areas of practice for professional nurse navigators have not been described (Cook *et al.*, 2013). Nonetheless, the Bi-Dimensional Framework proved to be of great importance in contributing to the enhancement of practice for the oncology nurse navigator with respect to the already established CANO domains of practice for nurses within the oncology field.

Figure 4 shows how the Bi-Dimensional Framework defined by Fillion *et al.* (2012), with its six concepts, and the core areas of practice identified in this study, corresponds to the domains of practice for oncology nurses, as outlined by CANO (CANO, 2006). In fact, this study is unique because the core areas of practice identified in this study can be used as a foundation to contribute to the enhancement of the practice standards (or domains of practice) established by CANO particularly for oncology nurse navigators distinctive to the diagnostic assessment phase.

These results support and illustrate the bi-dimensional nature of this role (enhancing continuity of care, while promoting patient and family empowerment) in a community-based cancer centre. These results also suggest that this role needs to be further defined; the development of the bi-dimensional navigation framework, as well as the core areas of practice has laid a foundation for consistency in role development and implementation. Acknowledgement of a comprehensive nurse navigation framework and core areas of practice by decision makers, managers and healthcare providers could lead to the development of similar roles with other diseases such as cardiovascular diseases and mental illness. The bi-dimensional nurse navigation framework described here can be used to guide the content of the nursing training modules to provide a consistent and patient-centered definition of the role, and systematic training reflecting the functions/core areas of practice of patient continuity of care and empowerment (Fillion *et al.*, 2012).

Dimension 1: Continuity of Care		
Concepts	**CANO Domains of Practice**	**Core Areas of Practice**
Informational Continuity: Use of information, disease- or person-focused, to make present care appropriate for each individual. Continuity of information is achieved through the use of diverse communication tools (Fillion *et al.*, 2012).	***Practice Domain 5-*** ***Facilitating Continuity of Care/Navigating the System:*** Promoting and facilitating continuity of care across care settings and between healthcare providers by sharing information on the individual/family's current situation, plan of care and goals. Assisting the individual/family to navigate the healthcare system through understanding its structure, system and process and providing them with strategies to work within that system (CANO, 2006).	***Patient-Focused Cancer Care:*** ▪ Providing timely and personalized information to patients and their families ▪ Ensuring the patients understand the composition of the diagnostic phase: the process, the services, and the options ▪ Being the resource for information (i.e. medical terms, diagnostic test procedures, symptom management), and explaining how the information affects the client as a patient and an individual ▪ Relaying and decoding information provided by the physician
Management Continuity: A consistent and coherent approach to the management of cancer that is responsive to a patient's changing needs. Providing a sense of security in future care for both patients by mapping the continuum of cancer care (Fillion *et al.*, 2012).	***Practice Domain 1-*** ***Comprehensive Health Assessment:*** Conducting timely and comprehensive assessments of the health and supportive care needs of the individual with cancer and their families across the cancer continuum using a systematic approach that is sensitive to language and culture. Considering the situational context and the needs and responses of the individual and family in determining the scope and depth of assessment (CANO, 2006). ***Practice Domain 6***	***Conduct Needs Assessment:*** ▪ Conducting comprehensive needs and resources assessment (initial and ongoing) - Telephone assessment: retrieving medical and symptom-related history of patient - Medical assessment: identifying symptoms experienced - Cultural assessment: understanding the cultural beliefs, practices, and values of patient ▪ Matching unmet needs with services within the cancer

	Decision-Making and Advocacy: Facilitating self-determination and informed decision making for the individual/family, in collaboration with other members of the interprofessional health care team. Communicating and documenting their preferred approach to care (CANO, 2006).	centre and the community ***Care Planning:*** ▪ Developing an individualized care plan based on the needs of the patient ▪ Explaining care plans, reducing uncertainty and anxiety, and decreasing barriers to cancer care adherence ***Shared Decision-Making:*** ▪ Involving the patients in making decisions about their care plan ▪ Empowering the patients to help make decisions that is appropriate for them ▪ Sharing information to allow for a mutual understanding and agreement in management options
Relational Continuity: Therapeutic relationship between a patient and healthcare provider, who develops accumulated knowledge of the patient as a person to map the cancer care journey (Fillion *et al.*, 2012).	***Practice Domain 2-*** ***Supportive and Therapeutic Relationships:*** Engaging in caring and therapeutic relationships with individuals with cancer and their families. Relationships are supportive and sensitive to changing physical and psychosocial-spiritual responses (CANO, 2006).	***Easily Accessible:*** ▪ Being easily accessible to the patients and families (in-person or through telephone) ▪ Creating trust and mutual respect ▪ Developing and maintaining an ongoing relationship with the patients and their families ▪ Using special communication techniques and ensuring the line of communication is constantly open for sharing of information

		Identify & Eliminate Barriers: ▪ Proactively identifying and eliminating specific barriers for patients/families and helping them work through these barriers: - Barriers to information: ensuring constant sharing of information by involving them decision making - Barriers to health literacy: decoding medical terminologies (i.e. test results or diagnostic procedures) - Barriers to accessibility (healthcare provider & services): being easily accessible and navigating the patients to appropriate services (within the cancer centre or community) - Barriers to mental issues: understanding the different psychological problems common in cancer patients and providing counselling and emotional support.
Dimension 2: Patient Empowerment		
Concepts	**CANO Domains of Practice**	**Core Areas of Practice**
Active Coping: Process of taking active steps to try to eliminate or reduce the stressor or to ameliorate its effects (Fillion *et al.*, 2012).	***Practice Domain 4-*** ***Teaching and Coaching:*** Preparing individuals with cancer and their families for the many different aspects of the cancer experience by providing education, psychosocial-spiritual support and counseling across the continuum (CANO, 2006). ***Practice Domain 6-***	***Patient Advocate:*** ▪ Being aware of individual needs (and concerns) of patients and advocating on behalf of them to ensure their needs are met Educational Support: ▪ Providing individualized education, based on the

	Decision-Making and Advocacy: Advocating on behalf of the individual/family, communicating and documenting their preferred approach to care (CANO, 2006).	patients' needs, educational level and situation using evidence-based techniques ▪ Reinforcing active coping
Self-Management: Supporting the person and family and strengthening his or her ability to accept the illness and regain control by using specific efficacy-enhancing techniques (Fillion *et al.*, 2012).	***Practice Domain 3-*** ***Management of Cancer Symptoms and Treatment Side Effects:*** Integrating and applying knowledge of cancer pathophysiology, disease progression, treatment modalities, treatment side effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions (CANO, 2006).	***Personalized Symptom Management:*** ▪ Assessing and monitoring symptoms (ongoing basis) - Conducting symptom assessments to identify any major symptoms experienced that may require more attention/alter the diagnostic plan ▪ Providing personalized symptom management education to patients (i.e. self-managing side effects and symptoms of standard diagnostic tests) ▪ Ensuring the informal caregivers understand how to take care of and help manage the patient's symptoms at home ▪ Reinforcing self-care behaviours
Supportive Care: Providing the necessary services as needed by those living with or their families to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs (Fillion *et al.*, 2012).	***Practice Domain 2-*** ***Supportive and Therapeutic Relationships:*** Engaging in relationships that are supportive and sensitive to the changing physical and psychosocial-spiritual responses (CANO, 2006).	***Resource Navigation:*** ▪ Conducting a needs assessment and matching unmet needs to supportive care needs ▪ Collaborating with multiple healthcare teams and community programs to facilitate provision of care required by the patients and families

		▪ Referring the patients and families to the cancer care organization and community services/programs to address unmet supportive care needs

Figure 4. Relationship between the Bi-Dimensional Framework, CANO Domains of Practice and core areas of practice.

Developing research

There are several research implications that arise from this study with respect to the methods employed for this thesis. This study, with its focus on lived experience or experiential learning as a form of knowledge, has emphasized the importance of participation of both the researcher and the participants in understanding the impact of the role of the nurse navigators on patient experience. These aspects of the research method ensure understanding the particular individual experience of the phenomenon as it is lived. In conducting this study, a renewed respect of the narrative as a powerful means for comprehending nursing practice was established. This leads to pondering how phenomenologically-informed participatory methods may be particularly valuable for understanding and in turn, enhancing the relationship, knowledge and skills acquisition in nursing practice within community health programs. Furthermore, by doing such conversational style qualitative research, it was possible to identify the concerns and barriers faced by the patients, and the challenges encountered by the nurse navigators. This information is especially beneficial at the local level in understanding the nurse navigator program and its effectiveness on standard of care.

Closing Thoughts

Nurse navigation is an emerging trend in cancer care. Oncology nurse navigators play a significant role in assisting the patients and their families with coordination of services across the continuum of care, and continued research is necessary in advancing the oncology nurses as nurse navigators. Nurse navigators are in a key position to enable continuity of care because their practice incorporates advanced knowledge and skills in patient-focused cancer care. They also adapt their practice to the emotional and supportive care needs required to promote patient empowerment.

This study has successfully achieved its goal, which was to determine the impact of the role of an ONN on lung cancer patient's experience within the diagnostic phase. The Bi-Dimensional Framework was effective in guiding the research project to determine the key outcomes of the study. In using this professional framework to guide the data collection and analysis, this thesis has identified ten core areas of practices for oncology nurse navigators, essential for the achievement of continuity of care and patient empowerment.

Although the overall study elicited positive responses, the patients felt they did not develop and maintain an ongoing relationship with their nurse navigators. Possibly a reason behind this statement is because this study focused on patient experience only within the diagnostic phase. Perhaps future research could look at how the nurse navigator's role impacts patient continuity of care and empowerment within the entire cancer care continuum, including the diagnostic, treatment and discharge/recovery phase. As developments of survivorship programs are becoming more standard in cancer care settings (Cook *et al.*, 2013), considerations should be given to the value of the nurse navigator role in these programs, particularly as their core areas of practice and expertise is providing education and support, make them a model candidate.

It would be rather interesting to also determine the impact of oncology nurse navigators within a multidisciplinary setting. The collaboration of other healthcare providers with the nurse navigators should be explored to get a comprehensive outlook of interdisciplinary team functioning and how it affects standard of care.

To conclude, this journey of conducting research to determine how the role of the oncology nurse navigator impacted patient experience was rather remarkable. The outcome of this study deepened my understanding of the many roles an oncology nurse navigator has and the immense need of their knowledge and skills in providing effective cancer care. In summing up the thesis, I leave the reader with the words of one participant: “I think it’s good to have that ‘in-between’…between the doctor and patient. To me, I thought of her as just a nurse before, but the name navigator now- they are doing more than what a nurse did. So I think their role is very important” (Anonymous participant, interview, March, 2013).

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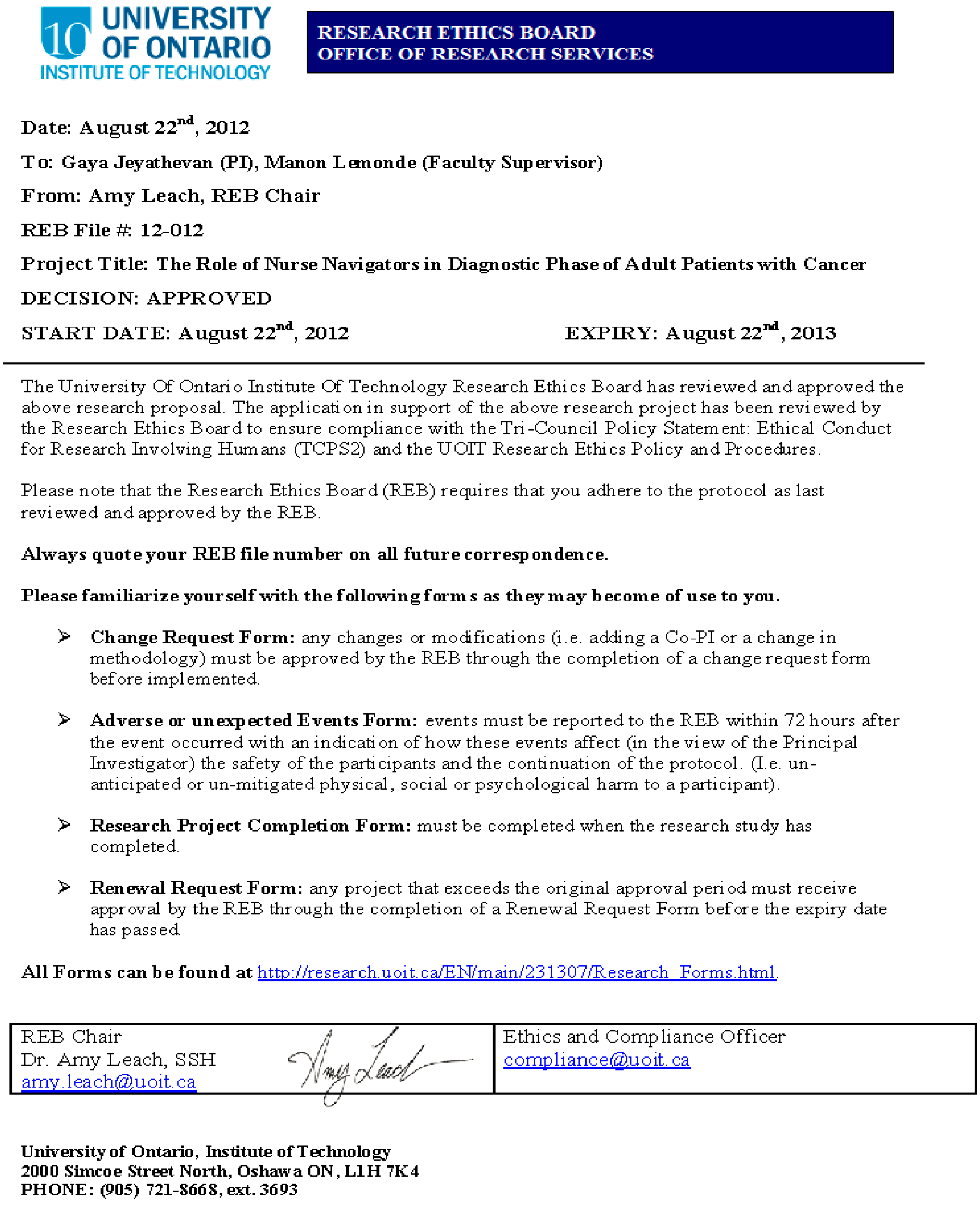
Appendix A

UOIT REB Approval Letter



UNIVERSITY OF ONTARIO
INSTITUTE OF TECHNOLOGY

RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

Date: August 22nd, 2012

To: Gaya Jeyathevan (PI), Manon Lemonde (Faculty Supervisor)

From: Amy Leach, REB Chair

REB File #: 12-012

Project Title: The Role of Nurse Navigators in Diagnostic Phase of Adult Patients with Cancer

DECISION: APPROVED

START DATE: August 22nd, 2012 **EXPIRY: August 22nd, 2013**

The University Of Ontario Institute Of Technology Research Ethics Board has reviewed and approved the above research proposal. The application in support of the above research project has been reviewed by the Research Ethics Board to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and the UOIT Research Ethics Policy and Procedures.

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and approved by the REB.

Always quote your REB file number on all future correspondence.

Please familiarize yourself with the following forms as they may become of use to you.

- **Change Request Form:** any changes or modifications (i.e. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or unexpected Events Form:** events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol. (I.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** must be completed when the research study has completed.
- **Renewal Request Form:** any project that exceeds the original approval period must receive approval by the REB through the completion of a Renewal Request Form before the expiry date has passed.

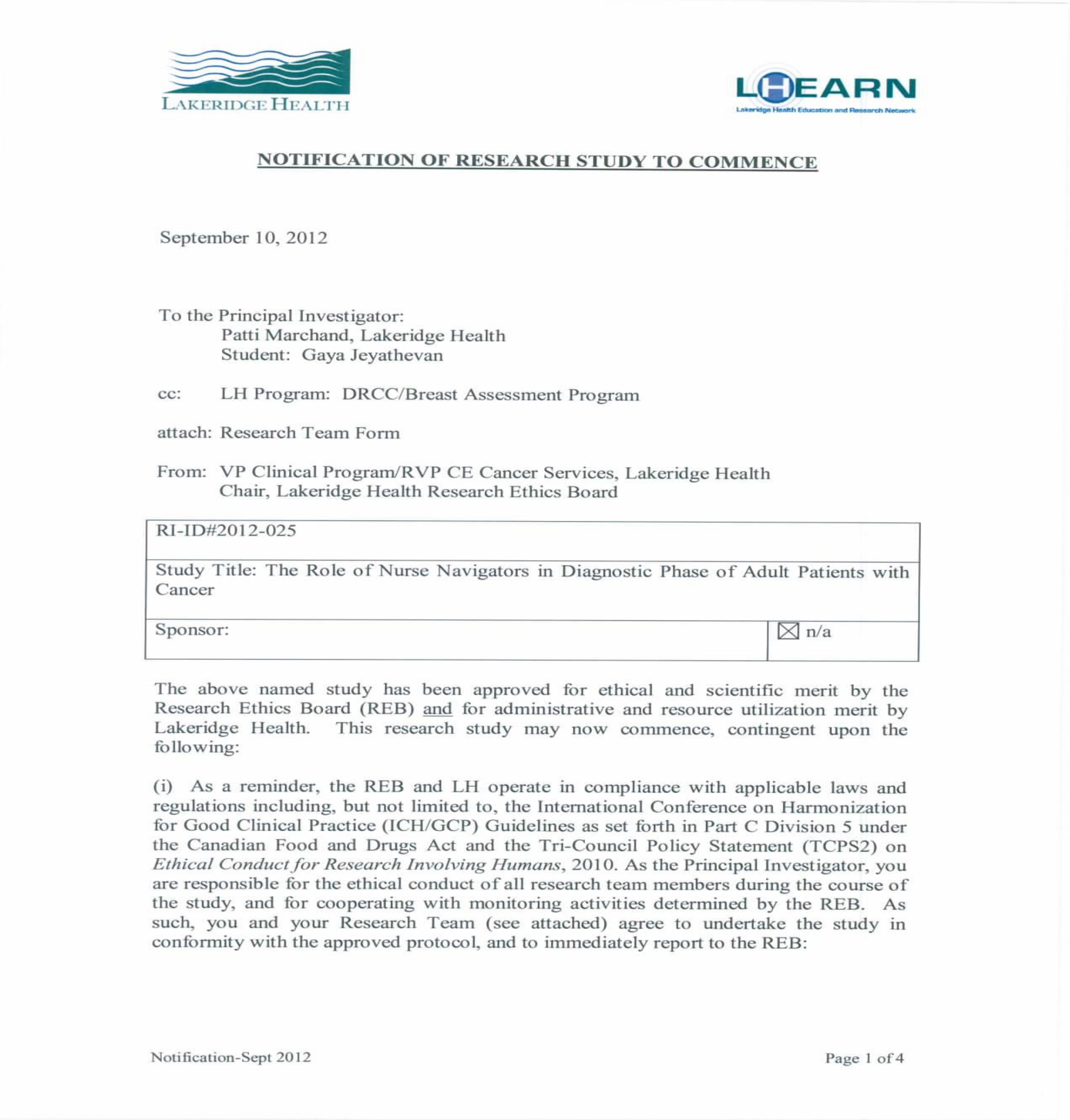
All Forms can be found at http://research.uoit.ca/EN/main/231307/Research_Forms.html.

REB Chair Dr. Amy Leach, SSH amy.leach@uoit.ca Amy Leach	Ethics and Compliance Officer compliance@uoit.ca

University of Ontario, Institute of Technology
2000 Simcoe Street North, Oshawa ON, L1H 7K4
PHONE: (905) 721-8668, ext. 3693

Appendix B

LH REB Approval Letter



LAKERIDGE HEALTH

LHEARN
Lakeridge Health Education and Research Network

NOTIFICATION OF RESEARCH STUDY TO COMMENCE

September 10, 2012

To the Principal Investigator:
Patti Marchand, Lakeridge Health
Student: Gaya Jeyathevan

cc: LH Program: DRCC/Breast Assessment Program

attach: Research Team Form

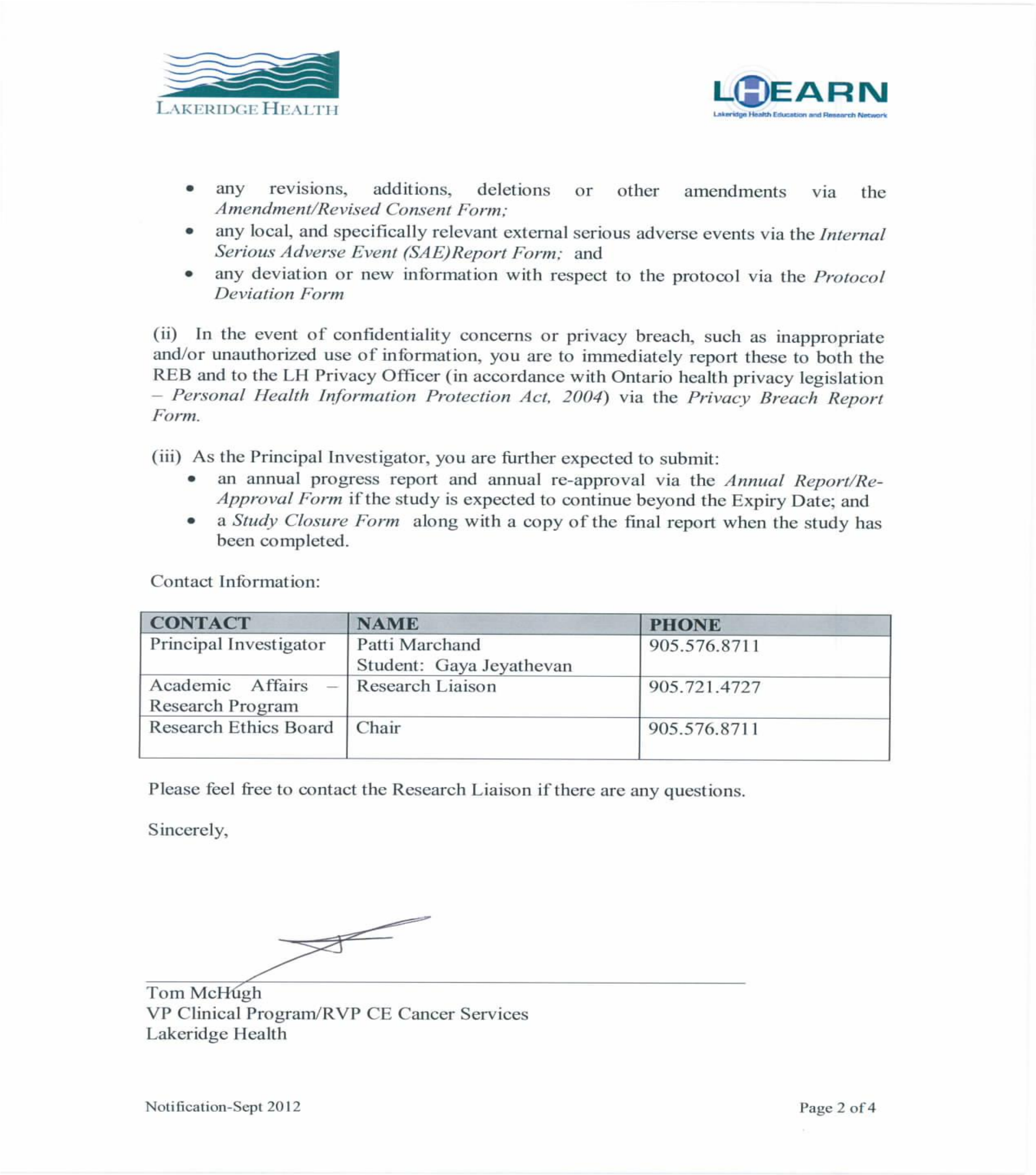
From: VP Clinical Program/RVP CE Cancer Services, Lakeridge Health
Chair, Lakeridge Health Research Ethics Board

RI-ID#2012-025	
Study Title: The Role of Nurse Navigators in Diagnostic Phase of Adult Patients with Cancer	
Sponsor:	☒ n/a

The above named study has been approved for ethical and scientific merit by the Research Ethics Board (REB) and for administrative and resource utilization merit by Lakeridge Health. This research study may now commence, contingent upon the following:

(i) As a reminder, the REB and LH operate in compliance with applicable laws and regulations including, but not limited to, the International Conference on Harmonization for Good Clinical Practice (ICH/GCP) Guidelines as set forth in Part C Division 5 under the Canadian Food and Drugs Act and the Tri-Council Policy Statement (TCPS2) on *Ethical Conduct for Research Involving Humans*, 2010. As the Principal Investigator, you are responsible for the ethical conduct of all research team members during the course of the study, and for cooperating with monitoring activities determined by the REB. As such, you and your Research Team (see attached) agree to undertake the study in conformity with the approved protocol, and to immediately report to the REB:

Notification-Sept 2012 Page 1 of 4



LAKERIDGE HEALTH

LHEARN
Lakeridge Health Education and Research Network

- any revisions, additions, deletions or other amendments via the *Amendment/Revised Consent Form;*
- any local, and specifically relevant external serious adverse events via the *Internal Serious Adverse Event (SAE)Report Form;* and
- any deviation or new information with respect to the protocol via the *Protocol Deviation Form*

(ii) In the event of confidentiality concerns or privacy breach, such as inappropriate and/or unauthorized use of information, you are to immediately report these to both the REB and to the LH Privacy Officer (in accordance with Ontario health privacy legislation – *Personal Health Information Protection Act, 2004*) via the *Privacy Breach Report Form.*

(iii) As the Principal Investigator, you are further expected to submit:

- an annual progress report and annual re-approval via the *Annual Report/Re-Approval Form* if the study is expected to continue beyond the Expiry Date; and
- a *Study Closure Form* along with a copy of the final report when the study has been completed.

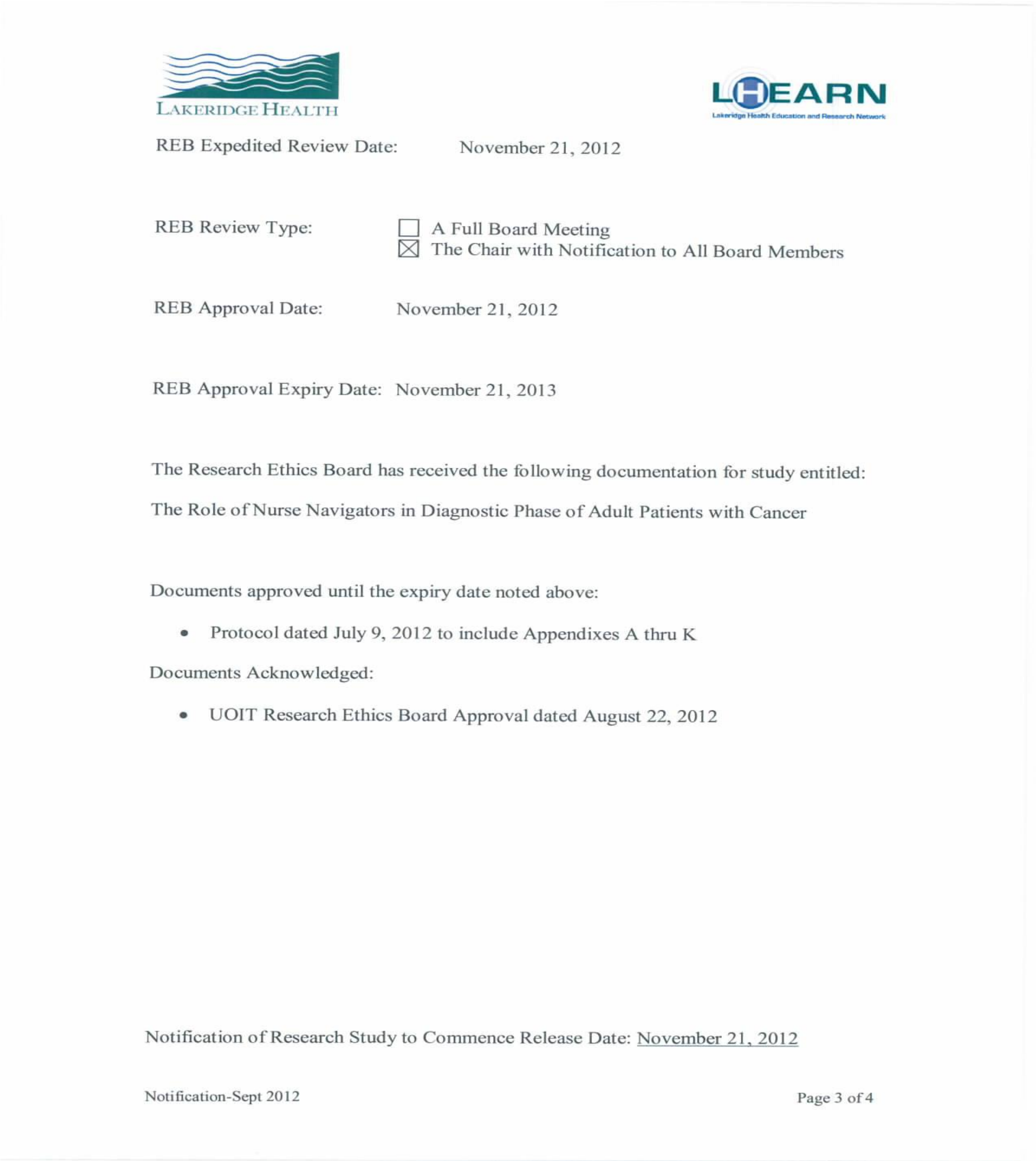
Contact Information:

CONTACT	NAME	PHONE
Principal Investigator	Patti Marchand Student: Gaya Jeyathevan	905.576.8711
Academic Affairs – Research Program	Research Liaison	905.721.4727
Research Ethics Board	Chair	905.576.8711

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

Tom McHugh
VP Clinical Program/RVP CE Cancer Services
Lakeridge Health



LAKERIDGE HEALTH

LHEARN
Lakeridge Health Education and Research Network

REB Expedited Review Date: November 21, 2012

REB Review Type:
☐ A Full Board Meeting
☒ The Chair with Notification to All Board Members

REB Approval Date: November 21, 2012

REB Approval Expiry Date: November 21, 2013

The Research Ethics Board has received the following documentation for study entitled:

The Role of Nurse Navigators in Diagnostic Phase of Adult Patients with Cancer

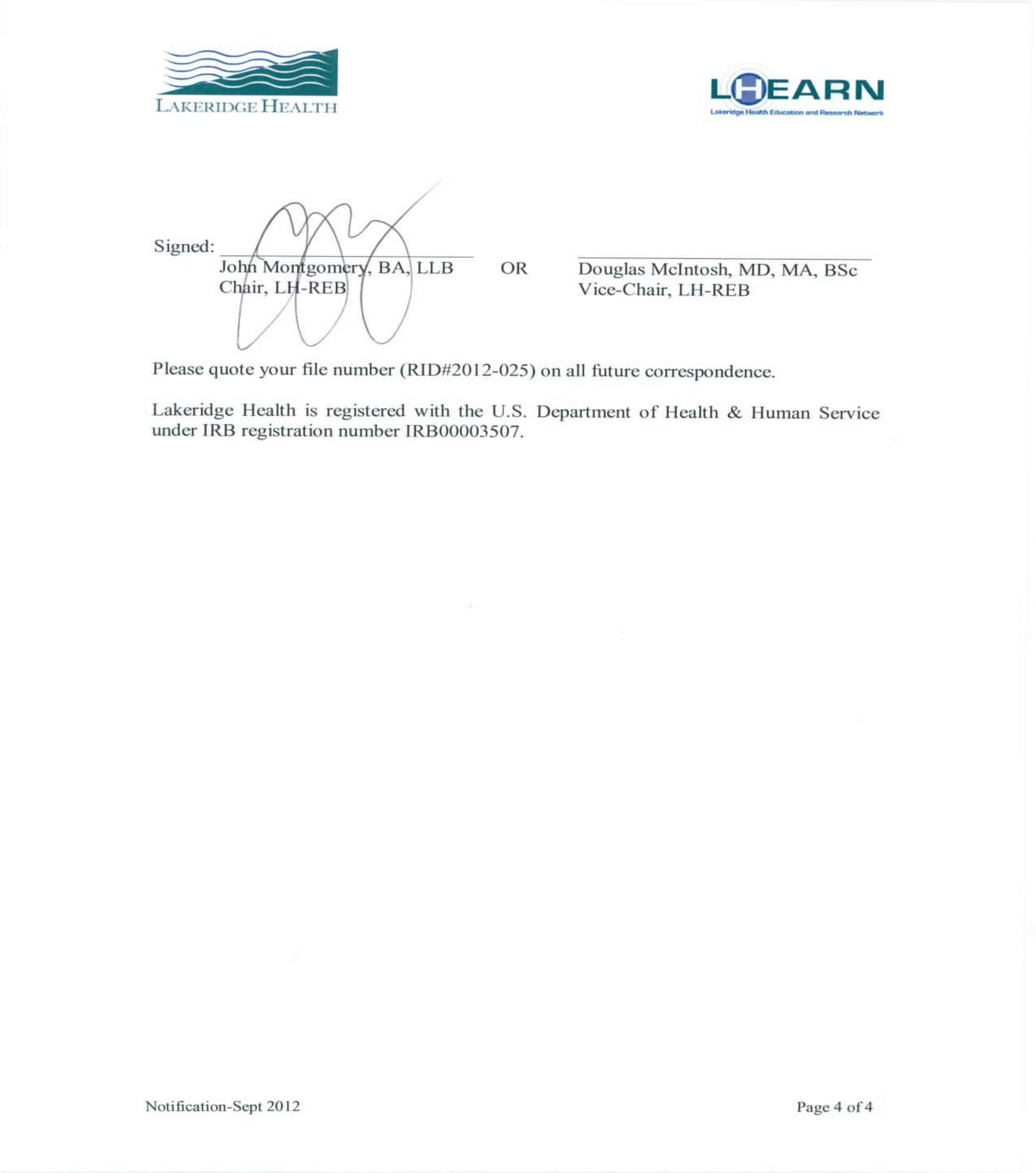
Documents approved until the expiry date noted above:

- Protocol dated July 9, 2012 to include Appendixes A thru K

Documents Acknowledged:

- UOIT Research Ethics Board Approval dated August 22, 2012

Notification of Research Study to Commence Release Date: <u>November 21, 2012</u>



LAKERIDGE HEALTH

LHEARN
Lakeridge Health Education and Research Network

Signed: ____________________ OR ____________________

John Montgomery, BA, LLB
Chair, LH-REB

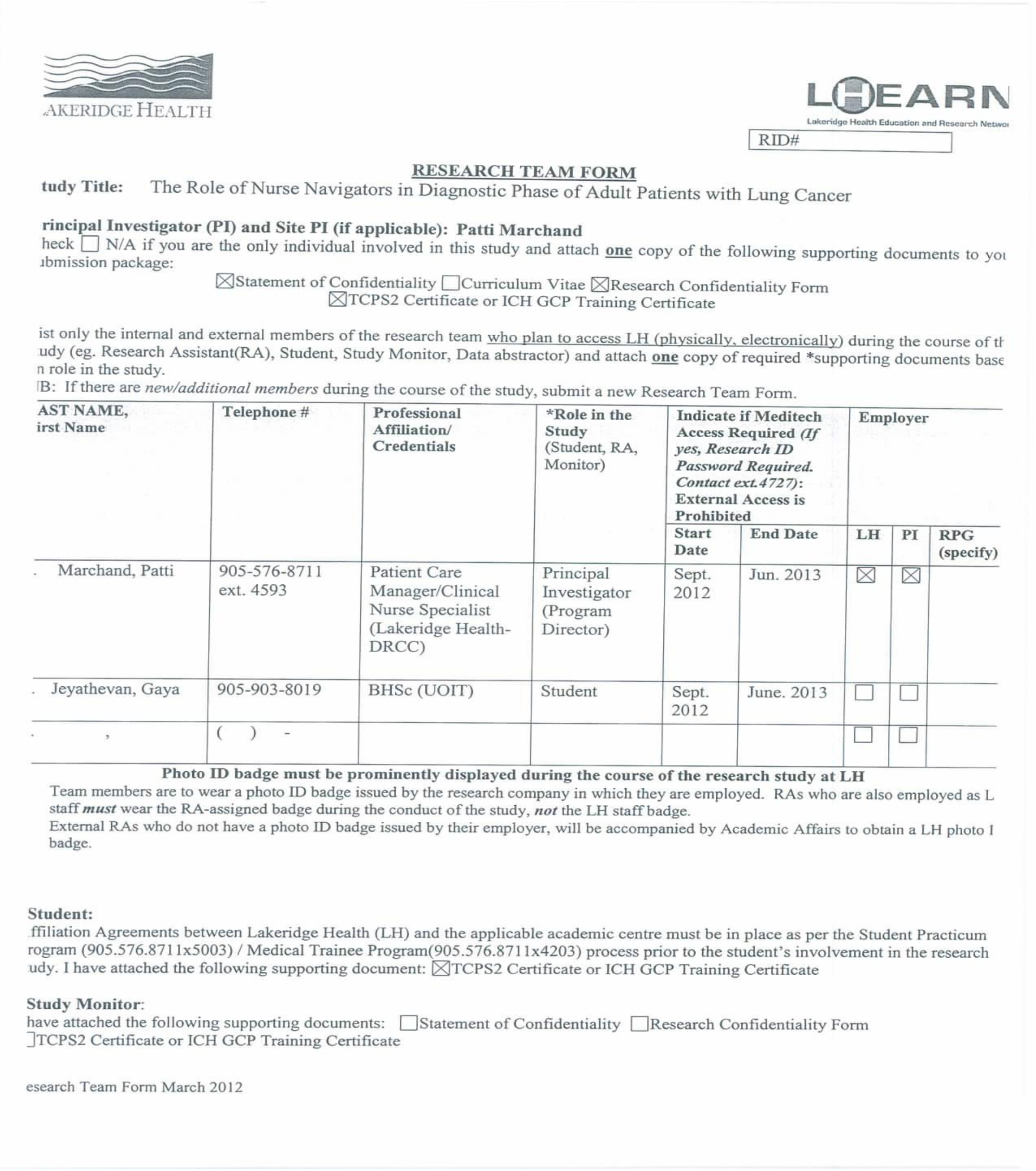
Douglas McIntosh, MD, MA, BSc
Vice-Chair, LH-REB

Please quote your file number (RID#2012-025) on all future correspondence.

Lakeridge Health is registered with the U.S. Department of Health & Human Service under IRB registration number IRB00003507.

Notification-Sept 2012

Page 4 of 4



AKERIDGE HEALTH

LHEARN
Lakeridge Health Education and Research Netwo

RID#

RESEARCH TEAM FORM

tudy Title: The Role of Nurse Navigators in Diagnostic Phase of Adult Patients with Lung Cancer

rincipal Investigator (PI) and Site PI (if applicable): Patti Marchand
heck ☐ N/A if you are the only individual involved in this study and attach **one** copy of the following supporting documents to yo ıbmission package:

☒Statement of Confidentiality ☐Curriculum Vitae ☒Research Confidentiality Form
☒TCPS2 Certificate or ICH GCP Training Certificate

ist only the internal and external members of the research team who plan to access LH (physically, electronically) during the course of th udy (eg. Research Assistant(RA), Student, Study Monitor, Data abstractor) and attach **one** copy of required *supporting documents base n role in the study.
IB: If there are *new/additional members* during the course of the study, submit a new Research Team Form.

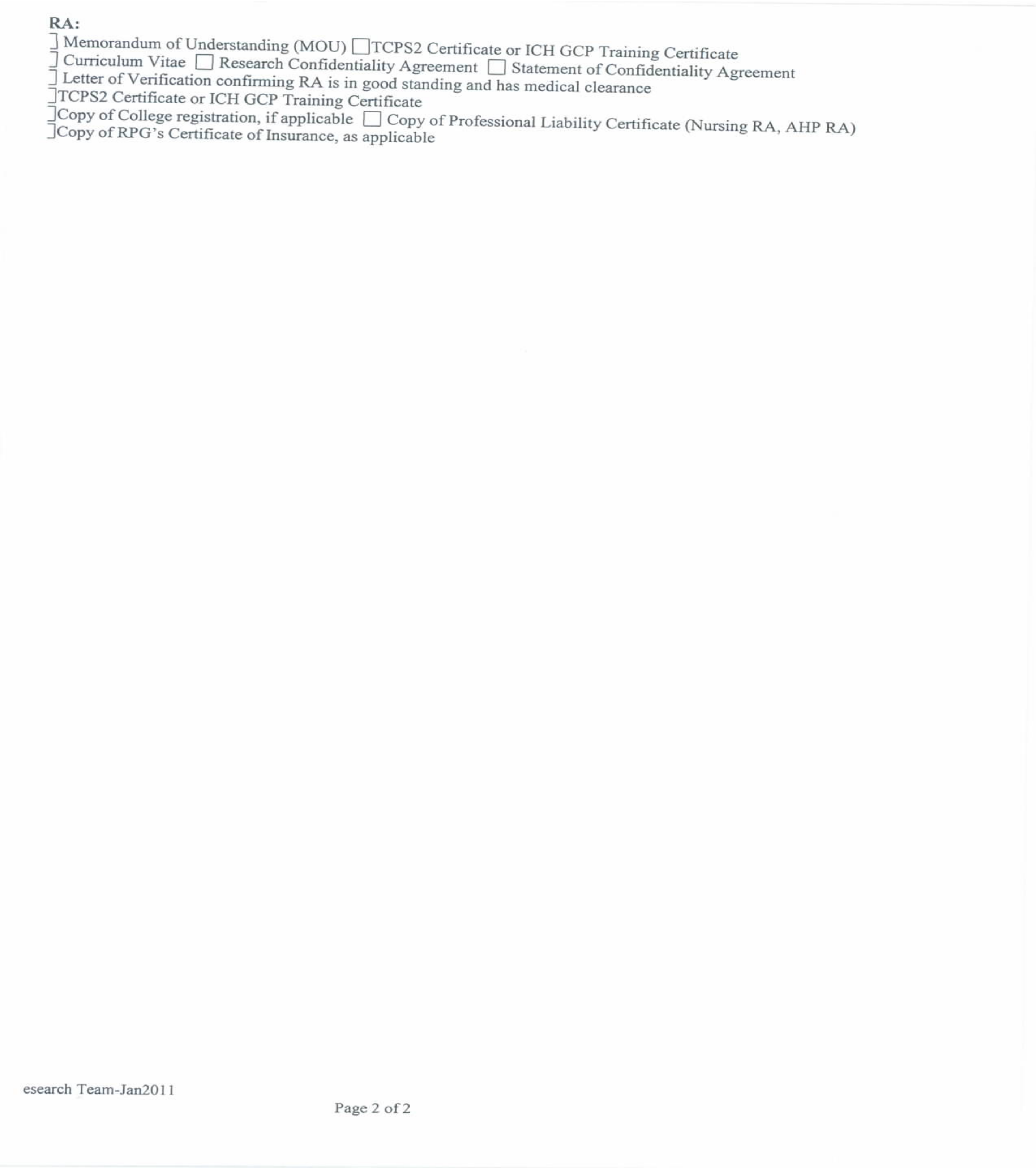
AST NAME, irst Name	**Telephone #**	**Professional Affiliation/ Credentials**	***Role in the Study** (Student, RA, Monitor)	**Indicate if Meditech Access Required *(If yes, Research ID Password Required. Contact ext.4727)*: External Access is Prohibited**		**Employer**		
				Start Date	**End Date**	**LH**	**PI**	**RPG (specify)**
Marchand, Patti	905-576-8711 ext. 4593	Patient Care Manager/Clinical Nurse Specialist (Lakeridge Health-DRCC)	Principal Investigator (Program Director)	Sept. 2012	Jun. 2013	☒	☒	
Jeyathevan, Gaya	905-903-8019	BHSc (UOIT)	Student	Sept. 2012	June. 2013	☐	☐	
,	( ) -					☐	☐	

Photo ID badge must be prominently displayed during the course of the research study at LH
Team members are to wear a photo ID badge issued by the research company in which they are employed. RAs who are also employed as L staff ***must*** wear the RA-assigned badge during the conduct of the study, ***not*** the LH staff badge.
External RAs who do not have a photo ID badge issued by their employer, will be accompanied by Academic Affairs to obtain a LH photo I badge.

Student:
ffiliation Agreements between Lakeridge Health (LH) and the applicable academic centre must be in place as per the Student Practicum rogram (905.576.8711x5003) / Medical Trainee Program(905.576.8711x4203) process prior to the student's involvement in the research udy. I have attached the following supporting document: ☒TCPS2 Certificate or ICH GCP Training Certificate

Study Monitor:
have attached the following supporting documents: ☐Statement of Confidentiality ☐Research Confidentiality Form
☐TCPS2 Certificate or ICH GCP Training Certificate

esearch Team Form March 2012



RA:

☐ Memorandum of Understanding (MOU) ☐TCPS2 Certificate or ICH GCP Training Certificate
☐ Curriculum Vitae ☐ Research Confidentiality Agreement ☐ Statement of Confidentiality Agreement
☐ Letter of Verification confirming RA is in good standing and has medical clearance
☐TCPS2 Certificate or ICH GCP Training Certificate
☐Copy of College registration, if applicable ☐ Copy of Professional Liability Certificate (Nursing RA, AHP RA)
☐Copy of RPG's Certificate of Insurance, as applicable

esearch Team-Jan2011

Page 2 of 2

Appendix C
Patient Consent Form

UOIT CHALLENGE INNOVATE CONNECT

LAKERIDGE HEALTH

Title of Project: The Role of Nurse Navigators in Diagnostic Phase of Adult Lung Cancer Patients

Date: September 2012

Introduction:
A collective case study to evaluate the overall patient experience of adult lung cancer patients based on the implementation of a nurse navigator program is being conducted by the principal investigator (PI), Gaya Jeyathevan, BHSc, under the supervision of Dr. Manon Lemonde, PhD, RN, at the University of Ontario Institute of Technology (UOIT). This research study is a single-centered case study and partnered with the Durham Regional Cancer Centre (DRCC) at Lakeridge Health.

The purpose of the research project is to evaluate the role of nurse navigators within the diagnostic phase on the overall patient experience of adult lung cancer patients within the Durham Region. At the end of this study, I want to determine the experience of the lung cancer patients, aged 18 and above, with respect to continuity of care and patient empowerment following a 2-4 month nurse navigator program within the diagnostic phase.

You are being invited to participate in this research study because you are a patient receiving cancer care at DRCC within Lakeridge Health. This study has been reviewed and received ethics approval through the Research Ethics Board at UOIT (File # 12-012) and the Lakeridge Health Ethics Board. Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact the Chair of the Research Ethics Board of Lakeridge Health at (905) 576-8711 or the UOIT Ethics and Compliance Officer at 905-721-8668 ext. 3693.

Your participation involves completing a socio demographic form and taking part in an interview session consisting of open-ended questions to discuss the impact of nurse navigator on the lung cancer patient empowerment and continuity of care. The interview will be tape-recorded and would last about 30 minutes. The completion of these interviews will be held in the meeting rooms within the hospital. Furthermore, with your permission the principal investigator may be observing the interaction between you and your nurse navigator during one of your appointments at the DRCC.

Voluntary Participation:
Your participation in this study is voluntary. Your decision to participate or not participate in this study will not affect the care that you are entitled to receive from DRCC or from your health care providers. You may also discontinue your participation at any time without any consequences to the care you are entitled to receive from DRCC or from your health care providers. If you feel uncomfortable answering any of the questions, you do not have to answer them. You do not waive any of your legal rights by agreeing to participate in the research study.

Confidentiality:
All information and data collected will be kept completely confidential. Your names, and contact information will not appear on any forms or on any type of publication. An ID code will be used as an identifier, as well as to keep all the names disclosed. All the interview recordings, consent forms, and personal information collected will be kept private in the faculty supervisor's (Dr. Manon Lemonde, PhD, RN, at UOIT) office at UOIT, and only the research team will have access to the data. All interviews (recordings and transcriptions) will be kept for 5 years after the completion of the research study. After the 5 year period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be destroyed by reformatting, rewriting or deleting. All the information provided by you will remain confidential and will only be utilized for the purpose of this research.

The written project will contain only group data, and will not contain reference of a single participant. The results of the study may be published or presented at professional meetings, or journals.

Risks and Benefits:
This research study will not personally benefit you; however, your participation in this study will provide evidence to the impact of the roles of nurse navigators on overall patient experience of cancer patients. Your participation will also enable us to effectively evaluate the nurse navigator program and how it affects the cancer patients.

The risks involved with your participation are very minimal. During the interview, if you have feelings of anxiety or upset, please feel free to contact the social worker at Lakeridge

Health 905-576-8711 ext. 4402. Also, you do not have to answer any of the questions and you have the right to withdraw from the study at any time without any consequences.

Compensation:
There is no cost to participate in this study, except for the time engaging in the interview. You will receive money to reimburse for your parking expenses for your scheduled interview on the day of the interview. You will not be reimbursed for parking costs for your scheduled interview if you decide to not participate in the interview.

If there are any further questions please, feel free to contact the principal investigator Gaya Jeyathevan, BHSc, at 905-903-8019 (gayathiri.jeyathevan@uoit.ca); or the faculty supervisor Manon Lemonde at 905-721-8668, ext. 2706 (manon.lemonde@uoit.ca).

In order for you to participate in this study, please sign this consent form below. Please bring the signed consent form to your scheduled interview.

I ______________________________, acknowledge by signing this consent form that I have read and understood the above information and is willing to participate in the above study. I give consent to:

Participate in the interview: ☐
Complete a demographics form: ☐
Allowing the PI to observe the interaction between myself and my nurse navigator: ☐

________________________________ ___________
Participant Full Name Date

________________________________ ____________
Participant Signature Date

________________________________ ______________
Researcher Signature Date

YOU WILL BE PROVIDED A COPY OF THIS CONSENT FORM FOR YOUR OWN RECORDS

Appendix D

Nurse Navigator Consent Form

Title of Project: The Role of Nurse Navigators in Diagnostic Phase of Adult Lung Cancer Patients

Date: September 2012

Introduction:
A collective case study to evaluate the overall patient experience of adult lung cancer patients based on the implementation of a nurse navigator program is being conducted by the principal investigator (PI), Gaya Jeyathevan, BHSc, under the supervision of Dr. Manon Lemonde, PhD, RN, at the University of Ontario Institute of Technology (UOIT). This research study is a single-centered case study and partnered with the Durham Regional Cancer Centre (DRCC) at Lakeridge Health.

The purpose of the research project is to evaluate the role of nurse navigators within the diagnostic phase on the overall patient experience of adult lung cancer patients within the Durham Region. At the end of this study, I want to determine the experience of the lung cancer patients, aged 18 and above, with respect to continuity of care and patient empowerment following a 2-4 month nurse navigator program within the diagnostic phase.

You are being invited to participate in this research study because you are a nurse navigator working at DRCC within Lakeridge Health. Your input on how your role as a nurse navigator affects the overall patient experience of the cancer patients assigned to you will be of great benefit. This study has been reviewed and received ethics approval through the Research Ethics Board at UOIT (File # 12-012) and the Lakeridge Health Ethics Board. Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact the Chair of the Research Ethics Board of Lakeridge Health at (905) 576-8711 or the UOIT Ethics and Compliance Officer at 905-721-8668 ext. 3693.

Your participation involves completing a socio demographic form and taking part in a focus group session consisting of open-ended questions to discuss the impact of nurse navigator on the lung cancer patient empowerment and continuity of care. The discussion during the focus group will be tape-recorded and would last about 45 minutes. The focus group will be held in the meeting rooms within the hospital. Furthermore, with your permission the principal investigator may be observing the interaction between you and your patients during one of your patients' appointments at the DRCC. Lastly, your participation in this study also involves agreeing to keep the content of the focus group discussion confidential.

Voluntary Participation:

Your participation in this study is voluntary. Your decision to participate or not participate in this study will not affect your employment at DRCC. You may also discontinue your participation at any time without any consequences to your employment at DRCC. If you feel uncomfortable answering any of the questions, you do not have to answer them. You do not waive any of your legal rights by agreeing to participate in the research study.

Confidentiality:

All information and data collected will be kept completely confidential. Your names, and contact information will not appear on any forms or on any type of publication. An ID code will be used as an identifier, as well as to keep all the names disclosed. All the focus group recordings, consent forms, and personal information collected will be kept private in the faculty supervisor's (Dr. Manon Lemonde, PhD, RN, at UOIT) office at UOIT, and only the research team will have access to the data. All recordings and transcriptions will be kept for 5 years after the completion of the research study. After the 5 year period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be destroyed by reformatting, rewriting or deleting. All the information provided by you will remain confidential and will only be utilized for the purpose of this research.

The written project will contain only group data, and will not contain reference of a single participant. The results of the study may be published or presented at professional meetings, or journals.

Risks and Benefits:

This research study will not personally benefit you; however, your participation in this study will provide evidence to the impact of the roles of nurse navigators on overall patient experience of cancer patients. Your participation will also enable us to effectively evaluate the nurse navigator program and how it affects the cancer patients.

The risks involved with your participation are very minimal. During the interview, if you have feelings of anxiety or upset, please feel free to contact the social worker at Lakeridge

Health at 905-576-8711 ext. 4402. Also, you do not have to answer any of the questions and you have the right to withdraw from the study at any time without any consequences.

Compensation:
There is no cost to participate in this study, except for the time engaging in the focus group.

If there are any further questions please, feel free to contact the principal investigator Gaya Jeyathevan at 905-903-8019 (gayathiri.jeyathevan@uoit.ca); or the faculty supervisor Manon Lemonde at 905-721-8668, ext. 2706 (manon.lemonde@uoit.ca).

In order for you to participate in this study, please sign this consent form below. Please bring the signed consent form to your scheduled interview.

I _______________________, acknowledge by signing this consent form that I have read and understood the above information and is willing to participate in the above study. I give consent to:

Participate in the focus group: ☐
Complete a demographics form: ☐
Allowing the PI to observe the interaction between myself and my patient(s): ☐

________________________________ ___________
Participant Full Name Date

________________________________ ___________
Participant Signature Date

________________________________ ___________
Researcher Signature Date

YOU WILL BE PROVIDED A COPY OF THIS CONSENT FORM FOR YOUR OWN RECORDS

Appendix E

Patient Letter of Invitation

Study Title: The Role of Nurse Navigators in Diagnostic Phase of Adult Lung Cancer Patients

Dear Sir or Madame,

This letter is an invitation to participate in a research study. As a Masters student in the Faculty of Health Sciences specializing in program evaluation at the University of Ontario Institute of Technology (UOIT), I am currently conducting a research under the supervision of Dr. Manon Lemonde, PhD, RN, from UOIT.

The purpose of this research project is to evaluate the role of nurse navigators within the diagnostic phase on the overall patient experience of adult lung cancer patients within the Durham Region. At the end of this research study, we want to get a better understanding of the experience of the lung cancer patients and nurse navigators with respect to continuity of care and patient empowerment based on the role of the oncology nurse navigators in the diagnostic phase.

If you decide to participate, you will be asked to engage in an interview consisting of open-ended questions to discuss the impact of nurse navigators on continuity of care and patient empowerment of your patient experience. Furthermore, with your permission the principal investigator (Gaya Jeyathevan) may be observing the interaction between you and your nurse navigator during one of your appointments at Durham Regional Cancer Centre (DRCC) at Lakeridge Health.

The meeting will take place in scheduled meeting rooms within the DRCC at Lakeridge Health and should last about 30 minutes. The interview will be audio taped so that I can accurately capture what is discussed. The tapes will only be reviewed by members of the research team who will transcribe and analyze them.

Participation is voluntary and confidential. Study information will be kept in a secure location at UOIT. The results of the study may be published or presented at professional meetings, or journals. Participation is anonymous, which means that no one (not even the research team) will know who the responses belong to. You will receive money to reimburse you for your parking expenses on the day of your scheduled interview with me.

Taking part in the study is voluntary. You may decide to quit the study at any time or decide not to answer any question you are not comfortable answering.

I will be happy to answer any questions you have about the study. You may contact me at 905-903-8019 (gayathiri.jeyathevan@uoit.ca).

Thank you very much for your consideration. I will contact you within the next week to follow up on your interest to participate in this study, and to answer any questions that you may have.

With kind regards,

Gaya Jeyathevan
905-903-8019
gayathiri.jeyathevan@uoit.ca

Appendix F
Script for Receptionist

Step-by-Step Instructions:

1. You will be given a list of patients names that are eligible to participate in this study
2. When the patient (or caregiver) comes to check in, please follow the script below and provide them with the package which includes the letter of invitation and the consent form.
3. If they ask questions, please inform them to take a look at the letter of invitation for further detail.
4. Please get a verbal consent from them stating they are comfortable in allowing me to get their phone numbers and contact them later on to follow up (mentioned at the end of the script).
5. If they verbally consent, please note this down on the verbal consent form attached.
6. If they consent, please also write down their name, and the date of the verbal consent.
7. If they say they are not interested, please say thank you.
8. (If they say they would rather call me, say that is fine.)

Script for Receptionists- Recruitment Process

Hello, Mr. /Mrs. ______.

There is a research study being done here by a Master's student from University of Ontario Institute of Technology.

These are the letter of invitation and the consent forms which have more details of the study.

Would it be alright to provide your phone number to the student so she can follow up with you to see if you are interested in participating in this study?

Appendix G
Verbal Consent Worksheet

Patient Verbal Consent Worksheet

Patient's Name	Verbal Consent Given (✓)	Date

Appendix H
Nurse Navigator Letter of Invitation

Study Title: The Role of Nurse Navigators in Diagnostic Phase of Adult Lung Cancer Patients

Dear Sir or Madame,

This letter is an invitation to participate in a research study. As a Masters student in the Faculty of Health Sciences specializing in program evaluation at the University of Ontario Institute of Technology (UOIT), I am currently conducting a research under the supervision of Dr. Manon Lemonde, PhD, RN, from UOIT.

The purpose of this research project is to evaluate the role of nurse navigators within the diagnostic phase on the overall patient experience of adult lung cancer patients within the Durham Region. At the end of this research study, we want to get a better understanding of the lived experience of the lung cancer patients and nurse navigators with respect to continuity of care and patient empowerment based on the role of the oncology nurse navigators in the diagnostic phase.

If you decide to participate, you will be asked to attend a short session to further explain the study in detail and answer any questions you may have. You will also be required to engage in a focus group consisting of open-ended questions to discuss the impact of nurse navigators on continuity of care and patient empowerment. Furthermore, with your permission the principal investigator (Gaya Jeyathevan) may be observing the interaction between you and your patients during one of their appointments at Durham Regional Cancer Centre (DRCC) at Lakeridge Health.

The focus group will take place in a scheduled meeting room within the DRCC at Lakeridge Health and should last about 45 minutes. The focus group will be audio taped so that I can accurately capture what is discussed. The tapes will only be reviewed by members of the research team who will transcribe and analyze them.

Participation is voluntary and confidential. Study information will be kept in a secure location at UOIT. The results of the study may be published or presented at professional meetings, or journals.

Taking part in the study is voluntary. You may decide to quit the study at any time or decide not to answer any question you are not comfortable answering.

I will be happy to answer any questions you have about the study. You may contact me at 905-903-8019 (gayathiri.jeyathevan@uoit.ca).

Thank you very much for your consideration. I will contact you within the next week to follow up on your interest to participate in this study, and to answer any questions that you may have.

With kind regards,

Gaya Jeyathevan
905-903-8019
gayathiri.jeyathevan@uoit.ca

Appendix I

Brief Introduction Template

INTERVIEW INTRODUCTION:

WELCOME:

First of all, I would like to thank you for taking your time out of your busy schedules and agreeing to be part of this interview. I really appreciate your willingness to participate.

INTRODUCTION:

As you all know, my name is Gaya. *Introduce each other*

PURPOSE OF FOCUS GROUPS:

The purpose of the research project is to evaluate the role of nurse navigators within the diagnostic phase on the overall patient experience of adult lung cancer patients within the Durham Region. At the end of this study, I want to determine the experience of the lung cancer patients, aged 18 and above, with respect to continuity of care and patient empowerment following a 2-4 month nurse navigator program within the diagnostic phase. We need your input and want you to share your honest and open thoughts.

GROUND RULES:

1. We want you to do the talking and participate as much as you can.
2. There are no right or wrong answers: your own experience and opinions are important. I would like to hear a wide range of opinions if possible.
3. Your participation in this study is voluntary. Your decision to participate or not participate in this study will not affect the care that you are entitled to receive from DRCC or from your health care providers. You may also discontinue your participation at any time without any consequences to the care you are entitled to receive from DRCC or from your health care providers. If you feel uncomfortable answering any of the questions, you do not have to answer them. You do not waive any of your legal rights by agreeing to participate in the research study.
4. I will be tape recording you, as well as taking notes to capture everything you have to say. We won’t identify anyone by name in our report. You will remain anonymous.

If you are okay, shall we move on to the consent forms and signing it?

Appendix J

Patient Socio-demographics Form

Participant ID: _______________

Gender: ○ Female ○ Male

Age: ______

Highest Level of Education:

○ High School
○ College Diploma
○ Baccalaureate Degree
○ Baccalaureate Degree
○ Master Degree
○ Doctorate Degree
○ Others (please specify): ____________________________

Marital Status: ○ Married ○ Single ○ Divorced ○ Widowed
○ Other (please specify):

Ethnicity:
○ Aboriginal
○ Asian (East & Southeast)
○ Caribbean
○ Latin, Central, & South American
○ Pacific Islander
○ African
○ Asian (South)
○ European
○ Middle Eastern
○ Other (please specify):______________________________

Employment Status:
○ Employed
○ Retired

○Not Employed

○Other (please specify):

Please briefly explain your diagnosis & any symptoms:

____

____

____

Appendix K

Nurse Navigator Socio-demographics Form

Participant ID: ________________

Gender: ○ Female ○ Male

Age: ______

Highest Level of Education in Nursing:

- ○ Baccalaureate Degree
- ○ College Diploma
- ○ Master Degree
- ○ Baccalaureate Degree
- ○ Doctorate Degree
- ○ Others (please specify): ______________________________

My years of working in oncology are ______________ years

My years of working within the diagnostic assessment program as a Nurse Navigator are ________ years

Employment Status:

- ○ Full-Time
- ○ Part-Time

Appendix L

Patient Interview Questions

Patient ID#: ________

Continuity of Care

Informational Continuity

1. Did the nurse navigator provide timely and personalized information or advice to you? Please provide an example of a time when this occurred.

Management Continuity

2. Did the nurse navigator explain treatment and care plans to you? Were you able to understand your treatment plan after being explained? Did this decrease any uncertainties you had previously? Was the nurse navigator able to decrease any barriers to cancer care adherence? Please explain what barriers you had in cancer care adherence and how the nurse navigator decreased these barriers.

Relational Continuity

3. Was your nurse navigator easily accessible? Please provide an example how the nurse navigator was able to maintain an ongoing relationship with you, and how it helped you.

Patient Empowerment

Active Coping

4. Did you receive any education and support by your nurse navigator to enhance your self-care? Please provide an example of a time when this helped to enhance your sense of personal health maintenance.

Self-Management

5. How has the nurse navigator assisted you in adjusting to and managing your altered health state? Did she provide you with personalized self-care instructions to manage your symptoms? Did your informal caregivers (i.e. family, friends) have necessary information about your health and managing your symptoms that they needed in order to help you out?

Supportive Care

6. Were you provided with the necessary services to meet your psychosocial, social, and spiritual needs (i.e. psychosocial support or intervention to help you or your informal caregivers)? Did your nurse navigator refer you to services within your community to address any unmet supportive care needs?

Appendix M

Nurse Navigator Focus Group Questions

Nurse Navigator ID#: _______

Continuity of Care

Informational Continuity

1. How does having access to, and understanding, a high level of information on the patients and their symptoms help with providing a continuum of care?

Management Continuity

2. How do you handle unmet needs of the patients? Do you believe it is important to involve the patients in planning their cancer care? How do you think participation of patient in care benefits the patients and their families?

Relational Continuity

3. How does initiating and maintaining an ongoing relationship with the patients help you as a nurse navigator to provide effective cancer care?

Patient Empowerment

Active Coping

4. How do you actively take steps to facilitate problem solving and decision making? How do you think this benefits the overall patient experience? What kind of advice or educational support do you provide to the patients on self-care and self-determination?

Self-Management

5. How often do you asses or monitor the symptoms of the patients? In what ways does providing symptom management ameliorate the patient’s overall cancer care and experience?

Supportive Care

6. What kind of services do you provide to the patients to meet their physical, emotional, psychosocial, social, and spiritual needs? How do you think by providing access to supportive care benefits the patients and their families?

Appendix N

Patient Data Analysis Chart

Continuity of Care	
Informational Continuity	*(How does the NN knowing/having access to information help the patient?)* **Patient-Focused Cancer Care** - "describing to me what was going to happen next." - "She was gathering information for the doctor" - "she was taking notes for me" - "everything was written down for me" - "she was doing my calendar" - "she was marking different pages in this book that the tests that he was prescribing" - "she stayed in after he(doctor) left. She said we're going to go through this again and there were a few questions but she was more than capable of answering" - "She was the one that went over everything, she was very patient with me, and no matter what question you ask, she answered the questions and it was a very relaxed atmosphere" - "no right or wrong question so she would answer them equally and then she went over a few common side effects, but made sure I understood if I had any other little things and made sure I knew them and their meanings" - "she was providing information on a timely basis" - "I would have to say probably my first visit because I was a little anxious not knowing for sure what was taking place" - "They had a booklet which was very helpful, and she went through the first stages of this process in the book" - "She explained everything that was going to happen with the surgery. She went through the booklets and explained the type of surgery and what was going to be involved with it and answered my questions"
Management Continuity	*(How does the NN being able to manage- conducting comprehensive screening and needs/resources assessment, empower patients- help the patient? How do they manage the care?)* **Care Planning** - she would go over things and I guess he (doctor) would read her

	report and then come in and go over little things as well after the meeting I have with her - she would explain things and then if I had any questions, then we’d answer them in the certain sections so like everything, you left there well educated about what was going on with the treatment - with her explaining each test what was going to happen, one I had to go to Sunnybrook for, it took so much of the tension off - This is an unknown, for me anyways, I was so nervous, not knowing what was going to happen - she was very helpful in explaining the whole process to me - I didn’t understand what type of surgery the doctor was going to do. So she explained the medical terms to me - I had the reassurance that the doctor was prescribing whatever he needs to know to do whatever he has to do - I didn’t question the procedure I was going through. It was done so professionally but it was personal too. For me it’s such a great result. It took a lot of rough edges off. I felt more comfortable that I’m being looked after, I’m in good hands - As far as tension and nervousness, the navigator certainly lowered it. Because of her professionalism, she was describing the different tests, like she’s knowledgeable - There was that sense of empathy - my dad had passed away 35 years ago and I watched him with his treatments and everything and it wasn’t nice. But the navigator was very patient and I felt very comfortable talking to her and she was generally warmly concerned. - She was very patient with me, and said it was understandable and explained why, and I knew why. It just helped me out a lot that they just listened to me - She just explained a little more of what was in the book or if I had questions and felt comfortable in asking her
Relational Continuity	*(How does the NN having an ongoing relationship with the patient benefits the patient?)* **Easily Accessible** - “she gave me her business card with her phone number and extension, and more than one occasion, especially on the first time, she stressed any questions contact me and if she’s not by her desk then leave a voicemail” - “I know I can call if I have to” - “she would get back to me ASAP” - “She gave me her phone number. I’ve written it in this little book, and told me to feel quite free to call her anytime if I had any

	questions or if something was even bothering me” ➔ “She was very helpful over the phone. She explained symptoms that might occur after I have my chemo” - “I called her several times if I had any questions. Because I felt that you can talk to her and I understand that is her job, rather than bothering the doctor. So she did help me” - “she was very efficient in getting back to me on time” - “I don’t really think that… I know I saw her during the first consult but I didn’t see her after that.”
Patient Empowerment	
Active Coping	*(How does the NN actively provide coping options to the patients?)* **Educational Support** - “Well it was a big cache of information too. She went through some of it with me, especially the tests, but there’s all kinds of brochures about lung cancer” - “Oh she’ll say like “how’s your breathing?”, she’ll ask me all kinds of questions” - “one of the nurses set up for community care… one of the community care nurses would come into my home and watch me give myself a needle. So they were just making sure I was doing it right” - “it was a lot of pamphlets that came. So we went all those and then she said if there’s any concerns or questions then basically mark a few pages and jot a few things down, and then next week we can call and she would call us back” - “We always talk about a few things like some of my side effects - “if I had any questions, they would answer it and I felt at ease talking to her” - “Just generally told me what I would feel like after having the surgery, and the symptoms that I would be going through after chemo” - “she went over the booklets”
Self-Management	*(How does the NN provide support in order for the patient to self-manage their altered health proactively?)* **Symptom Management- Personalized** - “The navigator is always doing my blood pressure, my pulse and my weight, she’s recording that” - “when I know when I have little tiny bumps in my mouth, and she

	explained to me I could either use a baking soda or mouth wash. And then she actually said we'd get you something for that. Then she had prescribed a mouth wash for that for me. So any little things, there's always something she'll be there for" - "She told us (informal caregiver-wife) how to take care of me, like from keeping from getting a cold, or just like different things that they bring to your attention" - "they give you helpful hints… How to stay healthy, and what to do" - "most of it is common sense stuff, but they just bring it to your attention" - "Through the booklets, yea, she explained how to manage my symptoms…and if I called her she would explain things to me as well" - "Now at the beginning she did go through it (booklets) and highlighted some areas and explained each of what that meant"
Supportive Care	*(How does the NN assist the patient/families in addressing their needs?)* **Resource Navigation** - "For a while, I had homecare come in" - "I think there's probably a lot more out there. It depends on the needs of the individual" - "There's something that can be arranged with meals on wheels. I think it's such a wide variety of services available and it all depends on the individual. I certainly got all my needs met. I'm not lacking in anything. Last week I phoned for a ride to come here" - 'Yes, it was available if I chose to use" - "we do have the card for the Hearth place and the different places that she's told us about. It's very informative. If you need anything, they make sure that you know that they are available, they will help us or direct us to where we should go" - "No, we didn't talk about that because I didn't need it. I think there are information in the booklet…see this is my second cancer so I know…I've had lymphoma for 15 years and I've been involved with a lot of groups, home care, a lot of the facilities. So she knew my history." - "Actually they were in this booklet in you needed them."

Patient experience based on the role of the ONN

Appendix O

Nurse Navigator Data Analysis Chart

Continuity of Care	
Informational Continuity	*(How does the NN knowing/having access to information help the patient?)* **Patient-Focused Cancer Care** - "individualize that care" - "target specific concerns" - "zone in on what's more important to that patient"
Management Continuity	*(How does the NN being able to manage- handle unmet needs, empower patients- help the patient? How do they manage the care?)* **Decision-Making (Shared)** - "decrease the anxiety of the unknown" - "it's more of a working together arrangement than us telling them what they have to do" - "finding out how much information they know already and how much information they are interested in receiving" - "sense a loss of power" - "empower them to help make a decision that's appropriate for them and involving them in the care then also will kind of help them to follow through with the plan of care rather than us giving the plan of care and they just have to follow it" - "it empowers them and they are more likely to follow through with the plan" - "they're going to be alerting us and finding out more information about as far as maybe there are needs that they're going to be requiring for their care" - "if we're able to talk to their families as much as we're able to talk to them, it kind of all helps them to be less anxious about the process" **Conduct Needs Assessment** - "phone assessment prior to the visit, the first visit for the patient, and based on their information needs, their social history, medical history, we target the care plan"

Relational Continuity	*(How does the NN having an ongoing relationship with the patient benefits the patient?)* **Identifying & Eliminating Barriers** - "helps us to be a little more proactive in identifying the barriers and helping patients and families work through them" - "they are more up to giving information or their concerns or be more open and then you can really get to what will help them through their journey"
Patient Empowerment	
Active Coping	*(How does the NN actively provide coping options to the patients?)* **Patient Advocate** - "helps to advocate for the patient" - "help to communicate better with the doctors" **Educational Support and Resources** - "upfront we provide lots of information to patients about what is happening" - "any medical terms or any investigations that they don't really understand" → "accessible to them" - "why they were doing each test, what the benefit of having that test was, and what would happen if they didn't do that test" - "the nurse always spends time with the patient on their own just to review the information the doctor's given and again go through the synopsis of any investigations that they may be going through" - "we provide them with resources" - "written as well as verbal instructions" - "lung cancer booklet that comes with the welcome bag" - "call their nurse navigator just to discuss anything"
Self-Management	*(How does the NN provide support in order for the patient to self-manage their altered health proactively?)*

	Symptom Management - "ESAS, but it's a symptom assessment scale" - "symptom scale is good to kind of open up the line of communication to see how their symptoms are" - "on the phone or face-to-face in clinic, there is some kind of symptom assessment done" - "We assess it at the same visit" - "Once you've identified the issues…have a plan of action of how we're going to resolve that" - "we would identify the resources such as palliative care or radiation treatment that help manage the symptoms" - "we can speak to the physician to say that this maybe something that they need"
Supportive Care	*(How does the NN assist the patient/families in addressing their needs?)* **Gateway to Resources/Community Services (Resource Navigation)** - "community resources such as homecare, hearth place, and sometimes it involves reaching out to other community agencies that are churches or ethnic related communities to help out that patient" - "improving patient experience conference where it's lead by patients and I think there is a few staff members on there just initiate it" - "It's a committee set to improve patient experience at the cancer center" - sometimes they're for the family members - "The social worker here are great for accessing all the other information that maybe we're not as familiar with too" → "They can hopefully plan easier, organize their time, have a little bit more control over things to help ease that process" → "Knowing that they're not in it alone" - "There are services for transportation, and the Cancer Society is linked with us for volunteer drivers and different supports"

The role of the ONN on patient experience