

**TREATMENT DECISION-MAKING IN
(STAGE II, STAGE IIIA AND STAGE IIIB)
NON-SMALL CELL LUNG CANCER**

**THE ART IN MEDICINE – TREATMENT DECISION-MAKING AND
PERSONALIZING CARE:
A GROUNDED THEORY OF PHYSICIANS' TREATMENT-DECISION
MAKING PROCESS WITH THEIR (STAGE II, STAGE IIIA AND STAGE IIIB)
NON-SMALL CELL LUNG CANCER PATIENTS IN ONTARIO**

**By
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The Art in Medicine – Treatment Decision-Making and Personalizing Care: A Grounded Theory of Physicians’ Treatment-Decision Making Process with Their (Stage II, Stage IIIA and Stage IIIB) Non-Small Cell Lung Cancer Patients in Ontario

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ABSTRACT

Introduction: In Ontario alone, an estimated 6,700 people (3,000 women; 3,700 men) will die of lung cancer in 2011 (Canadian Cancer Society, 2011). A diagnosis of cancer is associated with complex decisions; the array of choices of cancer treatments brings about hope, but also anxiety over which treatment is best suited for the individual patient (Blank, Graves, Sepucha et al., 2006). The overall cancer experience depends on the quality of this decision (Blank et al., 2006). Clinical practice guidelines are knowledge translation tools to facilitate treatment decision-making. In Ontario, guidelines have been developed and disseminated with the purpose to inform clinical decisions, improve evidence based practice, and to reduce unwanted practice variation in the province. But has this been achieved? To study this issue, the purpose of the current study was to gain an in-depth understanding and develop a theoretical framework of how Ontario physicians are making treatment decisions with their non-small cell lung cancer patients. The following research questions guided the study: (a) How do physicians make treatment decisions with their stage II, stage IIIA and stage IIIB non-small cell lung cancer patients in Ontario? (b) How do knowledge translation tools, such as Cancer Care Ontario guidelines, influence the decision-making process?

Methods: A qualitative approach of grounded theory, following a social constructivist paradigm outlined by Kathy Charmaz (2006), was used in this study. 21 semi-structured interviews were conducted; 16 interviews with physicians and 5 with health care administrators. The method of analysis integrated grounded theory philosophy to identify the treatment decision-making process in non-small cell lung cancer, from the physician perspective.

Findings: The theory depicts the treatment decision-making process to involve five key “guides” (or factors) to inform the treatment-decision making process: the unique patient, the unique physician, the family, the clinical team, and the clinical evidence.

Conclusion: Decision-making roles in lung cancer are complex and nuanced. The use of evidence, such as, clinical practice guidelines, is one of many considerations. Information from a large number of sources and a wide array of factors, people, emotions, preferences, clinical expertise, experiences, and clinical evidence informs the dynamic process of treatment decision-making. This theory of the treatment decision-making process (from the physician perspective) has implications relevant to treatment decision-making research, theory development, and guideline development for non-small cell lung cancer.

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CHAPTER 1: INTRODUCTION

1.1 Statement of Problem

Non-small cell lung cancer is an ailment in which malignant (cancer) cells form in the tissues of the lung. Lung cancer has become far more prevalent since the early 1900's, when it was first a rare disease (Winston, 2011). Small-cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) are the two main categories of lung cancer; with non-small cell lung cancer accounting for 85% of all lung cancers (Winston, 2011).

The Canadian Cancer Society (2011) reports that lung cancer is one of the leading cause of cancer-related deaths in both women and men. In the year of 2011, an estimated 25,300 Canadians were diagnosed with lung cancer and 20,600 died from it (Canadian Cancer Society, 2011). In Ontario alone an estimated 6,700 people (3,000 women; 3,700 men) died of lung cancer in 2011 (Canadian Cancer Society, 2011).

Clinical practice guidelines have been disseminated to treat both small cell lung cancer and non-small cell lung cancer patients. Field and Lohr (1990) define clinical practice guidelines as “systematically developed statements to assist practitioners and patient decisions about appropriate health care for specific circumstances (p. 38).” Guidelines can identify the most clinically effective care options based on the most current and relevant scientific evidence. They are knowledge translation tools that result from synthesizing this evidence and can serve as a tool to help reduce the gap between research and clinical practice (Straus, Tetroe, and Graham, 2009). Pisters, Evans, Azzoli, et al. (2007) explain that,

“the utilization of clinical practice guidelines may provide improvements in outcomes, improvements in medical practice, a means for minimizing inappropriate practice variation, decision support tools for practitioners, points of reference for medical orientation and education, criteria for self-evaluation, indicators and criteria

for external quality review, assistance with reimbursement and coverage decisions, and criteria for use in credentialing decisions” (p. 5507).

Thus, guidelines are an important knowledge translation tool to inform evidence-based medical practice (Harrison et al., 2010). The guidelines are to help standardize the management of the non-small cell lung cancer clinical decision-making process and practice.

In this project, there are two key Cancer Care Ontario (CCO) guidelines relevant to the treatment of patients with stage II and stage IIIA resected non-small cell lung cancer, and patients with stage IIIA and IIIB non-resected non-small cell lung cancer. Very broadly, these guidelines recommend:

- Patients with stage II and stage IIIA resected non-small cell lung cancer should receive cisplatin-based chemotherapy (Guideline 7-1-2 [Dec 2006]);
- Patients with stage IIIA and stage IIIB non-resected non-small cell lung cancer should receive chemo-radiotherapy with a cisplatin-based agent (Guideline 7-3 [Jan 2006]).
 - Important to note is that guideline 7-3 recommends chemo-radiation for good performance status patients with minimal weight loss. For poor performance status patients, palliative radiation or chemotherapy is recommended and for borderline patients sequential treatment may be considered.

A recent analysis of practice patterns by the 2010 and 2011 Cancer System Quality Indexes (CSQI) illustrate that the proportion of patients receiving these recommendations may be less than what would have been expected based on these recommendations.

Specifically, data illustrated that 33% to 40% of stage II and stage IIIA patients receive no

chemotherapy treatment following surgery and 20% to 40% of stage IIIA and stage IIIB receive no chemo-radiotherapy or any other treatment. Significant regional variation in practice patterns across the province also exist. It is unclear of why this variation exists. It is unclear if this variation is a sign of a clinical practice problem. Indeed, there may be many competing explanations such as the patterns reflecting a true under adherence to clinical recommendations (e.g. patients not being offered treatment options), poor generalizability of guidelines (informed by high quality randomized controlled trials of high functioning patients) to the general patient population, and patient refusal to treatment. It is important to better understand the gap between what is being recommended for non-small cell lung cancer by clinical guidelines, actual practice patterns, and how non-small cell lung cancer patients are being treated.

The science and practice of knowledge translation is useful in providing direction on how to solve knowledge to action gap. Knowledge translation is a process that involves the “synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health...and provide effective health care” (Straus et al., 2009, p. 4). The knowledge to action cycle (Straus et al., 2009) will be used to guide this project (Please see Appendix A for Knowledge to Action Cycle figure). In this cycle, I will focus on the step of knowledge tools/products (i.e. clinical guidelines) and the barriers and facilitators in using these tools in clinical practice.

I want to explore this issue further, because while the existing literature has been most useful in understanding the barriers and facilitators of clinical guidelines in general, to my knowledge, it fails to understand the decision-making process as a whole, and the suite of barriers and enablers relevant in the process. In effect, the circumstances of non-small cell

lung cancer patients may differ significantly than patients with other cancers, consequently, *because of the guidelines or in spite of the guidelines*, contributing to differing explanations of why certain treatment options (such as those recommended by the guidelines) are chosen over others. Indeed, Mayor (2009) states:

“Non-small cell lung cancers cover a heterogeneous group of diseases, accounting for around 80% of all lung cancers, which [were] previously lumped together because there was no apparent reason to use different therapeutic approaches for the various histologies. This has now changed, and choosing the best treatment option for non-small cell lung cancer patients is increasingly complex” (p. 15).

Thus, what treatment is appropriate for what case warrants a project that can take a deeper look into the treatment decision-making process in non-small cell lung cancer, and help us better understand the reasons behind a particular treatment choice for a non-small cell lung cancer patient. To this end, I have chosen to study the treatment decision-making process in non-small cell lung cancer from the physician and administrator perspective practicing in Ontario.

1.2 Study Purposes

The overall aim of this project is to understand the decision-making process of physicians, in the treatment of patients diagnosed with (stage II, stage IIIA and stage IIIB) non-small cell lung cancer. To this end, the following research questions guided the study: (a) How do physicians make treatment decisions with their stage II, stage IIIA and stage IIIB non-small cell lung cancer patients in Ontario? (b) How do knowledge translation tools, such as Cancer Care Ontario guidelines, influence the decision-making process? The intended outcome of this research was a theoretical perspective on the treatment decision-

making process grounded in the experience of the participants who are involved in the treatment of non-small cell lung cancer patients.

1.3 Topic Rationale

The Cancer System Quality Index (CSQI) suggested a variation in practice patterns in (stage II and stage IIIA and stage IIIB) non-small cell lung cancer management across Ontario. This is the significant issue in initiating the current study. The treatment decision-making process is important to study because there is a varying degree in the uptake of guideline (Guideline 7-1-2 [Dec 2006]; Guideline 7-3 [Jan 2006]) treatment across Ontario. By understanding *how* physicians are making treatment decisions with their non-small cell lung cancer patients will potentially give insight as to *why* particular treatment options (such as those recommending within the guidelines) are being chosen over others. Further, it will shed light on whether the variation seen in the CSQI reflects a quality of care problem or not.

A diagnosis of cancer creates a cascade of complex treatment decisions. The array of choices of cancer treatments brings about hope, but also anxiety over which treatment is best suited for the individual patient (Blank, Graves, Sepucha et al., 2006). The overall cancer experience depends on the quality of this decision (Blank et al., 2006). Blank et al. (2006) states that “poor-quality decisions detract from not only patient satisfaction but also treatment adherence, quality of life, and health outcomes” (p.212). So what are the routes taken to make an optimal treatment decision?

The treatment decision-making process specifically in the non-small cell lung cancer setting has largely been ignored in the literature. Some non-small cell lung cancer patients,

specifically stage IIIA and stage IIIB, are relatively a heterogeneous group of patients (Robinson, Ruckdeschel, Wagner et al., 2007), therefore choosing between available treatment options can be challenging. As a result of the complexity of this disease, the variability in the patients who present, and the difficulty in making a treatment choice, it is important for clinicians and researchers to think carefully about the ways in which decisions are being made with patients. Consequently, there is value in describing and trying to understand the treatment decision-making process by individuals involved in non-small cell lung cancer: clinicians, patients, and policy makers.

For the purposes of this thesis, I will focus on the treatment decision-making process from the perspective of the specialist physician. By uncovering the treatment decision-making process, one uncovers what factors are most important to physicians in determining how to treat their patients' cancer. Describing the treatment decision-making *process* induces one to recognize the strategies the patients and physicians collectively use to make optimal decisions without assuming a priori if one particular element (i.e. guidelines or patient preference, etc.) plays a more primary role than other elements. As a consequence, it helps one to understand the important elements that do play an important role in decision-making. Knowing the multiple key factors that affects the treatment decision-making process can help improve upon any current decision-making models to help patients and physicians make more “appropriate” decisions (Zafar, Weinfurt, Schulman et al., 2009).

Thus, the purpose of this study is to develop a theoretical framework to understand the decision-making process by physicians in the treatment of patients diagnosed with (stage II, stage IIIA and stage IIIB) non-small cell lung cancer. It is important to note that the literature has shown that physicians are not the sole or even leading arbitrators of clinical

decisions within this setting (Blank et al., 2006). The literature has described the patients being actively involved in the treatment decision-making process (Blank et al., 2006). However, by taking the physician perspective, the study allows for a greater insight into clinical guidelines, how physicians are using them, and their actual impact on the treatment decision-making process. A fuller appreciation of this can help design interventions aimed at facilitating optimum clinical practice and to create improved clinical practice guidelines that may be more implementable, and assist patients and physicians in making suitable decisions.

CHAPTER 2: LITERATURE REVIEW

2.1 Literature Review Objectives

In chapter 2, I describe the methods I use to conduct my literature review, and then move on to a discussion of the findings from this search. In their paradigm of grounded theory, Glaser and Strauss (1967) advise leading a review of the literature *after* developing an independent analysis of the data; because it helps “the researchers to control their research process and to increase the analytical power of their work” (Charmaz, 2006, p.6). This in turn also limits biases and allows the researcher to enter the data without any presumptions and see the data from a fresh perspective. Strauss and Corbin (1998) also advocate delaying the literature search and state that “there is no need to review all of the literature in the field beforehand” (p. 49). However Strauss and Corbin (1998) do suggest that the existing literature can be used as data for making comparisons. Therefore, they do not advocate that a literature search should be completely avoided when using a grounded theory approach.

Charmaz (2006) states that:

“Although scholars may don a cloak of objectivity, research and writing are inherently ideological activities. The literature review and theoretical frameworks are ideological sites in which you claim, locate, evaluate and defend your position” (p. 162).

Thus, in some instances of qualitative studies there are two literature reviews that are conducted: one before the study and one after, where literature can sometimes also be used as data. For the purpose of the current study, only one literature review was executed in the middle of data collection and data analysis. Conducting the literature review in the middle of data collection and analysis allowed me to enter the field with a fresh new “lens” with a limited amount of presumptions. As my theory began to take form, the literature search then

allowed me to ground my work and juxtapose it against earlier theories, and “defend my position” (Charmaz, 2006, p.162). By having the literature search in the middle, the literature search did not stifle “my creativity or strangle [my] theory” (Charmaz, 2006).

Before I conducted a literature review, I wanted to provide background information on non-small cell lung cancer. Providing background information of what non-small cell lung cancer is and who it affects would help contextualize the findings of the study.

My first objective of the literature review then was to determine whether any studies exist that provide insight into addressing the study research question: *How do physicians make treatment decisions with their stage II, stage IIIA and stage IIIB non-small cell lung cancer patients in Ontario?* Therefore I reviewed the literature on current decision-making models in the clinical setting. My second objective was to see if there were any studies that could address the sub-question: *How do knowledge translation tools, such as Cancer Care Ontario guidelines, influence the decision-making process?*

I also aimed to identify any gaps in the literature which the current study may help to address; and also discuss how the findings from the current study can be placed in relation to and contribute to the current literature (Polit and Hungler, 1991). (See Chapter 5 for this discussion).

2.2 Literature Review Search Strategy

To address the first objective of the literature review, I used the following keywords alone or in combination to conduct my search: decision-making, lung cancer, lung neoplasm, cancer, conceptual models, treatment selection, and physician-patient interaction. I used: Pubmed, EMBASE, PsycInfo, CINAHL, ProQuest Dissertations and Thesis, the Cochrane

Library, and Ovid. I limited the search to studies published in English only. I also hand searched the reference lists of relevant articles and used the references as leads to locate more articles that would help generate a strong overview of the topic of interest. As the literature search unfolded the treatment decision-making process illustrated itself as a dynamic, diverse, complex and emotionally-charged process. However, the literature also revealed that there were few studies that covered treatment decision-making process with lung cancer patients; consequently, the literature search had to be extended to treatment decision-making within the oncological setting and/or with patients with serious-illnesses. Once the literature search was broadened there was a plethora of evidence found on the overall treatment decision-making process within the medical encounter; ranging from quantitative studies and qualitative studies. Below I provide an overview of the literature related to the patient-physician treatment decision-making process in patients with cancer and serious illnesses.

To address the second objective of the literature search, it was important to find what the literature said about clinical guideline implementation. For this search I also used: Pubmed, EMBASE, PsycInfo, CINAHL, ProQuest Dissertations and Thesis, the Cochrane Library, and Ovid. I used the following keywords alone or in combination to conduct my search: clinical practice guideline, physicians' practice patterns, guidelines, guidelines in use, guideline adherence, and guideline implementation. I limited the search to studies published in English only. I also used the references of relevant articles as leads to find further relevant articles.

2.3 What is Non-Small Cell Lung Cancer?

Less than 15% of patients with non-small cell lung cancer survive past 5 years (Shi, Deng, Zhao et al., 2012). Consequently, non-small cell lung cancer is one of the leading causes of cancer mortality around the globe (Shi, Deng, Zhao et al., 2012).

In simplistic terms, cancer involves the unrestrained division of body cells that have undergone a genetic mutation or “genetic transformation into a cancer cell” (National Institutes of Health, 1999). The National Cancer Institute (2012) defines non-small cell lung cancer as: “a disease in which malignant (cancer) cells form in the tissues of the lung” (See Appendix B for the anatomy of the respiratory system). There are three different types of non-small cell lung cancer (National Cancer Institute, 2012):

- “Squamous cell carcinoma: Cancer that begins in squamous cells, which are thin, flat cells that look like fish scales. This is also called epidermoid carcinoma;
- Large cell carcinoma: Cancer that may begin in several types of large cells;
- Adenocarcinoma: Cancer that begins in the cells that line the alveoli and make substances such as mucus” (National Cancer Institute, 2012).

Following the initial diagnosis of non-small cell lung cancer, accurate TNM staging of lung cancer is critical for identifying an appropriate treatment (Molina, Yang, Cassivi et al., 2008). T in TNM stands for tumour, N stands for Node, and M stands for metastasis. The clinical stage of non-small cell lung cancer helps determine the suitability of particular treatments. Staging consists of: “assessing the primary tumour itself, the presence and location of lymph node metastases, and the detection of distant metastases (TNM)” (Leonard, Whyte, and Lillington, 2000, p. 391). (See Appendix C for the TNM classification table). As Leonard et al. state (2000), the international system of staging was revised recently in 1997. This is the 6th edition of the TNM staging and is relevant to the data from the

Cancer System Quality Index report. (See Appendix D for the 6th edition of the non-small cell lung cancer staging table). The TNM staging system has been revised in the last couple of years, and there is currently a 7th edition as well. Updates are again underway.

The survival of a non-small cell lung cancer patient is dependent on the stage of the disease (Leonard et al., 2000; Mountain, 1989). There is a 5 year survival rate of 10% in non-small cell lung cancer patients with metastases to the mediastinal lymph nodes (Leonard et al., 2000). In patients when there are no mediastinal metastases, the survival rate is 50% (Leonard et al., 2000).

Lin, Richard and Chang (1994) note that whether a tumour is resectable depends on the characteristics of the primary tumour, if lymph nodes are involved, and distant metastases. Surgical treatment is limited to stages I and II and a limited subset of stage IIIA non-small cell lung cancer (Leonard et al., 2000.)

2.4 Studies on the Clinical Treatment Decision-Making Process

There is an extensive amount of literature that has focused on the (clinical) treatment decision-making process (Pierce, 1996; Benbassat, Pilpel, and Tidhar, 1998; Guadagnoli and Ward, 1998; Levine, Gafni, Markham et al., 1992; Watt, 2000; Petrisk, Laliberte, Allen and Mor, 1997; Whittaker and Albeen, 1996; Chewing and Sleath, 1996). Some authors offer a definition of decision-making as: “situations in which a choice is made among a number of possible alternatives, often involving trade-offs among the values given to different outcomes” (Baumann and Dauber, 1989, p.69).

The literature illuminates that the first steps of a clinical treatment decision-making process is to consider the nature of the disease. The tumour, the location of the tumour in

the body, the characteristics of the tumour, the stage of the disease, and the location of metastases are primarily the first few factors of how patients suffering from cancer are treated (Zafar, Alexander, Weinfurt, et al., 2009). Other factors such as, comorbidities, performance status, quality of life, age of the patient, and patient preferences also greatly contribute to the overall treatment decision-making process (Zafar, Alexander, Weinfurt et al., 2009).

However, research has gone further than just looking at the nature of the disease as being the only step in the treatment-decision making process. Studies have focused on treatment decision-making from many perspectives, predominately focusing on factors that can assist patients in making optimal treatment decisions during this ‘process’; or focusing on the degree of involvement and actual roles patients would like to play within treatment decision-making (Watt, 2000). For example, Pierce (1996) in her study addresses issues concerning ‘unaided’ decision-making among patients with breast cancer and cardiovascular disease; and also offers a brief depiction of the decision making-process. Pierce (1996) explains that the treatment decision-making process begins with the physician presenting treatment options, followed by the patient’s decision. Pierce (1996) further explains that patients with breast cancer and cardiovascular disease generally adopt different treatment decision-making styles: there is a patient group that makes rapid and intuitive decisions with little distress; there is a patient group that requires more time to make a decision and are overwhelmed with the treatment options; and there is a patient group that takes more time to gather information, do research, and finally select a treatment.

Another example of the degree in which patients would like to be involved in the treatment decision-making process is illustrated in the Wenzel and Shaha (2008) study. In

their phenomenological study, Wenzel and Shaha (2008) report that breast cancer patients describe their treatment decision-making experience to involve seeking advice from their family members, and, also deferring treatment decisions up to their providers and taking more of a passive role in the treatment decision-making process.

Consequently, much of the patient-focused literature has examined the variability in patients' preferences in participating within treatment decision-making and factors, such as age, that may account for this variability (Strull, Lo, and Charles, 1984; Levinson, Kao, Kuby et al., 2005; Funk, 2004; Deber, Kraetschmer, and Irvine, 1996; Azoulay, Pochard, Chevret, et al., 2004; Kiesler and Auerbach, 2006; Say, Murtagh and Thomson, 2006; Fraenkel and McGraw, 2007; Müller-Engelmann, 2008). For example, studies have shown that younger patients prefer more participation (Arora and McHorney, 2000; Degner and Sloan, 1992; Frosch and Kaplan, 1999). Pierce (1988, 1993), in her study looking at the treatment decision-making process among patients with newly diagnosed breast cancer, found that older patients preferred following physician recommendations to make a fast decision without little conflict (Petrissek, Laliberte, Allen et al., 1997). Pierce (1988, 1993) also found that older women with breast cancer did not ask as many questions, seek more information, or converse about treatment options with their physicians, as much as the younger patients did during the treatment decision-making process.

Research has also focused on other socio-demographic variables such as educational level and gender to influence patient participation in treatment decision-making (Müller-Engelmann, 2008). Although some studies have demonstrated opposing results for gender association with patient preferences to participate in the treatment decision-making process (Elkin, Kim, Casper et al., 2007), a large number of studies have illustrated that women have

a greater tendency to want to participate (Levinson, Kao, Kuby et al., 2005; Vick and Scott, 1998).

Further, there have also been studies demonstrating that the level of education of the patient also affects his or her preference to participate; a highly educated patient has a greater tendency to want to participate than one that may be less educated (Strull, Lo and Charles, 1984; Elkin, Kim, Casper, et al., 2007; Janz, Wren, Copeland et al., 2004). However, studies have also shown contrasting results and illustrated that educational level is not entirely associated with patient preferences in wanting to participate within the treatment decision-making process (McKinstry, 2000).

As illustrated above, an extensive amount of the decision-making literature has focused on the decision-making process from the *patient perspective*. Conversely, there is also literature capturing the treatment decision-making process from the physician perspective. The physician, Dr. Woolever (2008) in his editorial highlights the decision-making process to involve heuristics: “informal problem-solving methods such as trial and error” (Woolever, 2008, p. 32). He also illuminates that physicians incorporate their own clinical judgements, knowledge and experience; including lessons they have learned from past mistakes (Woolever, 2008). Woolever (2008) also states that physicians consider: the patients life circumstances, including their socioeconomic status, health insurance coverage, work schedule, support structure, and religious and cultural preferences” (p.34-35). The physician’s also ask themselves important questions such as, what the probability is that the patient will adhere to a treatment plan and follow-up (Woolever, 2008).

Further, studies show since there has been a growing emphasis on evidence-based practice health care (Muir, 2004) physicians are cognizant of integrating evidence into their

decision-making process and routinely deciding what evidence to use and with which patient.

Sackett et al. (1996) define evidence-based practice as:

“Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice” (p.71).

In addition, however, the literature also illuminates that physicians are conscious that evidence, especially randomized controlled trials – although considered the gold standard on which to base clinical decisions – has limitations and are not always generalizable to the population they treat (Woolever, 2008; Rothwell, 2005; Kravitz, Duan, and Braslow, 2004; Starfield, 2006).

The literature also captures how primary health care providers and other health care personnel, such as nurses, make decisions and what additional factors influence the treatment decision-making process. For example, Orme and Maggs (1993) in their study examined the responses of diversely drawn 12 expert clinicians and their thoughts on the treatment decision-making process and found that decision-making is an important attribute of a clinician, and is based on: comprehensive knowledge, and “may involve risk-taking and can only flourish in a supportive environment” (p. 270). Thus, the literature has captured risk-taking as a feature of treatment decision-making (Orme and Maggs, 1993). Studies such as that conducted by Joseph et al. (1988) have also illuminated the factor of risk taking in decision-making, and the high comfort level of nurses taking risks when making clinical decisions.

In another study by McKinlay et al. (2002), videotapes of a patient-physician encounter for polymyalgia rheumatica (PMR) and depression were examined by physicians. The study found that physician characteristics such as age, medical speciality, and race significantly impact the decision-making process (McKinlay et al., 2002).

It is also noteworthy that the literature has identified factors such as the environment in which clinical practice is carried out to affect the decision-making process. While some authors such as Joseph et al. (1998) argue that the environment does not affect the decision-making process, other authors such as Prescott, Dennis and Jacox (1987) argue the opposite. Prescott et al. (1987) state that nurses employed in specialized and critical care units were more satisfied in how they made decisions compared to nurses that worked in other clinical areas.

Further, a great deal of the literature has covered treatment decision-making in the context of patient-physician relationships (Watt, 2000; Beisecker and Beisecker, 1993; Emanuel and Emanuel, 1992; Twemlow, Bradshaw, Coyne et al., 1997; Charles, Gafni, and Whelan, 1999). Watt (2000) explains that,

“The models for this relationship, which range from paternalism to collaborative problem solving, place the doctor-patient encounter at the centre of clinical decision-making with peripheral and varying importance assigned to the roles of significant others, past experiences, personal preference, and lifestyle choices on the decisions of the physician or the patient (p. 7).

The literature also expands on the topic of the ‘doctor-patient’ encounter and defines actual treatment decision-making models. Three latter models portrayed in the literature are: the paternalistic model – where physicians are solely responsible in making the treatment decision based on clinical evidence and personal experience (Watt, 2000); the informed

model – where the physician presents a sufficient amount of information of all the relevant treatment options with their benefits and risks to the patient, allowing the patient to make an ‘informed treatment decision’ (Charles et al., 1999); and the shared decision-making model – where there is a more ‘partnership’ relation between the patient and physician (Charles, Whelan, and Gafni, 1999). (Please see Appendix E for a table identifying necessary elements of all three decision-making models as defined by Charles et al. 1999). An extensive amount of the literature discusses these theoretical models, placing an emphasis on the shared treatment decision-making model and its implications within the medical encounter.

For many decades, paternalism has been a dominant approach in making treatment decisions (Charles et al., 1999), however in the most recent years, the shared treatment decision-making model has become increasingly commonplace in the medical encounter (Müller-Engelmann et al., 2008; Joosten, DeFuentes-Merillas, de Weert et al., 2008; Charles et al, 1999). The shared treatment-decision making model defined by Charles et al. (1997, 1999) is generally one of the most accepted definitions. Charles et al. (2003) defines shared decision-making “as an interactive process in which physicians and patients simultaneously participate in all phases of the decision-making process and together negotiate a treatment to implement” (p. 932).

Although, not completely relevant to the oncology setting, it is noteworthy that three decision-making models are also discussed in the nursing literature:

- The information-processing model. The fundamental assumption of this model is that the decision-maker retrieves information that they have stored in his/her short- and long term memory (Muir, 2004).

- The intuitive-humanist model. The fundamental focus of the intuitive-humanist model is the nurse's institution and professional experience and how it enriches the decision-making process as the nurse progresses in his/her profession (Banning, 2008; Benner 1982, 1984; Young 1987).
- O'Neill's clinical decision-making model. O'Neill's clinical decision-making model draws on the benefits of both the information-processing model and the intuitive-humanist model (Banning, 2008); and is based on "a computerized decision support system that uses both hypothetico-deduction and pattern recognition as a basis of decision making" (Banning, 2008, p. 191).

There is a treatment decision-making model within the literature for cancer treatment (Zafar, Alexander, Weinfurt et al., 2009) (Please see Appendix F for this treatment decision-making model). This treatment decision-making model assumes 'shared decision-making' as defined by Charles et al. (1997, 1999); and maintains an equal balance between both physician and patient values when deliberating about treatment options and choosing a final treatment decision (Gattellari, Butow, and Tattersall, 2001, in Zafar, Alexander, Weinfurt et al., 2009).

The current treatment decision-making model is dependent on factors that affect physician and patient perspectives when making a treatment decision. Physician perspectives are influenced by factors such as the clinical status of the patient, the stage of the disease, the degree of comorbidities, patient age and the ethnic group the patient belongs to (Zafar, Alexander, Weinfurt et al., 2009); patient preferences are influenced by the overall benefit of the treatment and quality of life (Zafar, Alexander, Weinfurt et al., 2009). Together, both physician and patient perspectives are pooled together in making a collectively agreed upon

treatment decision (Zafar, Alexander, Weinfurt et al., 2009). However, Zafar et al. (2009) points out that “while the current-decision making model is effective, it is limited by frequent imbalance in the degree of shared decision-making between patients and physicians” (p. 122).

There are a few published examples of the decision-making process in cancer from the physician and patient perspective. However, despite the large body of literature accumulated on this important topic to better understanding the treatment decision-making process in patients with cancer, to my knowledge there are no studies on the physicians’ perceptions of the treatment decision-making process that contextualize the process within lung cancer or a specific guideline context. Consequently, there have been no studies to date – to my knowledge – of the treatment decision-making process in non-small cell lung cancer. Further, it is also unclear the role clinical guidelines play within this process of making a treatment decision in the non-small cell lung cancer setting.

Thinking within a specific context allows one to find specific solutions to specific problems. By gaining insight into the *process* of how treatment decisions are made within non-small cell lung cancer, and making the process transparent to other key members involved in the care of non-small cell lung cancer patients can help improve: communication, patient care, inter-professional relationships, the allocation of resources, and the proficiency in decision-making. Consequently, the current study will aim to fill this gap within the literature. By recognizing the key multiple factors that are involved, and how they affect treatment decision-making in non-small cell lung cancer patients, points can be illuminated to help physicians and patients make more suitable concordant decisions, which will in turn help optimize treatment for patients with non-small cell lung cancer in Ontario.

2.5 Studies on Implementation of Guidelines and Their Role in the Clinical

Treatment Decision-Making Process

Evidence-based medicine has gradually become the gold standard for clinical practice (Goldman and Shih, 2011). The term originated from McMaster University and has been defined by “the integration of best research evidence with clinical expertise and patient values” (Sackett, 2000). One of the main tools used in the practice of evidence-based medicine is a systematic review of the clinical evidence put into the content of a guideline. Clinical practice guidelines are a means to enhance evidence-based medicine by creating an opportunity to systematically incorporate scientific evidence into medical practice (Field and Lohr, 1992). Wollersheim, Burgers and Grol (2005) state that “the aim of clinical guidelines is to improve quality of care by translating new research findings into practice” (p.188).

In most recent years, there has been a growing body of knowledge around the dissemination of clinical guidelines and their use. Studies have shown that guidelines are not being optimally used in medical practice (Bero, Grilli, Grimshaw, et al., 1998; Grimshaw, Thomas, MacLennan, et al., 2004; Eve, Golton, Hodgkin et al., 1996; Grol, 2000; Grimshaw and Russell, 1993; Grimshaw, Freemantle, Wallace et al., 1995). For example, after the release of a guideline for hypertension management, a survey revealed that only 40% of New Zealand physicians had read the guideline (Arroll, Jenkins, North et al., 1995 in Davis and Taylor-Vaisey, 1997). Thus, this variation in clinical guideline uptake has been recognized, and many studies have been solely devoted to understanding their implementation, or lack of.

The majority of the empirical literature has focused on identifying the barriers and facilitators of clinical guideline implementation (Spyridonidis and Calnan, 2011). Studies have

found that the barriers in the implementation of guidelines operate at many different levels, starting from the organizational level and system barriers, to the clinician level, down to the level of the patient (Spyridonidis and Calnan, 2011; Grol, 1997; Cabana, Rand, Powe et al., 1999; Foy, Walker and Penney, 2001; Pagliari and Kahan, 1999). (See Appendix G for a table that summarizes some of the barriers and enablers in the implementation of guidelines found within the literature). Such findings suggest that inquiry into the process of guideline implementation may render a better understanding of the actual role clinical guidelines play in treatment decision-making, and “the role of work place contextual factors in guideline implementation” (Spyridonidis and Calnan, 2011, p.118)

Consequently, studies have documented the medical decision making process, and have revealed that medical decisions are based on,

“a variety of medical and non-medical information gained from, e.g., patient’s history, socio-economic status, patient preferences, type and stage of disease, and are influenced by personal experience knowledge and the available, but restricted, resources” (Holzer, Fremgen, Hundahl et al., 2000, p. 364).

Other studies have shown that clinical guidelines also play a role in guiding treatment decisions, and “change...the process of care in the direction proposed by the guidelines” (Grimshaw and Russell, 1993, p.1320). Conversely, Holzer, Fremgen, Hundahl et al. (2000) in their study revealed that the “availability of guidelines did not automatically affect actual medical practice” (p. 366). However, to what degree do clinical guidelines play a role in the treatment decision-making process? There is relatively limited amount of literature that has focused on specifically contrasting the impact of clinical guidelines affecting treatment decisions relative to other factors between the individual physician and patient within the medical encounter.

Although many current research-based initiatives have concentrated on understanding the implementation of guidelines and assessing factors influencing their use in the medical practice, knowledge about the relative role they play in influencing a final treatment decision is less understood. This is true in the treatment of patients with lung cancer. This study will aim to fill this gap within the literature by offering an analysis of the treatment decision-making process and the role of guidelines in the clinical decision as the treatment decision unfolds in the non-small cell lung cancer context, and directly at the level of the individual physician.

CHAPTER 3: METHODS

3.1 Design Issues

There are three key issues when designing a study that involves human participants: (1) what research methodology would best answer your research question; (2) what specific research design would be appropriate in addressing the research objectives; (3) what is required of the participants. In the sections below, each of these issues is addressed.

3.2 Qualitative Research Approach

Qualitative studies are better suited to address participant perspectives and offer researchers access to deep-structured processes (Hoshmand, 1989). Qualitative research allows one to understand all sides of a dataset, and understand the complexity of a situation that is not best understood by quantification. Richards and Morse (2007) explain that one of the contexts in which qualitative methods are best to use is when one needs to “understand phenomena deeply and in detail” (p. 30), and discover central themes and analysis of core concerns.

The current study aims to explore a social phenomenon and to understand rationales and meanings from the participants’ perspective. Thus, the selection of the qualitative paradigm was rooted in the purpose of this study; which was to understand the *process* of treatment decision-making in the non-small cell lung cancer context, and the role clinical guidelines play within this treatment decision-making process.

3.3 Grounded Theory

Grounded theory, one of the most common choices of methodology for qualitative research, was introduced by Barney Glaser and Anselm Strauss as a systematic generation of theory from data that contains both inductive and deductive thinking with the goal to create a hypothesis based on theoretical ideas. It is generated by an iterative process involving the continual sampling and analysis of qualitative data, gathered from concrete settings, such as unstructured data obtained from interviews, participant observation and archival research (Richardson, 1996). (See Table 3.1 for the components defining grounded theory practice by Glaser and Strauss, 1967; Glaser, 1978; Strauss, 1987) This method has been used in areas as diverse as social psychology, health psychology and cognitive science.

Table 3-1: Components Defining Grounded Theory Practice

Glaser and Strauss (1967; Glaser, 1978; Strauss, 1987) define grounded theory practice by:
• Simultaneous involvement in data collection and analysis
• Constructing analytic codes and categories from data, not from preconceived logically deduced hypotheses
• Using the constant comparative method, which involves making comparisons during each stage of the analysis
• Advancing theory development during each step of data collection and analysis
• Memo-writing to elaborate categories, specify their properties, define relationships between categories, and identify gaps
• Sampling aimed toward theory construction, not for population representativeness
• Conducting the literature review after developing an independent analysis.
(Charmaz, 2006)

The method has evolved since its original inception. For example, Strauss and Corbin (1994) argued against the concept of a pre-existing reality and acknowledged, instead, the significance of the various perspectives and ‘truths’, and have extended and emphasized the range of theoretically sensitizing concepts that must be attended to in the analysis of human action/interaction (MacDonald, 2001, p.137). As such, new techniques including questioning, far-out comparisons and flip-flop techniques to make the researcher more aware and to heighten the sensitivity to the analysis that has evolved (Strauss and Corbin 1990, 1998). Their version of grounded theory favours innovative technical procedures as oppose to elaborating upon the earlier strategies of grounded theory. More recently, Clark (2005) extended the notion of grounded theory by the use of situational analysis. Situational analysis uses maps to increase the visibility of complex theories and can reveal complicated interconnections in ways written words cannot. It requires the analysis process to begin as soon as the researcher gets a hold of the data. Furthermore, coding and diagramming are also done alongside with situational analysis as well.

Most recently, Charmaz (2006) argued that the constructivist grounded theory reshapes the interaction between researcher and participants in the research process and in doing so brings to the fore the notion of the researcher as author. This perspective focuses on the researcher assembling a theory as a result of their understanding of the data collected from the participants, or the participant’s narrative. In other words, instead of having a conceptual account of an experience, precise and comprehensive details are more significant. Researchers following the constructivist grounded theory go deeper than the shell to analyze the meaning in the data obtained to better understand the morals, ideologies and principles. To further enhance the data, Charmaz (2006) advises to even record the description of the

situation, communication and personal remarks of how the interview went. Hence, the main highlight of the constructivist grounded theory is the importance of how deeply the data is analyzed and treated through the use of literary styles of writing and more deliberate efforts to raise codes/terms to concepts, for example.

The primary method of investigation in this project was guided by grounded theory (Charmaz, 2006) to explain a given social situation and illuminate the processes that are taking place within that situation (Baker, 1992). In this study, the decision-making process, from the perspective of physicians, for the treatment of non-small cell lung cancer patients was the ‘social situation’ or phenomenon that was being explored. The treatment decision-making process was then built into a conceptual theoretical framework. Therefore, as Polit and Beck (2006) state that grounded theory research questions are likely to ask ‘process’ questions. Since the present study investigated a ‘process’, the proposed method was an appropriate design to use.

3.4 Sampling and Recruitment Issues

A. Sampling and Sample Size Determination

In qualitative research studies use purposive (non-probability) sampling strategies that help to ensure and identify information-rich cases that can offer an in-depth understanding of the research objectives (Creswell, 2007; Patton, 1990). Therefore, traditional sample size calculations that are used in quantitative analyses are not appropriate for the methodology used here. In qualitative research, the sample is not intended to be statistically representative; therefore, probability sampling is not appropriate (Ritchie and Lewis, 2003). A general guideline for qualitative research is to study only a few sites and/or

individuals (Creswell, 2007). The purpose of qualitative research is not to “generalize the information but to elucidate the particular, the specific” (Creswell, 2007, p. 126). Patton (1990) suggests that a study should have “minimum samples based on expected reasonable coverage of the phenomenon given the purpose of the study” (p. 186). Further, Lincoln and Guba (1985) suggest that sample selection should be to the point of redundancy.

The sample consists of medical oncologists, radiation oncologists, surgeons/surgical oncologists, and health care administrators from across different regional cancer centres and programs in Ontario. Health care administrators plan and direct the delivery of health care. They are either specialists in control of a specific clinical department, or generalists who direct a whole facility or system. The administrators interviewed within the current study are Heads of provincial and regional cancer programs that supervise the delivery and quality of cancer services in all of Ontario, or their respective regions.

The rationale for the sample is to include: regional variability, cancer centre versus community practice variability, variation as a function of practice patterns illustrated in Cancer System Quality Index data, and a variation in the types of oncologists treating patients with non-small cell lung cancer. This variation is important, particularly in a grounded theory study, where Charmaz (2002) explains that “a grounded theory is durable because it accounts for variation; it is flexible...” (p.511). Thus, “the open-ended feature of the grounded theory methods approach” (Charmaz, 2002, p. 312) proved to be helpful for this study and allowed it to capture the variability necessary to produce a vivid in-depth accurate theoretical framework of the process of treatment decision-making in non-small cell lung cancer.

Approximately 20-30 participants align with methodological norms for a grounded theory study, as recommended by Creswell (1998). The sample in this study consists of a total of 21 participants:

- 6 medical oncologists
- 4 surgeons/surgical oncologists
- 6 radiation oncologists
- 5 health care administrators

In early stages of research, criterion sampling was used as a preliminary sampling technique to gather participants that would help explore the topic, and indicate important categories that would help begin to understand the phenomenon and start forming the skeleton of a theoretical framework.

The following eligibility criteria were used to enrol participants:

- Must be involved with the treatment of non-small cell lung cancer patients in Ontario (directly or indirectly: directly means that he/she is a physician who treats non-small cell lung cancer patients in a cancer centre or hospital in Ontario; indirectly means that he/she have a role as a provincial and/or regional cancer program administrative leader in lung cancer)
- He/she must read, write, and speak English

Because the categories defined through criterion sampling were “thin” and their properties were not yet defined, in-depth, or clear (Charmaz, 2006), the second stage of sampling employed theoretical sampling. Theoretical sampling is an important component in the development of grounded theory (Cohen and Crabtree, 2006). It is defined by Charmaz

(2006) as “seeking pertinent data to develop your emerging theory” (p. 96). The purpose of this sampling technique is to further refine the emerging categories from the data, and advance these categories by developing their properties until no new properties arise—in other words, ‘saturating’ the categories (Charmaz, 2006). Since the present research used grounded theory, theoretical sampling was appropriate to employ, and helped further develop the theoretical framework of how physicians are making treatment decisions with their non-small cell lung cancer patients.

It is important to note, however, that theoretical sampling cannot be planned before embarking on a grounded theory study. “The specific sampling decisions evolved during the research process itself” (Strauss and Corbin, 1990, p.192). Theoretical sampling helped decide where to sample next based on the analysis. The research process then circled through the iterative cycles of gathering data, including new theoretical sampling decisions, data analysis and interpretation, and theory construction, simultaneously. Given this, sampling continued until “theoretical saturation” (no new insights into the research question being generated) was achieved (Lincoln and Guba, 1985).

For the current study, 21 participants were sufficient to reach theoretical saturation, which, again, aligns with Creswell’s (1998) recommendation of the number of participants typically needed in a grounded theory study (to reach saturation – e.g., one or more interviews with participants in each category that yielded no further insights).

B. Recruitment

It is important to note that, because of my lack of position and knowledge within the medical community, and being a ‘newcomer’, it was difficult “entering into the field” and

recruiting participants. Therefore, there was an important element of gate keeping involved. Gatekeepers are individuals who facilitate access to potential participants because of their trusted positions within a community (Borrayo, Buki, and Feigal, 2005). Thus, gatekeepers invariably play a large role in facilitating research, and provide successful access for researchers to individuals who may be more inclined to refuse participation in a study without support of a key figure (i.e., chair) within the community. It is also important to note that the choice of a wrong gatekeeper can distort and potentially endanger the research (Borrayo et al., 2005; Lee, 2005). Gatekeepers within each of the clinical specialities (i.e., the surgical oncology community, the medical oncology community, and radiation oncology community) assisted in the recruitment of participants for the study.

Upon receipt of ethics approval from the McMaster University Research Ethics Board (see Appendix H for Ethics Approval Letter), the Director of the Cancer Care Ontario guidelines program invited the Clinical Program Heads of Radiation Oncology, Surgical Oncology, and Systemic Therapy Program to identify and nominate key participants for the project (see Appendix I for Program Head Invitation Letter). The letter of assistance and participation described the aims and methods of the study, and informed the participants of what would be expected of them if they were to participate in the study.

Lee (2005) notes that researchers need to convince the professional gatekeepers that the research they are about to embark on is important, credible, and competent, and focus attention to gaining their support of the study (Holloway and Wheeler, 2002, in Lee, 2005). In doing so, gaining the support of gatekeepers helps maintain access to the necessary participants (Lee, 2005), and helps facilitate the participants' involvement in the project. The

response from each gatekeeper was instant and positive. The additional gatekeepers (the Program Heads) identified 10 key informants each.

After assessing each referral to ensure eligibility, a letter of invitation, consigned by the Director of the guidelines program and the Clinical Program Head, was sent to each eligible participant (see Appendix J for the Invitation Letter). The invitation also described the aims and methods of the study, and also informed the recipients what would be expected of them if they were to participate in the study.

After two-three weeks, the candidates responded to the letter, either agreeing to or declining participation in the study. A letter was sent to positive respondents to set up an interview (See Appendix K for interview invitation letter to physicians; and Appendix L for interview invitation letter to administrators). Participants that did not respond to this letter were followed up by phone calls to set up interviews. The response letters to setting up the interviews and phone calls provided potential participants with additional details about the interview process, and what participation in this interview would entail.

Some physicians who had originally agreed to participate withdrew from the study because of busy schedules. Therefore, alternate recruitment strategies included verbal referrals made by other physicians and/or administrators, which became participants in the study (snowball sampling; Patton, 1990). The participants' referral strategy (snowball sampling; Patton, 1990) was a successful way to recruit participants. The demographic characteristics of the study participants are presented in Chapter 4.

3.5 Research Setting

The participants indicated a convenient time and location for both interviews they completed. All the enrolled participants preferred being interviewed in their offices in their respective hospitals. The interviews lasted 30-60 minutes each. Each interview was audio taped for accuracy and to record the details of the participants' responses. No one was present in the interview except the physician and (me) the interviewer. However, because the interviews took place in a hospital setting during the office hours of the participants, some of the physicians who were being interviewed would be interrupted by phone calls, or other physicians coming into the office to ask patient-related questions. Some physicians also had to attend patients during the interviews and would leave the office for several minutes. The recorder was stopped at these times, and restarted once the physicians were ready to continue again. Other times, physicians would continue to work on their computers, looking at patient information (i.e., PET or CT scans) during the interviews; these physicians would occasionally swivel their chair to face me, but return to their computer screens to continue working.

At the end of the interview, each participant was sent a letter, thanking them for their time and participation in the project.

3.6 Data Collection

A. Individual Interviews

Focus groups and individual interviews are common data collection strategies of grounded theory methodology (Zeller, 1986). Given time limitations of participants (physician), their varied experience, and the potential challenges associated with the hierarchy

between senior and junior physicians, the focus group strategy was not chosen here (Greenbaum, 1992; Parsons and Greenwood, 2000). Instead, semi-structured interviews were conducted. Interviews provide an effective way to reflect on the perspectives of the participants, and engage with them in the reflection process (Charmaz, 2002). A semi-structured style ensures the interviewer is also in control of the process of acquiring information from the interviewee; however, the researchers are free to follow new leads as they arise (Bernard, 1988, in Partington, 2001); thus, they provide an appropriate level of flexibility and enable participants to elaborate in areas that may not have been identified as relevant or important by the researchers (Gill, Stewart, Treasure et al., 2008). To this end, an interview guide was developed; it posed open ended questions that allowed the easy flow of ideas and issues to emerge during the interview. (See Appendix M for interview guide for physicians; and Appendix N for interview guide for administrators). The interview questions and recorders were tested by a pilot interview using one medical oncologist. The pilot interview provided helpful feedback about the nature of the interview questions and the interview process.

Each interview was recorded using a Sony digital recorder. In addition, notes were taken to capture significant non-verbal communication and to capture details of the interview setting. Before the recorders were turned on the interviewer verbally shared that informed consent was assumed via email when physicians agreed to participate in the project, as well as making them aware that they would not be identified on the recording, that all responses would be kept strictly confidential and would be only shared with the research team members. Further, interviewees were informed that the report would not identify them

as a respondent and that they would be given a special ID (or pseudonym). None of the participants expressed any issue with being recorded.

The interview consisted of open-ended questions about how physicians make treatment decisions with their non-small cell lung cancer patients and questions eliciting their narratives about their experiences with this phenomenon. Probes were used to help ensure that the participants provided significant amounts of details regarding the planned topics in the interview. These concerned the characteristics of their patients; the role knowledge translation tools, such as guidelines, play in the treatment decision-making process; and, the more central issue, how they went about making a treatment decision with a non-small cell lung cancer patient. Information about their patients and who they were also helped contextualize aspects of why certain treatments were being chosen over others. I was able to explore themes emerging from the data by following a continuous cycle of simultaneous data collection and analysis.

The themes that emerged from the initial interviews developed into codes and formed the basis of future interviews and selection of future participants. The later interviews were then used to examine any new emerging themes as well as the old themes from the earlier interviews in more detail. The developing nature of this simultaneous process of data collection and data analysis was consistent with the constant comparative method, which is an important feature of the grounded theory methodology (Glaser and Strauss, 1967; Strauss and Corbin, 1998). Creswell (2007) describes this process as the “zigzag process: out to the field to gather information, into the office to analyze the data, back to the field to gather more information, into the office, and so forth”. By using the constant comparative process, it was possible to determine if theoretical saturation was

reached, meaning that no new themes or insights into the phenomenon being explored were emerging. Therefore, number of interviews conducted for data collection was determined by category saturation “and whether the theory [was] elaborated in all of its complexity” (Creswell, 2007, p. 64). A category “represents a unit of information composed of events, happenings, and instances” (Strauss and Corbin, 1990, in Creswell, 2007, p. 64). As the study neared completion, participants who were selected for interviews, but not yet actually scheduled for an interview, were notified and thanked for their efforts.

B. Demographic Questionnaire

At the end of each interview conducted with the physicians, physicians were asked to answer a brief demographic questionnaire (See Appendix O for the demographic questionnaire). This questionnaire was posed only to allow for exploratory sub analyses that would consider any background characteristics that affected the phenomenon under investigation. The demographic questionnaire aimed to capture the physicians’ roles in the hospital along with their clinical responsibilities, their ages, and how long they have been in clinical practice.

3.7 Data Management

All interviews were transcribed verbatim. The transcribed interviews were reviewed for accuracy and any references to names were removed, and the transcripts were anonymized. Initial coding was done manually. Then, the transcripts were entered into Atlas.ti, a qualitative data analysis program, and organized and coded. To facilitate analysis, memos were created using the memo function within Atlas.ti.

3.8 Data Analysis and Interpretation Procedures

Data analysis and data collection fed into one another. As Strauss and Corbin (1998) describe, grounded theory “describes and explains the system or behavior under study, and consequently is a methodology for developing theory that is grounded in data systematically gathered and analyzed” (Strauss and Corbin, 1994, in Cutcliffe, 2000, p1477). Creswell (2007) explains the method of “taking information from data collection and comparing it to emerging categories as the constant comparative method of data analysis” (p. 64) (Refer to Appendix P for a visual description of the analyzing process in the grounded theory approach). Charmaz (1990) states that “the major strength of the grounded theory method is its open-endedness and flexibility. Since analysis and data collection proceed simultaneously, a researcher can follow up on ideas as he or she creates them” (p.1168).

Thus, in this study, data analysis began with the first interview, and it was transcribed, and continued simultaneously with the data collection process. Analysis included writing field notes during the interviews and after, writing memos, and coding interviews. However, because of unforeseen circumstances and delays in the transcriptionist turn-around times, it was difficult to analyze each interview prior to the next interview. Therefore, initial cursory analysis was employed by listening to the recordings and reviewing field notes before coding the transcripts.

The analytical process was based on immersion into the data, and it was an iterative process of sorting, coding, and constant comparisons, all of which characterize the grounded theory method. The grounded theory begins its analysis through coding (Walker and Myrick, 2006) (See Appendix Q for a visual depiction of the types of coding and coding terminology.) The constructivist approach to grounded theory outlined by Charmaz (2006)

allows for flexible coding processes (Charmaz, 2006). The purpose of a flexible coding process is that the theory can be derived inductively from the data. Charmaz (2006), in her paradigm of grounded theory, acknowledges that the researcher “defines” what is happening through collective interpretations with the participants (Charmaz, 2002, p. 684). Thus, data analysis in the present study was led by the analytical methods outlined by Charmaz (2006). There were four main types of coding in the data analysis process; initial (or open), focused, axial, and theoretical. These four coding procedures then aimed to develop an abstract theoretical framework or grounded theory from the narratives the participants shared (Charmaz, 2000).

Initial/open coding started off as a microanalysis, which was principally utilized to conduct a thorough examination of all the interviews. Microanalysis was conducted by-hand and without any software assistance. During microanalysis, line-by-line coding and analysis is carried out to generate initial categories and to propose relationships among those categories (Strauss and Corbin, 1998). Charmaz (1990) explains that,

“Line by line coding during the initial coding prompts the researcher to study the data, to dispel earlier preconceived assumptions about the data, and to begin viewing the data analytically...Line by line coding keeps the researcher examining the collected data, rather than lapsing entirely into theoretical flights of fancy which have little connection with the data” (p.1168).

When a new idea would emerge, a new code was created and attached to the corresponding segment of text. Then, recurring codes slowly emerged and eventually a list of codes was generated. The list of codes was inserted into Atlas.ti using the code feature. This code list was modified and continued to develop with further analysis within Atlas.ti.

Microanalysis and code generation flowed logically into the phases of analysis: initial/open coding.

Thus, initial/open coding raised ‘codes’ to tentative categories (Creswell, 2007). Open coding, then, fed into focused coding. Charmaz (2006) defines focused coding by taking significant and earlier codes that occurred frequently in the data to “sift through large amounts of text” (p.57). “Focused coding requires decisions about which initial codes make the most analytical sense to categorize your data incisively and completely” (Charmaz, 2006, p.57). Thus, as part of focused coding, themes that were found to be theoretically similar or connected in meaning were grouped together as concepts (or major categories) and labelled.

During axial coding, the researcher tries to understand categories and their “relationship to other categories and their subcategories” (Walker and Myrick, 2006, p. 553). Thus, the researcher returns to the data, looking for what Creswell (2007) terms causal conditions: “factors that caused the phenomena...actions taken in response to the phenomena...and broad and specific situational factors that influence the strategies” (Creswell, 2007, p.64).

The axial coding process used in the present research involved exploring the relationships between the major categories and their subcategories. This included the relationships between the major categories, asking how they were connected, or influenced or contradicted each other. This was achieved through drawing diagrams and maps throughout the research process, and by writing memos that provided details about the categories and their relationships. Charmaz (1990) explains that writing memos allow the researcher to move thoroughly into the in-depth analysis phase and gives the researcher “a tool for engaging in an extended on-going dialogue with [him/her]self”(p.1169). The memo

that provided a summary of the analysis became the earliest version of the emerging theory. This earlier theory was shared with other research members or peer debriefers, who offered their feedback and shared suggestions for further analysis.

The final step in coding was theoretical coding. Theoretical coding was the process of integrating and refining the theory, by conceptualizing “how the substantive codes may relate to each other as hypotheses to be integrated into a theory” (Glaser, 1978, p.72, in Charmaz, 2006). Theoretical codes illuminate the relationships between the categories generated in focused coding (Charmaz, 2006). Theoretical codes help “tell an analytical story” and move it “into a theoretical direction” (Charmaz, 2006, p.63). Thus, theoretical coding was used to restructure the data and tell an analytical story of the participants’ experiences (Charmaz, 2006; Strauss and Corbin, 1998).

The constant comparative method of grounded theory means that this research process is not as linear as it may seem. Throughout the research process, there was a constant comparison between the interview transcriptions, for patterns, common threads, emerging theories, and relationships between descriptive categories. Simultaneously, earlier data collection and analysis were used to inspire future data collection and analysis. Finally, the goal of analyzing the data was to identify common, recurrent themes that united the data, and led to the identification of a common theory to describe the dataset.

To strengthen the analysis of the data, enhance researcher and theoretical sensitivity, and ensure rigour (as recommended by LeCompte and Goetz, 1982), data analysis and interpretation was also employed by one other researcher. The researcher openly coded two interviews and analyzed them. The two interviews and their emerging themes were then discussed by both the researcher and me; where my thoughts were both questioned and

challenged. I also made analytical and self-reflective memos to document my analytical process and “to make implicit thoughts explicit, and to expand the data corpus” (Morrow and Smith, 1995, in Creswell, 2007, p. 290). I also kept a self-reflective journal that allowed documenting of personal feelings towards the participants’ narratives and how they changed during the research process. In addition, an analytical journal was kept, recording emerging codes and categories that not only could track how they changed over the course of the research, but also ensuring that they could be shared with other analysts.

3.9 Trustworthiness (Rigor)

In qualitative research, “trustworthiness refers to a conceptual soundness from which the value of the research can be judged” (Marshall and Rossman, 1995 in, Brown, Stevens Jr, Troiano, et al., 2002). The conceptual soundness is the equivalent to the concepts of reliability and validity employed in quantitative research (Brown et al., 2002). Trustworthiness of a study is enhanced through spending time in the field, triangulation of data (examining data from different sources), and being aware of the subjective lenses that the researcher carries (Brown et al., 2002). Lincoln and Guba (1985) outline four criteria through which trustworthiness can be evaluated: credibility, transferability, dependability, and conformability. These, together, establish the “applicability, consistency, and neutrality” of the research study (p.143).

Credibility refers to the degree to which the data collected reflects the multiple realities of the phenomenon under investigation (Lincoln and Guba, 1985; Brown et al., 2002). In the present study, credibility was sought by trying to collect data that accurately reflected the views of the participants. One of the ways to ensure credibility is through

member-checking. Member checking is when the resulting model is taken back to the informants and presented to them for validation (Morse, 1994). Because of time constraints and the participants' busy schedules, it was not feasible to submit a summary of research findings to the participants. Therefore, at the end of each interview, participants were given a summary and reiteration of the information they shared as a means of member checking to ensure that my understandings and interpretation of the information and views they shared truly reflected the participants' personal interpretations of their own experience.

As my theory slowly emerged from simultaneous data collection and data analysis, the last few participants were used to verbally present and discuss the emerging theory of the treatment decision-making process and allow them to discuss, challenge, and adjust the interpretations. The individual participants did not suggest major adjustments to the summaries provided, beyond offering further information.

Another method of ensuring credibility was through peer debriefing. Peer debriefing is when “a project is discussed with colleagues who are not working on the same project” (Lincoln and Gube, 1985, p. 308). The peer debriefer was used to offer an additional perspective for the data analysis and propose additional avenues to explore. The peer debriefer was a qualitative expert who offered different perspectives on the data as well as challenged my views.

Transferability aims to ensure that the findings of the study are applicable to another setting or can be appropriately applied to another setting (Lincoln and Guba, 1985; Brown et al., 2002). Determining the strength of transferability, then, is heavily reliant on the researcher. Lincoln and Gube (1985), and Firestone (1993) state that researchers should provide adequate contextual information and description about the fieldwork sites to allow

the reader to make the transfer (in Shenton, 2004). Thus, the researcher should think through descriptions of all aspects of the research study. I, being the lead researcher of the present study, was responsible to thoroughly describe all aspects of the study, offering detailed descriptions of the research, the participants, the methodology, and the interpreted results. In this study, the final thesis serves as a thorough description and a means of addressing transferability. Interview transcripts, patient demographics and information, and other information about the study will be kept for this purpose, and then will be destroyed in accordance with the guidelines of the research ethics board and to ensure participant confidentiality.

Dependability aims to ensure that the methodological procedures are followed, and that the data illustrate the changing conditions of the experience being examined (Lincoln and Guba, 1985). A reflexive journal served as a tool to monitor my changing thoughts, assumptions, and feelings throughout the research process. Further, a qualitative expert on the research committee with an understanding of grounded theory (Charmaz, 2006) served as an “auditor” to review the methods of data collection, coding, and procedures outlined in the thesis, and to make sure that they were appropriately executed.

Confirmability requires that an alternative researcher can confirm the study when presented with similar data (Lincoln and Guba, 1985). For the current study, confirmability was sought by keeping an audit trail of movement through the data and a record of major decision points. The audit trail also consisted of:

“chronological narrative entries of research activities, including pre-entry conceptualizations, entry into the field, interviews, group activities, transcription, initial coding efforts, analytical activities, and the evolution of the survival and coping theoretical model” (Morrow and Smith, 1995, in Creswell, 2007, p. 291).

Kuch (1994) states that one of the ways for a study to be considered dependable is for its process to be audited (p. 977). Thus, not only was confirmability maintained, but also dependability was maintained through keeping an audit trail.

3.10 Ethical Considerations

As part of its quality improvement mandate, Cancer Care Ontario aimed to better understand: the treatment of non-small cell lung cancer patients in Ontario, the role of the CCO-PEBC clinical practice guidelines, and the potential barriers and enablers to the application of the treatment recommendations outlined in practice guidelines (7-1-2 [Dec 2006] and 7-3 [Jan 2006]). The mixed methods study was called: *The Analysis and Assessment of Physician Practice Patterns in the Treatment of Non-Small Cell Lung Cancer Patients in Ontario: Working Together to Optimize the Treatment of Non-Small Cell Lung Cancer Patients in Ontario*. The current study was the qualitative component of this larger mixed methods study. Thus, as with all research projects conducted at McMaster University, documents giving a thorough description of the goals of the study were submitted to the McMaster University Research Ethics Board (REB). The study did not begin recruitment until the REB granted approval. When the REB granted approval, letters of invitation to participate in the study were sent out to the potential participants. As each participant agreed to participate via email, informed consent was assumed. At the beginning of each interview, an oral reminder of prior informed consent was given to ensure that it was still in effect.

The transcriptionist signed a confidentiality agreement before beginning her work with the project (see Appendix R for the transcriptionist confidentiality agreement). MP3 recordings were transferred securely on a password protected USB key between the

transcriptionist and me. As part of the agreement, the transcriptionist was told to destroy any hardcopies, electronic, or audio forms of data from her computer once she was done transcribing. Each transcript was also password protected; and each participant (e.g., name, age, and position) was linked to a unique ID number. All transcripts were anonymized; replacing any non-participant names within the transcripts with pseudonyms. Demographic information was also collected after each interview. The demographic sheet was labelled only with the participant's unique ID number. Every effort was taken to ensure confidentiality and secure collection and storage of the research data. Digital sound files, interview transcripts and any other research data were kept on a password protected personal laptop. Each interview transcript file was further individually password protected as well to ensure confidentiality. Any loose sheets of data (e.g., demographic questionnaires, printed transcripts) were kept in a secure filing cabinet. Any hardcopy of confidential information that was no longer needed was shredded immediately. All study data, raw and analytical, was only accessible to other research team members directly working on this project (e.g., my thesis committee members).

There were not many ethical concerns that emerged during the interview or overall research process. However, it was soon apparent that in the oncology community everyone seemed aware of everyone else; therefore, it appeared that specific examples outlined in the paper might identify respondents. Thus, an ethical concern that did arise was how to balance the authenticity of the participants' narratives and not compromise their descriptions. I carefully worked around this issue by using pseudonyms and cautiously leaving out any specific markers (i.e. names of specific institution and cancer centres/participant roles in the institution) or specific examples that may possibly identify a participant.

CHAPTER 4: FINDINGS – The Process of Treatment Decision-Making with (Stage II and Stage IIIA and Stage IIIB) Non-Small Cell Lung Cancer Patients

In this chapter I begin by describing the physicians who participated in the study by presenting information about their demographics. I also discuss the health care administrators that participated in the study. I then move on to discuss my own presumptions of the phenomenon under investigation. Finally I present my understanding of the phenomenon through comparing the experiences of the participants, and being aware of my own preconceptions, and how they were shaped by the data. This analysis, as described in chapter 3, follows the data analysis and interpretation procedures outlined by Kathy Charmaz (2006).

4.1 Study Participants

The study sample consisted of 21 participants: 6 medical oncologists, 4 surgeons/surgical oncologists, 6 radiation oncologists, and 5 health care administrators. There were 16 physicians in total and 5 health care administrators – 3 of the 5 administrators also had clinical backgrounds. Table 4-1 presents the demographic characteristics of only the medical oncologists, surgeons/surgical oncologists and the radiation oncologists. The demographic information helped provide background information for each physician, and allowed for an opportunity to conduct any subgroup analysis if time permitted. Demographic information was not collected from the administrators as the administrators were theoretically sampled solely to gain an administrative perspective on only the use of guidelines in Ontario, and to understand the implementation of clinical guidelines, and not the overall treatment decision-making process.

Table 4-1: Physician Demographics

Variable	Physicians (n=16)	
Physician Speciality	Medical Oncologist	6
	Surgeon/Surgical Oncologist	4
	Radiation Oncologist	6
Gender	Female	2
	Male	14
Age (yrs)	≤ 25	0
	26-35	2
	36-45	6
	≥46	8
Years In Medical Practice	≤10	6
	>10	10
In Addition to Clinical Responsibilities, Other Roles in the Cancer Centre/Hospital	Educational duties or roles	12
	Research duties	10
	Quality improvement activities, locally, regionally, provincially	8
	Administrative duties (i.e. division lead, clinician group leader)	11

Table 4-2 presents the information of the Local Health Integration Networks (LHINs) involved in the study, the corresponding hospitals within those LHINs and the number of physicians and administrators involved from those hospitals.

Table 4-2: Ontario’s Local Health Integration Networks (LHINs) Involved

Ontario’s Local Health Integration Networks (LHINs)	Ontario Hospital/Cancer Centre Involved	Participants Involved	
Toronto Central LHIN	Princess Margaret Hospital, Cancer Care Ontario, Mount Sinai Hospital, Toronto East General Hospital	Medical Oncologists	2
		Surgeons/Surgical Oncologist	1
		Radiation Oncologists	3
		Administrators	3
		Total Participants	9
Champlain LHIN	The Ottawa Hospital Regional Cancer Centre	Medical Oncologists	1
		Surgeons/Surgical Oncologist	1
		Radiation Oncologists	0
		Administrators	0
		Total Participants	2
North East LHIN	Sudbury Regional Hospital	Medical Oncologists	1
		Surgeons/Surgical Oncologist	0
		Radiation Oncologists	0
		Administrators	0
		Total Participants	1
South East LHIN	Kingston General Hospital, Cancer Centre of Southeastern Ontario (Kingston)	Medical Oncologists	1
		Surgeons/Surgical Oncologist	1
		Radiation Oncologists	0
		Administrators	0
		Total Participants	2
Hamilton Niagara Haldimand Brant LHIN	Juravinski Cancer Centre	Medical Oncologists	0
		Surgeons/Surgical Oncologist	0
		Radiation Oncologists	1
		Administrators	0
		Total Participants	1
Mississauga Halton LHIN	Carlo Fidani Peel Regional Cancer Centre/ Credit Valley Hospital	Medical Oncologists	1
		Surgeons/Surgical Oncologist	1
		Radiation Oncologists	2
		Administrators	1
		Total Participants	5
North West LHIN	Regional Cancer Care – Northwest Hospital: Thunder Bay Regional Health Sciences Centre	Medical Oncologists	0
		Surgeons/Surgical Oncologist	0
		Radiation Oncologists	0
		Administrators	1
		Total Participants	1

4.2 Researcher Reflexivity

The characteristics of a grounded theorist are presented by Strauss and Corbin (1998). Strauss and Corbin (1998) state that the grounded theorist should have:

- “The ability to be flexible and open to helpful criticism
- The ability to step back and critically analyze situations
- The ability to recognize the tendency toward bias
- The ability to think abstractly
- A sense of absorption and devotion to the work process
- Sensitivity to the words and action of respondents”

(Strauss and Corbin, 1998, p. 7)

Unlike objectivist grounded theory, where the researcher aims to balance his/her objectivity and believes that analysis and data emerge directly from the experience of the participants, constructivist grounded theory recognizes subjectivity. The grounded theorist that follows the constructivist paradigm does not strive to be objective but instead transparent about his/her research process, his/her analysis, and his/her interpretation that are made with his/her participants (Charmaz, 2000).

“How one views the world is influenced by what knowledge one possesses, and what knowledge one is capable of possessing is influenced deeply by one’s world view. The conditions under which people live and learn shape both their knowledge and their world views” (Ladson-Billings, 2000, p.258).

As Ladson-Billings (2000) intricately outlines we are a product of our subjectivities.

Qualitative research takes recognition of this fact and acknowledges that the researcher is the instrument of data collection and analysis (Brown et al., 2002). It is *I* who made the decisions of what participants to select, what questions to ask my participants, and how to ask them;

and finally, how to analyze the voices of my participants. The application of these methods and the research decisions I made required me to be open about my subjectivities and experiences and be transparent and cognisant of how they influenced my study (Lather, 1993). The meaning of someone's experience can be imposed when you allow your subjectivities to bleed into your analysis. Thus, I had to distinguish the "I" from the "eye". Through being transparent, I was able to look with a fresh "eye" instead of my "I" and recover the meaning of the participants' experiences. Setting aside my thoughts and assumptions, and setting aside my "I," I was able to render a totalizing story, a transparent inscription of the treatment decision-making process and highlight its complexity and richness.

Further, in qualitative research, researchers are encouraged to go through a reflexive process (Ortlipp, 2008). Primeau (2003) defines the reflexive process, also known as reflexivity as:

“...a qualitative research strategy that addresses our subjectivity as researchers related to people and events that we encounter in the field. Reflexivity also addresses the subjective nature of the research account as a narrative constructed by us as researchers. Reflexivity enhances the quality of research through its ability to extend our understanding of how our positions and interests as researchers affect all stages of the research process” (Primeau, 2003, p. 9).

I chose to acknowledge my experiences, views, and feelings, during the research process through keeping reflective journals. I entered into reflexivity across the complete research process, including situating the research study, gaining access, interviewing, managing self, and telling *the story*. I spent time reflecting on my own experiences, understanding what it means to make a treatment decision, and the impact of my reflection on how I interpreted and perceived the data.

4.3 Emerging Theoretical Categories/Theoretical Framework

Setting the Stage

All phases of the clinical treatment pathway are critical. A thoracic surgeon serves as one of the gatekeepers of the non-small cell lung cancer population; and is the first to engage in clinical activity that enables the diagnosis and staging of the patient. Staging the patient is one of the most important steps and determinants in managing the disease — it dictates the “ideal management for the patient” (SO1). Sometimes patients do come in directly through internists, and respirologists, and/or medical oncologists. However, generally, thoracic surgeons see patients first. Here, the first interaction is a consultation where the patient’s medical history is noted, an examination is done, and available laboratory and radiology data is examined. Thoracic surgeons look at factors within the patient such as whether the patient has metastatic or non-metastatic disease, and whether it is a locally advanced case or an adjuvant case. Thoracic surgeons, therefore, look at pathology and the imaging information to determine what type of lung cancer the patient has.

Usually there is a gatekeeper. So usually the surgeons are the gate keeper because they get referred the patients first. So as soon as a family doctor or a general medicine doctor identifies a patient with lung cancer one of the things that gets done is they get referred to a thoracic surgeon to consider surgery as the first option and often that is part of the diagnostic process...So there is inherently a requirement for communication between the surgeon who refers the patient and the decision making that they are going to make about whether the patient is a surgical candidate or not. So the surgeon sees patients all the time that have small lung nodules that are great operable candidates and they do the appropriate work-up and do the appropriate treatment. When they can't do that or when they think they are going to get into trouble, that's when they start involving the radiation oncologists and other people because until we know what it is, I'm not useful technically. I mean, the surgeon -- I am useful in the sense that I can order biopsies and things like that but the surgeon often times is the one who ends up doing the bronchoscopy or gets involved. So we do get some referrals from pulmonologists and things like that with patients who have been diagnosed but a lot of our referrals

come from thoracic surgeons so there is inherently a need for collaborative discussion about patients (RO5).

Two aspects of the knowledge of these physicians provide the necessary context for understanding their experience in making the treatment decision with their non-small cell lung cancer patient: (1) they make sure that they are aware of the diagnosis and the stage of the disease of the unique patient in front of them (which sometimes flows into the treatment decision-making process because of physicians wanting to confirm the stage and to avoid any ambiguity in staging); and (2) they make sure that the patient is aware of their diagnosis and is ready to make a treatment decision. Although the process of treatment decision-making is set in motion with the entry of the patient into the physician's consulting room and his/her "sit down" to discuss treatment options, it is important for the physician initially to make sure that the patient is aware of his/her diagnosis and the stage of the disease.

A lot of the times patients come in and they don't really even know what is going on. So you'll ask them, "so what did the surgeon (or whoever), tell you?" I always ask. This is my very first question whenever they come in because I want to frame the discussion. I want to know what they know before what I tell them. So I always ask, what did the surgeon or whoever the referring doctor was, tell you about what is going on and what options you have. Often times when they come from the surgeon, the patient [will say] "well I know I have a cancer and I know it's not operable... the surgeon can't remove it so... they are asking you to see me." They don't know if they are stage IV sometimes, they don't know if they are stage III. They don't know where the lymph, where the tumour is, where the lymph nodes are. All they know is that they have cancer and it can't be removed... I think it is probably just a reflection of the patient's selective hearing stuff. So they hear what the surgeon -- I mean the surgeons that refer the patients, you read their notes, and their notes pretty clear state what is happening. And so, I think that often times, the patient will just kind of get the take home message ... (RO2).

Consequently, together with spending time with the patient, educating him/her, and making sure that the patient understands his/her disease and what it means, the next step is to make sure the patient is ready to discuss his/her treatment options. Physicians reflect on

the readiness of patients to discuss treatment. Some patients may be eager to discuss treatment, while others may not be ready to do so. For example, one physician talks about a patient who is not ready to undergo any treatment. The physician, however, keeps his doors open for the patient to return any time he/she wants to discuss and undergo treatment.

Another physician gives a similar account of a patient who is not ready to start treatment:

She is from Haiti and she needed to look after her sick mother and she couldn't be on chemotherapy because she couldn't have her hair fall out because she couldn't worry her mother. Now this is not uncommon...she's gone to Haiti now I think, but my door is open and she knows that (MO1).

Another physician shares his account of waiting till the patient is ready to discuss his/her disease:

Sometimes the patients will want to think about things and other times they will just say fine, let's get on with it. If they want to think about it, which there is no problem in doing that, I usually have them come back and see me in a week... (SO1).

It is also noteworthy that the treatment decision-making process is not exclusive to one physician and the patient. It may go through many people: one physician and his/her patient; to another physician and the same patient; to one physician and his/her patient and also the family; and/or between a physician and a physician. For example, in the initial process of being diagnosed and staged, surgeons already may have operated on the patient, but the patient may be a candidate for adjuvant chemotherapy, and the surgeon will usually recommend that the patient see a medical oncologist. However, the discussion to have chemotherapy or not already begins with the surgeon, even before continuing to a medical oncologist.

...In those cases where it is kind of a surprise and you're recommending that [adjuvant chemotherapy] they go and see an oncologist, sometimes there is a resistance but again, what I'm telling them is that 'I'm not telling you that you have to have chemotherapy but you should at least meet a medical oncologist, just to close the loop'. The decision is always theirs (SO3).

Thus, treatment decision making is not always a linear process; sometimes it takes a bit of time and involves a series of interactions with people. There are different treatment decisions along the disease continuum. For example, the decision is made about surgery but the decision about adjuvant chemotherapy cannot often be made until after surgery and the pathology report is available. Thus, there is the constant interplay of different factors, including the patient's readiness and willingness to discuss treatment interventions and to undergo treatment, and the physician's patience in this process. *Setting the stage* provides a basis for the possible recommendations that can be made. Thus, once the disease has been perceived by the physician and the patient, the "stage has been set," and the dynamic process of treatment decision making begins. The physician then not only sees the disease, but sees the *unique individual* who carries the disease and begins the treatment decision-making process in that way.

From Setting the Stage to the Treatment Decision-Making Process

The proceeding sections describe the five important guides that inform the treatment decision-making process of patients with stage II, stage IIIA and stage IIIB non-small cell lung cancer. Although there is recognition of the clinical differences and ramifications between stage II and stage III non-small cell lung cancer patients, and that within these stages there are individual differences in the complexity of the disease presentation, these differences DO NOT alter the *process* of treatment decision making. Medical oncologists, radiation oncologists and surgeons/surgical oncologists all intimately describe their experiences with their non-small cell lung cancer patients, slowly unfolding similar layers of

the decision-making process through their narratives and recollections of their patients; finally to reveal the same central guides (or factors) involved in this population of patients when making treatment decisions: (1) The Unique Patient, (2) The Unique Physician, (3) The Family, (4) The Clinical Team, and (5) The Clinical Evidence. All guides (or factors) are intertwined with one another, with one affecting the other during the decision-making process.

A. THE UNIQUE PATIENT

We try and decide based on the objective stuff we have. We've got to see the patient, look at the comorbidities and then look at the patient wishes (MO1).

Clinical Status of the Patient

The treatment decision-making process begins with an assessment of the patient's clinical status. Physicians make sure that the patient's full staging workup is completed, and then start by recognizing the clinical features and clinical state of the individual patient in front of them. For example, the size of the tumour, the spread and severity of the disease in the body, weight loss, lymph node involvement, epidermal growth factor receptor mutations, and functional status (i.e., do the patients have the capacity to get back and forth from the hospitals?) are a few factors that are examined in non-small cell lung cancer patients.

Assessing how physically fit the patient is – to see if they can withstand certain treatment side effects, like the toxicity of chemotherapy – plays a large role in the treatment decision-making process. Asking questions such as: How frail is the patient? Will the patient be able to withstand the treatment recommendations? are important. Physicians use scales and

criteria like The Eastern Cooperative Oncology Group (ECOG) Performance Status to describe and summarize the level of function, and:

“Assess how a patient’s disease is progressing, [and to] assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis” (Eastern Cooperative Oncology Group, 2000) (See Appendix S for ECOG performance status description).

Different physicians may focus on different medical and physical aspects of the patient when considering the management of the disease. Medical oncologists may specifically pay attention to a patient’s pulmonary reserve and his/her kidney function. Radiation oncologists may look at the pulmonary function, the patient’s breathing status, emphysema, tumour sizes and their spread, and surgeons may focus on the patient’s cardiovascular system, his/her respiratory system, and his/her pulmonary function and ask questions like: Do these patients have heart disease? Do they have a history of strokes? Heart disease and strokes are examples of comorbidities, which also have an impact on the appropriate treatment options. Physicians always aim to understand the interaction between comorbidities, treatment, and outcomes because these factors are important when treating non-small cell lung cancer. Comorbidities may limit what may be done for a patient. For example, one physician describes the implication of bad kidneys for a patient with non-small cell lung cancer:

[If] there is someone [who has] got bad, crummy kidneys and is very frail after their operation, well it doesn’t matter for those people even if the recommendation for [them is] adjuvant chemotherapy for their stage of disease, when you look at the patient you would say... “no, you know it may help you a little bit but we have other side effects we need to worry about...” (MO3).

When assessing the patient’s clinical status, physicians also recognize the fact that no two patients are ever alike; and they acknowledge that it is difficult to pin one specific facet that

will have one specific treatment modality. Many physicians illustrate the uniqueness of each patient by referring to the “very complicated” (MO1) group of stage III non-small cell lung cancer patients.

...stage III they are going to have about two weeks of not being able to swallow...They are going to need to come into hospital. They have needs, pains, hydration, and different things and there is a real range. Some people have no trouble, some people do, people who get a bit more radiation have a bit more trouble, people who get less, so you know, there is -- every single case is different. No stage III is ever the same (MO1).

Stage III non-small cell lung cancer patients are a group of patients physicians use to illustrate how they begin individualizing treatment within the treatment decision-making process. Many physicians describe the complexity of stage III patients and the heterogeneity of this group.

...I will show you ten stage III's and they will all look differently, so there is a big variation and -- it's close to very critical structures: the heart, the lungs, the spine, so it is very individualized because of that. I would say most of our patients do understand what we recommend and do go along with it (RO6).

The theme of individualizing treatment also come to the fore as physicians discuss the complexity of non-resected stage IIIA and IIIB non-small cell lung cancer patients and several nuances in the management of this disease. Physicians speak of options of radical treatment, palliative treatment, or no therapy (See Appendix T for a glossary of terms); and whether a patient receiving palliative or curative treatment depends on the nuances of the patient's specific medical factors.

One of the limitations of IIIB particularly if it's bulky is the size of the radiation field... Can radiation therapy be administered at a radical dose with acceptable toxicity and sometimes the pulmonary function of these patients precludes that. You can't give it therefore they can't have the chemo-radiation therapy administered with curative intent (MO5).

Another physician discusses a patient and shares the basis of her decision to treat the patient palliatively.

Recently I saw a 74 year old patient who was referred with inoperable IIIA lung cancer. He was symptomatic with cough and could only walk about a block on the flat. He had lost a significant amount of weight, approximately 25 pounds over a three month period. I felt that he was not a candidate for aggressive chemotherapy in addition to radical radiation treatment, so the decision with him was to offer him a short course of palliative radiation to his chest (MO6).

However, other physicians acknowledge that whether a goal is palliative or curative depends to a great extent not only on the stage of the disease and the clinical status of the patient, but also on the patient's demographic details and personal and social circumstances. Consequently, the decision to treat a patient with palliative or curative intent is tightly interwoven with the treatment decision-making process, considering all the characteristics of the individual unique patient.

...you are looking at a tumour that in another patient you wouldn't think twice -- you would go for curative treatment and you have a patient that you are bit worried how are they going to manage with toxicity, they don't have a lot of support, they are not pushing for it and it is really hard because the easy thing to do is say, "oh okay, never mind. Let's treat you palliatively. Let's treat you less aggressively..." (RO6)

Another physician describes a case of an unreliable alcoholic patient who is a better candidate for palliative treatment than curative treatment.

...he was a stage IIIA patient unresectable and he had borderline features in terms of his overall performance status, and his breathing status; but he was on the younger side and looking at his nodes and things like that, your initial impression was that we would probably give him a shot at giving him concurrent chemo-radiotherapy for six weeks and go for it but he didn't show up for two appointments and just wasn't a very reliable person in terms of his capacity to come back and forth and things like that. So my conversation with him was that "this is not a walk in the park, it's not going to be straightforward, you have to make it every visit. If there is something wrong you have to be able to seek medical attention," and he wasn't very reliable so at the end of the day I offered him just to give him a palliative course of radiotherapy... (RO1).

Thus, the treatment decision depends on the dialogue between the patient and the physician, and individualizing treatment means recognizing that every patient has unique clinical and non-clinical characteristics.

Demographic Details of the Patient

I spend a lot of time with my patients -- a lot of time talking...I usually wind up spending 45 minutes to an hour with them...One thing that I've learned over the years is that you can never spend too much time with patients and their families...(SO4)

A physician creating a bond with the patient and getting to know him/her is part of the groundwork of the treatment decision-making process. The physician asks questions such as: What does the patient do for a living? Is the patient of a lower socio-economic class, less educated? Where does the patient live? Is he/she living downtown in community housing? What is the social history of the patient? Does the patient drive? Does the patient speak English? Does the patient have a drug plan? What kind of family does he/she have? Physicians establish bonds with their patients which, in turn, opens up communication, allowing the physicians to gain their patients' trust, eliciting patient information beyond clinical considerations, and patients' preferences. For example, one physician describes how he gets to know his patients:

... I talked about in a way they understand and you use different language. If it is their native language that is fine, if it's English you may explain things differently and use different words from one person compared to another with the same stage of disease depending on their culture and all the other sort of things (SO1).

Establishing bonds allows physicians to learn details of the patient's demographics: his/her age, culture, literacy, English fluency, socio-economic status; which all play a critical role in the treatment decision-making process with non-small cell lung cancer patients.

For example, the age of a non-small cell lung cancer patient is an important demographic detail when making treatment decisions. The older the patient is (i.e., 75 years old), the less likely it is perceived that the patient can withstand the side effects of particular treatments, for example, the toxicity from chemotherapy. Physicians explain that sometimes extreme age can also cause cognitive decline, and this can make patients unsuitable candidates for certain treatments. Of course physicians take into consideration that not all older patients are alike. Again, individualizing treatment is critical.

... For example, [with patients] that are 82... you are really concerned about chemotherapy. It's an interesting question of age and when is somebody too old for what. Radiation is probably the best tolerated by age so I don't think we would have any age at which we would say you are too old for radical radiation, especially if the volume is not too big but in the 80's surgery is much more risky and chemotherapy is more toxic. So some people use 75 and above, other people use 80 and above, most people try not to use -- the proper thing is to [not] use age alone because there could be a 75 year old who is fantastic and there could be a 70 year old who is dreadful right? So the proper thing I think is to take a factor into your decision making but not only make a decision [based] on age... (RO6).

It is also important to note that the importance of creating bonds with the patients is illuminated in this discussion on age. The importance of speaking to the patient helps the physicians understand what kind of 60, 70, 80 year old the patient sitting in front of them actually is. For example, one physician speaks about a patient who he learns through a discussion with his patient, is playing golf five times a week at the age of 80:

For me age is nothing but a number... I saw an 80 year old guy last week...He was 80; he was golfing 5 times a week...And he hadn't lost any weight, he looked like he was 60, so I said 'why not'? His protoplasm was probably 60. He looked way younger. He wanted it. He said "I want chemo-radiation", so he wasn't actually booked to see a medical oncologist. He was booked to see me [a radiation oncologist]. He had a locally advanced lung cancer. He was booked to see me only for sort of aggressive radiation or something like that but when I assessed him, I said, "no, no, no, this guy should get the benefit of the doubt". So I always give people benefit of the doubt a lot of the times and maybe that is just my [way]... (RO2).

Understanding the details of the patient’s age is not achieved by simply seeing an age written down on a patient’s demographic questionnaire, and physicians take note of this by acknowledging the important difference between seeing a patient “in person” versus seeing a patient “merely on paper.”

There is nothing quite like having the patient in front of you to give a good opinion...There are patients who look good on paper and don't look so good in the room. There are patients who don't sound so good on paper but actually look very fit and in fact they've demonstrated that physician assessment, even though it might not be perfect, and we might not get all the toxicities and stuff, and our ECOG may not be...what they report, we are actually the best determinant of prognosis (MO1).

A non-small cell lung cancer patient’s socioeconomic status also plays a role in the treatment decision-making process, and making treatment decisions without considering this factor is considered a “disservice” (MO5). Physicians speak of non-small cell lung cancer patients (other lung cancer patients included) being vulnerable and with a limited amount of resources compared to other cancer patients. They characterise this population group as having limited access to care. Driving to cancer clinics, paying for gas, paying for parking, and taking time off work are issues. For example, physicians say that the affordability of supportive drugs limit patients of a lower socioeconomic status in their treatment choices.

So under 65 -- oral medications. Huge problem...So if you have good drug coverage from your company, that's great but our lung cancer patients many are unemployed, they work in low status jobs where they have no drug coverage. Many of them are relatively new to the country. They don't have drug coverage or when they get sick, they get fired... It's devastating. I mean these poor people; first of all, they are dying and then their company fires them and cuts off all their benefits. It happens all the time. All the time. Especially in lung cancer (MO1).

Physicians also speak about patients who do not speak English and how this factor has an impact on the treatment decision-making process. Physicians explain that patients who do not speak English sometimes defer the responsibility of a treatment decision to a

family member (discussed later), offering minimal input themselves, or defer the treatment decision to the physician. Often, however, there are translators present, but physicians do acknowledge that important information may or may not be lost in translation (discussed later).

...There are a lot more people in Brampton that don't speak English as their first language. Some of them don't speak it at all so a lot of it will be through translation. The decision making process in that population may be a little bit more, like I said, those are the patients who most often will defer to you to make the decision... (R01)

Conversely, patients who are fluent in English have an impact on the treatment decision-making process that differs from the impact of patients who are not as fluent in English. In fact, physician's share that English fluency also influences health literacy:

In cases where people are more internet savvy and things like that, they will go – I can remember the last person I saw from Oakville was like that. Their family was very involved, they were asking me about CyberKnife and how does that fit into this and that, and can we get this. So there is a difference definitely (R01).

Another physician shares the following on patients that are both fluent in English and educated:

I would estimate more and more, maybe 50% of our patients are very educated and proactive. They have their own folder with their own results, they've read the internet, they know what is happening and they take a long time too because they are almost too educated. They want to talk about what would Houston do and what would New York do and what they do in Germany, but anyhow a lot of patients are reasonably educated or learned. Maybe they don't know at the beginning but they are able to learn to know what to do to be involved. But then at least a third of our patients, if not more, are completely the opposite (R06).

Culture also plays a role in the treatment decision-making process. There are not many physicians who discuss culture, but some physicians explain that certain cultures seem to be opposed to invasive treatments.

... It may just be that there are some cultures that are less accepting of really aggressive therapy on older patients...I have had that experience most often with Chinese descent but I don't know if that's universal but usually it seems to be that way...They tend to not want to do surgery and I don't know why that is (RO5).

Personal and Social Circumstances and Patient Wishes

Patient values are not always tied to demographic factors, but choices in favour of particular treatments are also guided by the personal and social circumstances of a patient. Physicians do not find decision-making that straightforward — it is the process of reflecting on the inherent values of the patient, their beliefs, perceptions, and attitudes, and the personal and social conditions present in his/her life. What are the patient's goals as far as care is concerned? The physician aims to understand the patient's expectations, as well as clear up any misunderstandings and misconceptions of particular treatments the patients sometimes has. Patient fears sometimes stem from these misconceptions and doing selective research to support these misconceptions; but physicians explain how these fears prompt them to address the understandable fear rather than to dismiss it:

I mean obviously our job is to offer people the best medical treatment; but it is also to listen to the patient and decide and hear [what] the patient [has to] say, if patients are hesitant or if they seem reluctant, I mean those are people that obviously you would explore to a greater extent. "What is going through your mind? What is it about this that you are hesitant about?" Often it is just a misunderstanding and sometimes patients just require greater clarification. But if some patients truly do understand what you are saying to them and they elect to not pursue that sort of treatment, well that is their choice (MO2).

Another physician explains fear brought about by a movie:

...And then there are other people, of course, who just don't like chemo. They've seen a lot of movies and Hollywood loves to make chemo look terrible, because it wouldn't sell if everyone sailed through chemo and felt great, right? ...Yeah, I've had one patient tell me he saw a movie the night before he was seeing me and he saw how sick the person got and he doesn't want any chemo...He had already

made up his mind. I didn't even have to open my mouth when I met him. He had made up his mind that he wasn't having chemo, based upon a movie he saw (MO4).

Yet another physician explains fears of treatments that are not always overcome by the patient, even though physicians try to address them:

I have had patients refuse [a recommended treatment], patients decline treatment because of the fact that they just felt they had lung cancer, they felt it was a 'death sentence' and they didn't really want to proceed with aggressive treatments so they were more comfortable proceeding with palliative treatment but the kind of treatment that you can give them when they are symptomatic and they are not necessarily symptomatic at that time. So sometimes, yeah, they are afraid of radiation, they are afraid of chemotherapy, they are afraid of what might come ahead in terms of side effects and uncertain benefit...but it is always a decision process, so you are always in discussion with the patient about what their alternative options are (RO2).

Other fears stem from side effects from previous treatments. Physicians explain that some patients have other illnesses unrelated to cancer, and the treatments of those illnesses influence their fears and attitudes towards any further treatments. The attitude, “I've had enough” (SO1) resonates from patients that carry these attitudes and fears; and physicians try to dispel their fears by explaining their diagnosis, their treatment options, and the reasons for recommending those treatment options in a manner patients can understand.

Patient preference is a substantial element in the treatment decision making process. Non-small cell lung cancer patients differ in their choices to pursue particular treatments. Some patients who do not want any treatment decide to pursue naturopathic medicine. Some patients do not find it worth pursuing a treatment because of the side effects. Some patients aim to live longer and so value longevity. Some patients value the quality of life above the quantity of life. An increase survival rate from a particular treatment does not justify undergoing it. Some patients' choices are aligned with what the physician recommends; they are therefore motivated to receive treatment. Some physicians speak of patients who are

prepared to undergo treatments and accept adverse effects for relatively little benefit; while other patients have goals of not having treatment at all. Some patients do not mind pursuing aggressive treatments, and are willing to reap the benefits of treatment in exchange for the side effects. Physicians also speak of some patients wanting aggressive treatment even if the physician does not recommend it:

One of the problems, I think is when patients shouldn't have treatment...Or the patients are too ill to have treatment because they have very poor lung function, they can't have a radical dose of radiation therapy administered with reasonable safety or they have some comorbidity that would result in an unacceptable risk of toxicity. It's difficult to explain that to this group of patients or to any patients that they shouldn't -- so our problem in terms of discussing the treatments, etc. are not persuading the patients this is a good thing, that most of the patients want to have something done to have the best chance of surviving. I find it tends to be for those patients who get referred for whom adjuvant therapy is not appropriate they feel as if they have been deprived of something that they ought to have had (MO5).

The importance of patient choice therefore is not dismissed, but instead is embraced and tightly woven into the treatment decision-making process. Physicians recognize the variation in patient preferences and address each patient's preference individually as they make treatment decisions with him/her. Every patient has a choice.

So for stage III, yes, they have an opportunity to say "get lost, not interested" and I encourage that because I never want to have my patients say to me at the end of treatment, "how could you do that to me?", or "I wish I'd never done this." I need them to be as informed as possible going in (MO1).

The personal and social circumstances of the patient also play a role in the treatment decision-making process. However, it is noteworthy that when asked how social and personal circumstances play a role in the treatment decision-making process, most physicians described negative examples, and placed an emphasis on recognizing that the social and personal context of a patient's life can place certain constraints on his/her ability to pursue one treatment and not another. One physician intimately describes how one patient's role as

a caregiver to her old mother limits her in embracing the opportunities being provided to her to manage her cancer. The patient's fear of "worrying her mother" if she loses her hair ultimately determines the fate of her treatment decision to have no treatment at all.

I had a young lady that I wanted to start on some therapy and she said, you know, she was by herself, she's young but she is fairly isolated and socially frail, physically not frail, no physical contraindications to chemo at all but she said to me, that she didn't want chemo, she was afraid of chemo, and we tried to do some teaching to try and support her and educate her a bit more about the different ranges of things; "I've got gentle chemo or target therapy, lots of things..." [I said], but she basically said that she wanted to go home. She is from Haiti and she needed to look after her sick mother and she couldn't be on chemotherapy because she couldn't have her hair fall out because she couldn't worry her mother. Now this is not uncommon... People have these [personal] concerns. This happens all the time and so you need to work with your patient to do the best you can for them in terms of their cancer care but recognize that they have lives and needs that sometimes transcend their cancer which is going to take their life, right? This happens and you just have to support them (MO1).

Another example of a patient's personal and social circumstances is the lack of a support network. Physicians explain that the presence or absence of support networks in a patient's life plays a large role in the treatment decision-making process. This issue leads to the importance of family involvement and their role in the treatment decision-making process. Physicians explain that the lack of support networks often contribute significantly to treatment decision-making and sometimes ultimately determine what treatments are implemented.

... You give these people huge doses of chemo and they are by themselves, if they die in their house, nobody is going to know... There are a lot of these old guys with lung cancer and they've got no social support whatsoever (MO1).

Most physicians speak of community support and services like the Cancer Society or private volunteers to help work around these types of barriers, but they also acknowledge that if one was to gain the patient's perspective, one would perhaps hear differently.

Physicians comment on how patient’s wishes are not to be violated. Physicians share that the patients may want therapy, they may not, they may not like the sound of the side effects, they may not mind them, and they may refuse a treatment because they do not want it. Consequently, the treatment decision-making process is a dynamic process which takes into consideration all the details of the patient and the clinical status coupled with the personal details. Physicians recognise that when one treatment is appropriate for one non-small cell lung cancer patient, it does not mean that it is appropriate for another. Physicians comment continuously on individualizing treatment and approaching each case on an individual basis. Physicians look at patients holistically, and not from one facet.

In summary, the unique patient then consists of three subsections that are important to the treatment decision-making process in (stage II, and stage IIIA and IIIB) non-small cell lung cancer: the clinical status of the patient, the demographic details, and finally, the personal and social circumstances and patient wishes.

B. THE UNIQUE PHYSICIAN

“Making a Judgement Call”- Physician Experience, Knowledge and Judgements

Each individual is an intricate mosaic of differing opinions, thoughts, experiences, and subjectivities. This statement adds weight to the category of the “unique physician.” If there is a “unique patient” that sits in front of the physician, there is also a “unique physician” that sits in front of the patient. Each physician comes with his/her own individual beliefs, attitudes, values, his/her own clinical expertise and experiences, and his/her own unique insight into each case.

Thus, physicians' judgements and perceptual qualities vary. Two physicians can look at the same PET scan and see identical things, or they can see two very different things; and if physicians do agree about what they see, they may still differ on their judgement of how they feel the condition should be treated. Thus, the treatment ultimately implemented and deemed appropriate stems from the physicians' judgement of what they may feel is the right thing to do in specific circumstances. What should be offered to the patient, or what treatment should finally be implemented cannot be answered without reference to their own individual understanding and judgement of what they see in front of them.

I certainly think that they [Guideline 7-1-2 (Dec 2006); Guideline 7-3 (Jan 2006)] are good guidelines but they don't replace good clinical judgment either (MO6).

The participants' length of clinical experience, the institution in which he/she practices, and the patients the physicians see all shape the physicians' judgements. To begin with, physicians understand that whether or not they believe they have an objective opinion, they cannot take it for granted that their experience and intentions are an important part of the treatment decision-making process with the patient sitting right in front of them. Many physicians explain that, at times, making treatment decisions with their non-small cell lung cancer patients extends beyond the clinical evidence; it has more to do with the results in their own hands. If, in their own judgement, the approach has given them good results in the past, they are more motivated about recommending it to a similar patient. In addition, they find that the more enthusiastic they are about a particular treatment, the more likely it is that a patient will accept the treatment. Therefore, their response to past outcomes develop a complex set of signals – often subconsciously – of how they should proceed with recommending particular treatments that provided optimal outcomes for patients in the past.

However, it is important to note that physicians are cautious about applying this experience, and keep in mind that not all patients are alike – especially stage III non-small cell lung cancer patients – and that patient stories from the past do not always relate to the present patient story in front of them. Together with their experience, however, coupled with the facts of the unique patient, physicians reveal that experience and results with previous patients always play a role in how they proceed with any specific patient.

...maybe I have been labeled here as a little more aggressive but I usually push for patients to get concurrent treatment for stage III if they are a candidate and they are willing to go through it. Some of my colleagues are a little more philosophical... It's experience, right. It's experience – a lot of it is if you've had a bad [experience] – I haven't had anyone who is on concurrent chemo-radiotherapy who ...has stopped treatment. I've pushed them all through treatment...but there are people who have had experiences where they've gone to the ICU or they've gone through this whole treatment and just managed to push the patient through...so when you see over and over again the patients fail and they have a tough time going through treatment, I'm sure that has a weight on how you approach the next patient... When you are a little younger, or earlier on in your practice, I don't know, you have this feeling that you are going to cure everyone (R01).

Other physicians speak about individual judgement at the level of staging the patient which, as is eventually revealed, is not always the initial step in the treatment decision-making process, but sometimes becomes a component in the treatment decision-making process when it is presented with a level of uncertainty. Again, the physicians illustrate this with stage IIIA and stage IIIB non-small cell lung cancer patients.

The stage III area is probably one of the more challenging and controversial areas in oncology to treat because there is such a wide variability of patients within it. And all that really indicates is that our staging system is fairly poor...I think we all stage the patients in our heads but there are many different varieties of stage IIIA and IIIB patients that get very different treatments and so there is a lot of clinical judgment that goes into making those decisions, some more evidence-based than others...It really is one of the most challenging areas to work in terms of making treatment decisions (R04).

Other physicians speak of experience in a way that will allow them to take more risks in offering treatments to their non-small cell lung cancer patients. Physicians speak about their confidence about other physicians and how differing experiences, opinions and judgements alter their decision on how a patient can be treated.

So I had a guy this spring that came in to me from another institution in the area where they didn't think the surgery could be done and had given him some chemotherapy and then sent him down to me for consideration of radiation. When I saw him...[it] look[ed] like a surgical case and so I talked to our surgeons here and they said, "yeah, he's resectable" and so they took him to the operating room. That kind of illustrates the fact that there are -- when people say they can and can't get surgery, it largely is an assessment by the treating surgeon about that patient at that institution with their experience...the short version is that there are surgeons out there who are much less aggressive and would bail out sooner. Our surgeons are very aggressive and are very good and so things that are unresectable elsewhere are resectable here (RO5).

This radiation oncologist (above) also reveals that sometimes individual judgement is also influenced by the institution to which the physician belongs. The institution to which a physician belongs also shapes his/her confidence and attitudes towards risks and treatment thresholds - consciously or subconsciously. This reveals the differing environments of the conversations among all the disciplinary groups, which are addressed in the next guide.

There is a wide variation in skill level and comfort level among physicians; and each physician speaks about his/her characteristics differently. Some surgeons are comfortable operating near the spine, others are not; some are willing to take the risk of giving radiation therapy and/or chemotherapy to their patient, others are not. Thus, judgements among physicians vary, and with being influenced by the individual patient factors, the physicians' judgements are also affected by their attitudes towards risk, and their own individual treatment threshold. One physician, who has been in practice less than 10 years, speaks about taking risks and giving the patients the "benefit of the doubt."

I think all of us are willing to give people the benefit of the doubt. If I get somebody who is 45 who comes in with a horrific cancer, I'm going to give him the best shot I can, even though there are some guidelines that might suggest that I shouldn't go after that aggressively because the chance of being cured is very low. I think it's very unlikely that the guideline is going to be directly preventing me from doing something or recommending me not to treat someone (RO5).

To illustrate the point further, a physician talks about a patient he/she is willing to offer chemo-radiation to because the patient seems like a healthy 80 year old who is playing golf five times a week, and is fit enough to receive chemo-radiation. However, he also recognizes that another physician might judge the same patient differently.

... I mean often times –for instance the medical oncologist I'm sending him to has been practicing for 30 years, so he's probably seen an 80 year old go through chemo and doesn't like it. He may say that the toxicity may be too great for [him/her] even though [he/she] is such a good 80 year old, and he'll [still] sort of say no. And that is fine, but my impression at the beginning is always, if I can, I'll try, because I always want to try to do the best; and if the patient is willing and understands the risk then that is fine (R02).

Thus, the treatment decision-making process is based on the individual physician's judgement and reasoning.

“Giving Patients Direction” – Physician Recommendations

The way physicians' experiences and judgements translate and present themselves to the patients during the treatment decision-making process is in the form of treatment options being presented; and then followed by that, what the physician thinks is the best way to manage the disease out of those treatment options; in other words, giving his/her treatment recommendations. Physicians place importance on giving treatment recommendations, and see it as a way of giving the patient “direction”.

You know once upon a time it was all shared decision making; but I think it's very important that the physician give a clear direction on what they think this patient's best decision would be based on what you can learn from the patient about their values and stuff (MO1).

Another physician shares a similar thought:

...so I think that the first and most important and the most appropriate thing is for the best medical decision to be made in terms of the recommendation of the best medical treatment for that cancer (MO2).

Therefore, there is a role in the treatment decision-making process for individualizing the judgment with respect to the management recommendations. These treatment recommendations come in many forms and depend on the individual physician who is making the recommendation.

Physicians' recommendations are based not only on their experience and personal judgement, but also from their own interpretation of the literature, their judgement of the benefit and risk ratio, alongside individualizing this ratio and making it meaningful to the individual patient in front of them. Thus, it is important to note that this factor ties in not only with the unique characteristics of the patient and individualizing treatment, but also with the important “clinical evidence” factor – discussed later – that informs the treatment decision-making process. It illustrates that factors that inform the treatment decision-making process are not mutually exclusive, but instead are tightly interwoven with one other.

...even for those patients who meet that criteria I talk to them generally about the fact that, even with an aggressive approach of chemotherapy with radiation, that the expected long term control is pretty small. You are going to tell them a number around 15% for IIIB, and so going through the treatment is not a walk in the park; and there probably is some benefit to them in terms of improvement in median survival of patients who go with an aggressive approach as opposed to a palliative approach, but that's in a population level and is not an individual thing. You try to communicate in that type of a fashion; and then I give them the final choice as to what they want to do. It depends. Patients are different. Some of them are a little more sophisticated and kind of weigh the benefits and the risks and make a decision based on that. I would say most of the patients at the end of the day defer to you as the physician and say “what would you do?” And again you try to drive them to give their own opinion (RO1).

Another physician explains:

The decision to treat the patient this way, or the other way is really based on what is the risk-benefit ratio for that person with that stage of cancer. So there is a lot of individualizing in your management recommendations for this patient population...They [the patients] care about the risk, which is the side effect. And they care about the benefit. The side effect is easy to answer, even though I'm a surgical oncologist. I can tell them what the common side effects are... and what number of patients in a 100 treated with those drugs would get a side effect, what it does to them, how they feel, stuff like that... Then you have to give them a little reminder – most of these folks don't know anything about statistics – statistics are fine for one person and if you haven't treated the patient with whatever, you don't know where they are in that spectrum, so you have to remind the patient that these are the common side effects, say 50% of patients will get nausea or something for a few days, it doesn't mean that you are in the 50%, - you are in the other 50%, or whatever... (SO1).

Style of Decision-Making: The Shared- or Informed-Treatment Decision

Consequently, it is noted that the physician's recommendation is rooted in his/her knowledge of the case, his/her judgement of the benefit-risk ratio for each individual patient, and his/her own judgement, experience and understanding, instead of just a neutral recitation of treatment options. What is illuminated is that how the patient reacts to these recommendations and the degree to which the patient desires to participate in the decision-making process forms the basis of whether a treatment is a shared treatment decision or an informed treatment decision. The treatment decision-making process with patients may reflect a shared treatment decision-making style, an informed treatment decision-making style, or elements from both styles.

One physician describes a shared decision between the patient and herself:

I usually go through the data, I tell them all the different options, and I say to them "this is what I recommend, what do you think" and then we will come to some kind of arrangements together. So I do believe in shared decision making ... (MO1)

However, another physician describes that making a shared decision throughout the treatment decision-making process is not always that straightforward. There can be a range of patient responses. Some patients have done their own literature searches and are fixed about what they should receive. In cases such as these, the physicians explain that they cater to how the patient has reached the decision. They ask questions such as: Have you come for a treatment recommendation? Or have you come to have your treatment facilitated? Do you want me to facilitate your treatment or do you want me to recommend what I think is best for you with your input? Of course, the range of patient responses also includes the physicians making the final treatment decision by saying things like: “Just do whatever you think is right, doc.” (MO5) Nevertheless, physicians explain a push-back to such responses, and encourage the patient to share the decision with them. Of course, it is important to note here that the following quote (below) not only encourages non-small cell lung cancer patients to make shared decisions, but also illuminates how physicians are being trained in Ontario – to relieve suffering, but also, to enhance patient autonomy:

I try to drive them to make the decision rather than me telling them what to do and sometimes patients find that a little bit difficult because they say that ‘I’m coming to you and you are supposed to tell me what I’m supposed to do.’ But I have been trained in the last 10 years, that it is a joint decision making process. So I always tell them what my recommendation is but they don’t necessarily have to go with that (R02).

Another physician describes more of an informed decision made during the treatment decision-making process:

...but the final decision is theirs [the patients] based on having the appropriate knowledge and facts to make a decision. Now sometimes the patients won’t or can’t make a decision, and the family won’t or can’t, and then you basically tell them the same thing, only this is really what you are going to do best with (SO1)

Although the physicians share that the final treatment decision is ultimately the patients, they are not hesitant in telling the patient that the treatment option they may be choosing is unbeneficial, if it in fact is.

If I think that somebody is making a decision that will significantly limit their life expectancy or significantly worsen their outcome, I will tell them (MO1).

Physicians feel that their roles as health care providers are not to make the final decision, but instead, to present patients with treatment options during the treatment decision-making process, explain to patients why they are presenting those options, and help patients make an optimal choice. If the recommendations are not necessarily consistent with the patient's wishes, they offer a second opinion and alternative treatments. When patients decide that they do not want to agree to the recommendations or have any treatment – which physicians often explain can happen – then physicians try to understand why, and make sure that the patient understands everything that is shared by the physician in the treatment-decision making process; including making the patient understand that delaying treatment in some cases can potentially decrease the chances of helping them and hinder the chances of benefit. If the patient decides against treatment or to have an alternative treatment than what is recommended, the physician accepts that the patient has his/her own opinion, rationale and wishes and wants to make his/her own decisions. One physician who is in medical practice for more than ten years shares the following comment:

I'm long past the point in my career where I get really upset or excitable about patients not deciding to do what we think is the right thing to do. I have learned over the years that you can lead them to water, you can't make them drink (MO5).

Most physicians predominately describe the treatment decision-making process as one to be shared, and also illuminate one of the important elements of the shared treatment

decision-making process — checking for understanding (Charles et al., 1997). Making sure that the patient understands the complexity of the disease and the treatment options and their risks and benefits is also seen as an important part of the treatment decision-making process. Again, each physician has his/her own individual style in establishing understanding. Some physicians use verbal communication, some use pamphlets, and others draw.

...I say [to the patient], “this is the radiation, this is where your tumour is, this is where your nodes are, this is what we are treating and that is why you are going to get these side effects.” And to actually pictorialize it gives them a bit more of an understanding and appreciation of what they are going through because they don’t understand. They [the patient] will [ask] “why is my esophagus going to hurt if you’re treating my lung?” And then you’ll say, “well look, this big yellow line that is covering all this stuff is 95% of the radiation dose and your esophagus is sitting right there.” And then they will be like, “oh that makes sense” (RO2).

Finally, all this information, physician judgments, their recommendations based on these judgments, the recommendations based on the clinical evidence, and physicians’ interpretation of the risks and benefits for the individual patient in front them can be incorporated into the treatment decision-making process - keeping in mind that no decision is irrevocable.

In summary then, the unique physician includes three subsections that are important to the treatment decision making process in (stage II, and stage IIIA and IIIB) non-small cell lung cancer: the physician’s experience, knowledge and judgments, the physician’s recommendations based on these judgments, and finally, the physician’s style of treatment decision-making – informed and/or shared.

C. THE FAMILY

Trusted family members are a critical source of support during the treatment decision-making process. Because non-small cell lung cancer is a complex medical condition and requires treatment with side effects that can have an impact on a patient's day-to-day living and functioning, physicians encourage patients not to come by themselves when making treatment decisions. Consequently, family and friends also affect the treatment decision-making process, where family members are perceived to have four unique roles.

Family as Support Network

Physicians explain the importance of non-small cell lung cancer patients' family members and their impact on the treatment decision-making process. Physicians state that some patients come with a strong support network and other patients do not. A family member may strengthen and support the individual directly by responding to their needs, and empower them to get through treatment.

Consequently, because the patient has someone to help with everyday tasks, to help with getting back and forth from the hospital, and to assist them with daily activities they otherwise couldn't perform themselves, physicians explain that getting the patient through treatment is not as difficult as getting a patient who does not have a support network through treatment. For example, one physician explains the risk of chemotherapy for a patient who does not have a support network versus one that does:

A lot of care of patients falls on family so having a supportive family member, a spouse or a family member who is there for you is very important. So people who live alone we worry about them more. For chemotherapy, living alone is a factor; an elderly patient who lives alone if they get sick with fever

and sepsis, they could die. So the risk of chemotherapy in a patient who is either not sophisticated or educated to recognize it, lives alone and is elderly is high. So those issues are a big factor (RO6).

Another physician speaks about getting a patient through radiation treatment and its side effects without a support network:

Radiation, in particular, you have problems swallowing –so there is significant pain so they have to be able to maintain their calories so they don't lose a lot of weight. If they start losing weight they are in a lot of trouble. They are not going to heal properly, they are going to get really sick they are going to get dehydrated and then they are going to end up in the hospital with electrolyte imbalances. It's a huge problem so to actually eat, you have to think of a meal, get yourself to the grocery store, buy the food, bring it back, cook it and then eat it. If you are exhausted and sick, you can't do it...So I actually say to people, like when you are not feeling well enough, who is going to do this stuff? ...If they bring a family member with them, great, the family member will say, "I will" ...Yeah, but if they don't and if they come by themselves, it's really hard. It's really hard to see how you are going to get somebody through treatment (RO3).

Yet another physician speaks about an anaemic patient who also lives by himself and the pitfalls of recommending chemotherapy to him:

... I have a guy who lives by himself, he doesn't go outside, and we want to give him the best treatment. We dragged him in for chemo but he'd get tired, he'd be anemic, he'd have to go to the local Emergency, he'd have to call 911. It's very hard for these patients to sometimes get here and negotiate that second piece. I try to never let that stop me from giving therapy but sometimes I'm sure that it shortens therapy. Right? If your patient just can't get here, it's just too hard for them to manage it [without support]. It will change a treatment whether you stop giving it, or whether you drop the dose, or whatever else..." (MO1)

The lack of a support network does change the course of treatment and has an impact on how treatment decisions are made. One physician explains his train of thought when recommending a particular treatment to a patient with support versus someone without it.

...you are looking at a tumour that in another patient you wouldn't think twice -- you would go for curative treatment and you have a patient that you are a bit worried how they are going to manage with toxicity; they don't have a lot of support, they are not pushing for it and it is really hard because the easy thing to do is say, "oh okay, never mind. Let's treat you palliatively. Let's treat you less aggressively" but I don't know if that is [the] best thing for that person because if you [had] the same

tumour for somebody else [with a support network] one would say, “you have a chance for a cure let’s go for a cure” (RO6).

Family Present in Medical Consultation as “Support”

Most patients when they come to see me with suspected lung cancer are here with at least one family member or more. If they come by themselves, I always ask what family or friends [are] around because this isn’t a journey that patients necessarily should be taking alone (SO4).

The engagement of the family member in the treatment decision-making process and his/her presence during the consultation provides the patient with care and both tangible and psychological support. The family member can also assist the patient in understanding the treatment options being presented, and record detail information for their own optimal understanding in case the information is required later. Consequently, the family member’s role as a “support” during the consultation has many facets.

It is important to note that physicians explain that family members do not always sway decisions, but are present during the consultation to improve their own understanding. However, at other times, family members can adopt dual roles. Physicians illustrate that sometimes family members encourage a patient to have treatment when the patient does not want it. At other times, family members and patients agree on what they think the patient should have. In other cases the patient may want a particular treatment, but the family member is interested in exploring other options for the patient. Consequently family members influence patients in both directions.

Sometimes the family members will encourage the patient to go for more aggressive treatment because they are a good support, but sometimes the family members will sort of discourage them as well (RO2).

In other cases, family members serve as a support during the consultation for writing information down. Physicians say that family members sometimes hear more than the patient; sometimes patients hear the word “cancer” and forgot about everything else, therefore the family member serves as a recorder and records the information the patient misses.

I always ask them [the patient] at the end, I say, “do you understand that or any specific questions that you may have about it? Does it make sense?” ...because if it doesn’t make sense then I have to re-explain it...But most of the time, they say “yeah” and then, if they have a relative there, sometimes the relative is writing stuff down so there is some sort of documentation of what I have said (RO2).

At other times, physicians say, the family member serves as a larger window onto the patient’s life and help the physicians understand the patient’s daily functioning and what the patient’s lifestyle is like. Family members serving as windows onto the patient’s life, have an impact on the treatment decision-making process by helping the physician make recommendations that are more suitable for the patient.

It is not really discouraging but what is it? You feel because you only have a sort of a snap shot. You see the patient for that one hour and you make a decision based on that. But they [the family members] have seen them for months now. I had a patient that I was -- maybe wrongly offered them combined chemo-radiation for a stage III lung cancer and their family was [saying], “Well I don’t know whether he can tolerate -- I’ve seen him in the last few months and I think that he is just slowly going downhill and even though he looks okay now, I’m just worried that in a couple of months he is going to be worse and that this is just going to start to take its toll on him. So I’m not necessarily sure whether he can tolerate that.” And sometimes, I had a patient like that but I still offered it to him ... but he was slowly going down the tubes. And so...this is why I say [I] kind of wrongly maybe offered him an aggressive treatment. He was a bit elderly too...And so, he didn’t actually make it through even his radiation...and you know I think that at the end of the day, I may be sort of over sided with what the family member was saying (RO2).

Family as Medical Interpreters

Physicians say that the use of medical interpreters for patients who do not speak English helps patients better understand both their disease and the treatment options being presented during the treatment decision-making process. Family members of the patients serve as interpreters and translators.

Sometimes we have certain families where they have the elder person in the family not speak English very well; where it's almost like a lot of the decision making is done through one or two individuals who... speak English better and things like that. That's very different than other families where there are multiple medical people in the family and it's one of their siblings or someone else...so [that] can be challenging (RO1).

Physicians do not share any thoughts on information being “lost in translation.” However, physicians do share that at times, family members filter the information they want their family member – the patient – to hear and know about treatment options and his/her disease. Physicians express examples of people not wanting to tell their family members – the patients – that they have cancer, which ultimately influences the treatment decision-making process. One physician points out that specific cultural groups are firmly against sharing the word “cancer” with their family member – the patient:

I mean there are some cultures that don't want to hear the word cancer...Italians, Portuguese; Italians particularly the family [will say] “don't tell my mother that she's got cancer”, that sort of stuff... But that's a cultural thing and there are ways around that. You can use another term for cancer but in reality...the patient knows what's going on. They get all these tests done; they know basically what is going on (SO1).

Physicians grapple with not knowing how much information the patient actually knows about treatment options and the complexity of his/her disease when the family member is serving as a translator. To resolve this anxiety, physicians explain, they sometimes bring in translators to make sure the patient understand the information being exchanged in

the treatment decision-making process. However, patients and their family members do not always look upon external translators favourably.

Once, I wasn't convinced that the family member was telling anything to his mom, so I got a translator...Yeah, he was pretty mad...He started yelling and screaming and saying, "you know, I'm taking my mom out of here, you are insulting us, you don't think I am providing good care?" and I said, "if you take her out you are not providing good care" (RO3).

It is important to note that physicians find professional translators to help in the treatment decision-making process for patients who cannot speak English and do not have family members to translate for them.

A number of them have children, often children who speak the language so they come with them, but we have a lot of patients that don't have children or the children are working. They can't always take a day off to come with them so we spend a lot of money as an institution on translators (RO6).

Family as Cancer Survivor or Cancer Victim

Physicians speak about patient fears playing a role in the treatment decision-making process and having an impact on how treatments are administered and ultimately chosen. Some of these fears are conditioned by a loved one who has gone through cancer. Physicians explain that attitudes and perceptions of recommended treatments are potentially influenced by a family member who has gone through a similar treatment and suffered adverse effects.

...a large number of patients declined chemotherapy or a lot of them didn't get it because the patients actually didn't want it. So some of these factors are [that] they have had a loved one that they've recently lost to cancer or they have had some other bad chemotherapy experience (MO1).

However, physicians clear misconceptions and also individualize treatment, telling the patient that what was suffered by the loved one is not necessarily going to happen to them.

A lot of it you will find if you go to a clinic and you talk to somebody who has lived with it; their husband had it or their close relative had it, or a close friend had it, [they all have had] a similar disease or went through a similar type of treatment process that they will sort of reflect upon; and use their experience to guide their own decision making and they will say basically, “my uncle had stage III lung cancer and went through chemo-radiation and he didn’t live more than 8 months so what is the point in me going through it?” So they will make decisions based on that. You will give them evidence but they will say, more often than not, “that’s not going to happen. I’m not going to be the 20% survivor at 5 years; I’m going to be the 80% who died in the first 2 years -- whatever it is.” But they will sort of reflect upon that and make a decision based on personal experience. That happens a lot too (RO1).

Similarly, physicians explain that some patients are extremely motivated to participate in the treatment decision-making process and receive treatment. A cancer survivor in the patient’s life is one of the contributing factors to this attitude. Cancer survivors in patients’ lives help serve as a source of strength and motivation to get better. Physicians explain that the attitudes of patients and their core beliefs help direct and impact the management of their disease.

In summary then, the family consists of four subsections that are important to treatment decision-making in (stage II, and stage IIIA and stage IIIB) non-small cell lung cancer: family as support network, family present in medical consultation as support, family as medical interpreters, and finally, family as cancer survivor or cancer victim.

D. THE CLINICAL TEAM

“Informal Discussions” – Internal Smaller Meetings with Each Other Within the Institution

Physicians describe a multidisciplinary approach to the treatment of patients with stage II, stage IIIA and/or stage IIIB non-small cell lung cancer. Physicians illuminate a collaborative multidisciplinary care framework for non-small cell lung cancer patients who

are complicated cases or patients that are outside the “norm” (i.e., stage IIIB non-small cell lung cancer patients).

They [stage III] are almost invariably presented at the tumour board formally, or if we don't have time, we do our own multidisciplinary discussion before we start treatment and that is only in extreme cases where they can't be presented at the tumour board because you really need multiple inputs. You definitely need radiation and medical oncology input. Surgical input is always very helpful (MO1).

Physicians express that collaborating and discussing complicated cases with their colleagues allows everyone to work together and contribute their expertise so that an optimal treatment decision can be selected for the non-small cell lung cancer patient. The involvement of other physicians illustrate the non-linearity of treatment decision-making and how often treatment decision-making can bounce from patient and physician, to physician and physician, back to the patient and physician (or vice versa). For example, one physician speaks of a patient who has not been seen by a thoracic surgeon before he comes to see him. In this case, he not only refers the patient back to the surgeon, but also collectively meets with the surgeon and a radiation oncologist to make a joint decision on what should be the most optimal care of management for this patient. Decisions are made among all three specialists on whether or not this patient will benefit from chemo-radiation treatment only, or whether surgery is going to be entertained after chemo-radiation. Another physician speaks intimately about the importance of “togetherness” and a discussion of appropriate treatment options for a particular patient:

In [specific city mentioned] we have a multidisciplinary sort of approach to patients with cancer. Generally all patients with lung cancer are seen by medical radiation oncology and thoracic surgery. If it is a stage, so again, if the patient comes to the cancer assessment clinic and it is felt they have inoperable but locally advanced disease, that patient will be referred by a thoracic surgery to both medical and radiation oncology. Together we will come up with a treatment plan as to whether or not we think that such a patient is suitable for combined modality treatment in the hopes of cure.

Part of that decision making will be by the radiation oncologist to decide whether or not the disease that they have can be radiated to a curative dose. If that is possible, then those patients would be assessed by a medical oncologist to determine whether or not they should have concurrent chemotherapy along with that, since that has been shown to be superior to radiotherapy alone. If a patient with IIIA or IIIB is not felt to be well enough to tolerate radical radiotherapy then a treatment decision will be made between the medical and radiation oncologist as to how best to palliate that patient (MO2).

Consequently, the collaborative effort and the informal discussions between physicians about their non-small cell lung cancer patients plays a role in the treatment decision-making process where a kind of joint decision is made among specialists.

“Formal Discussions” – Tumour Boards/Multidisciplinary Cancer Conferences (MCC)

Treatment decisions are often collaborative and not just an individual decision.

Advanced and complicated cases are brought to tumor boards.

Most of the time stage II is straightforward so many of those patients will not get discussed at MCC although you could argue that everybody should be discussed at MCC... The real challenge is stage III patients because as you said yourself, there is IIIA and IIIB, there is potentially resectable and not resectable and there is a big variation in what is appropriate... (RO6).

The treatment decision-making process with non-small cell lung cancer patients (as explained above) is not an isolated event between the physician and patient, but instead is a dynamic process, moving from the medical consulting room – from patient and physician – to an assembled crowd of specialists. The tumor board is a robust meeting that is attended by all the different members of the multidisciplinary lung cancer team. Here a team of different specialities – medical oncologists, radiation oncologists, thoracic surgeons, respirologists, pathologists, pulmonologists - discuss different patient cases and broadcast their judgement and technique in managing their patient’s disease. Tumour boards are a

conference where short vignettes listing medical symptoms, and in some cases, personal and social circumstances of patients are presented. It is a place for honest and valuable discussion in the hope of improving patient outcomes. Physicians discuss patients that do not fit the cookie-cutter prescription (RO2).

Physicians offer detail descriptions of why certain non-small cell lung cancer cases are brought to tumour boards, such as: if the patient does not wish to have the recommended treatment, if there are patient factors such as advanced age, radical treatment, concerns about staging and a definition of stage based on imaging (i.e., PET or CT scans) that are not straightforward, concerns about pathology, combinations of different modalities, or any clinical conundrums that require discussion. It is very collegial and there is substantial collaboration between all disciplines. Personal circumstances of the patient are discussed if they are of a nature that will dictate consideration of another form of treatment (S01).

...it's so good to have a tumour board because even though there is evidence for things, and there are guidelines for things, you will always have that patient that is falling into a bit of a grey zone and you need discussion and sort of issues around it. You know because they talk about comorbidities in these trials but they don't talk about how severe the heart disease, how severe the diabetes, at least I don't remember them, because you remember the take home message, the sort of basic stuff but you don't remember a lot of the nitty gritty. So often times you will see a patient who has a great performance status, no weight loss and then has 10 comorbidities, so are they a suitable candidate? And so, that is something that you bring up in rounds (RO2).

Physicians also explain that not everyone agrees with everyone else at the tumour boards, but generally a consensus for the patient is reached. The consensus is then taken back to the patient and discussed. Some physicians explain that patients prefer the input of several opinions in their case.

Some physicians describe the tumour board as a place where work is scrutinized and judged if it is outdated, overenthusiastic, or unjustified by medical evidence. However,

invariably physicians respond by saying: “I don’t have a problem with holding my work up for scrutiny” (MO1). Nevertheless, it is not “holding your work up for scrutiny” that is the big theme in the discussion of tumour boards; instead, it is the much-needed, valuable discussion that is generated between the major disciplinary groups for complicated non-small cell lung cancer cases at these multidisciplinary cancer conferences. Almost all physicians describe the tumour boards as playing a large role in the treatment decision-making process, but the degree to which this guide is involved in the overall treatment decision-making process depends on how “complicated” the individual patient case is and whether the patient falls in the “grey zone.” Most physicians use stage III non-small cell lung cancer to illustrate this point and agree that because of the heterogeneity and complication of stage III non-small cell lung cancer patients, most of them are brought to tumours boards to discuss.

Stage III is incredibly complicated...very few stage III patients are the same...and they almost always require, in fact, they always require multidisciplinary discussion...So for the most part, HIB is considered not resectable but there is no question that there are quite locally advanced tumours. I’m going to use some cancer terms here: T4 N0 or T4 or N1, for example, that you might consider combined modality therapy too and then resection. So we try and get that sorted out at a tumor board upfront. We try and make these decisions upfront. For people who are not resectable we try and do concurrent chemo rounds (MO1).

One physician also explains that tumour boards are a place where younger physicians can learn because there are much more experienced physicians present at these tumour boards who will give their insights on what they think will be reasonable approaches to how these patients should be treated (R02).

Again, physicians clearly depict the treatment decision-making process as a non-linear, non-isolated event. The treatment decision-making process is dynamic, moving from between patient and physician, to between different physicians, and then maybe back “to the

consulting room” between the patient and physician for further deliberation. Therefore, discussions with “the team” are very important in the treatment decision-making process. The knowledge and experience of different disciplinary groups woven together in a detailed discussion of a patient is used toward the attainment of the ultimate goal - the most optimal care for a patient.

In summary then, the clinical team includes two subgroups that are important to treatment decision-making in (stage II, and stage IIIA and stage IIIB) non-small cell lung cancer: “informal discussions” which are internal meetings with each other within the institution, and, “formal discussions” which are tumour boards and multidisciplinary cancer conferences (MCC).

E. THE CLINICAL EVIDENCE

The Physicians’ (and the Institution They are Attached To) Individual Interpretation of Clinical Evidence and Its Use

The treatment decision-making process consists of physicians’ individual judgements. A part of these judgements is their interpretation and use of the clinical evidence, which plays a significant role in the treatment decision-making process. Throughout the treatment of non-small cell lung cancer patients, physicians use applicable resources in order to make evidence-based decisions with their patients. Each physician possesses his or her own interpretation of most up-to-date medical literature, and has unique insights into the particulars of his/her individual patient cases. For example, one physician discusses not only her management approach to her stage IIIA non-small cell lung cancer patient in relation to

the evidence pertaining to adjuvant chemotherapy, but also individualizing treatment for her unique patient:

Age is interesting. So the evidence for adjuvant chemotherapy helping people probably goes up until about 75, there is good data. Beyond 75 the data gets a bit sketchy. Certainly into people in their 80s it gets very sketchy. So then it becomes very individualized. If I think somebody is very fit and definitely will manage therapy and I think that they are probably likely to live 5 or 10 years without this diagnosis of lung cancer, then I try to always recommend it. Sometimes we modify it... (MO1).

Consequently, sometimes when evidence is not as definitive, each individual may interpret the evidence differently; this is particularly true for evidence regarding stage III patients in contrast to stage II patients. There is a lot of variability regarding stage III patients and the quality and quantity of evidence to inform different presentations is not optimal. Therefore, when seeking information on how to best treat their non-small cell lung cancer patients, physicians share that they feel most comfortable searching, appraising, and synthesizing the literature themselves. Although this is a laborious method of answering evidence-based questions, physicians feel that examining the literature themselves adds more value to certain kinds of treatment decisions they make with their patients. The synthesis of the literature allows them to judge the interpretation and consider alternative interpretations. Consequently, it is important to note that physicians conducting their own interpretation of the empirical literature, and drawing their own conclusions from the results of several studies, causes variations in physician thought about the management of non-small cell lung cancer. For example, a physician from an urban setting emphasises that an individual who looks at the clinical evidence from a different angle and with a different perspective, yields different arguments.

Standard of care for stage III non-small cell lung cancer is concurrent chemo-radiation... There is potential role for surgery so there have been randomized studies that have looked at chemo-radiation

alone versus chemo-radiation plus surgery and very interesting result of a large randomized study that has been interpreted differently and counts to this issue of values of the health care team (RO6).

Other physicians point to the distinct differences between the ways “they” – alluding to the institution in which they practice – treat patients, compared to the way others treat. A common clinical interpretation can become a group norm within a practice setting. For example, a physician shares the differences in the management of stage III non-small cell lung cancer disease compared to a colleague who practices elsewhere:

In people with stage III disease, where we are trying to cure them, why would we short change them and only give them two cycles of therapy? Now this is different from what you will see [elsewhere], where they only give two cycles. The evidence currently doesn't contradict either but doesn't support either. It's a bit confusing... So [elsewhere] uses that as their idea for getting rid of all the other treatment but that is not actually what we use. We use the original SWOG regimen. So that is our rationale behind concurrent chemo-radiation... (MO1).

Another physician explains his institutional policy of the tri-modality approach in the treatment of patients with stage IIIA non-small cell lung cancer:

But our institutional policy here is for all patients with resected IIIA disease who are fit to come for a discussion about radiotherapy, although it is a bit variable from staff to staff here, many of them do get post-op radiation and that generally follows chemotherapy since the chemotherapy has a more proven benefit... So for patients with non-resected disease, again, it's controversial whether surgery plays any role in stage IIIA disease that has been diagnosed upfront but our institutional policy is for patients with non-bulky single station N2 nodal disease to be considered for pre-op chemo-radiotherapy followed by surgical resection (R04).

Yet another physician points out the use of surgery of stage III patients, but also the use of consolidative therapy:

...Stage III is a bit of a funny one...I mean the standard of care for stage III is at least the induction chemorads part is relatively the same...What differs is some places are more aggressive about having surgery as part of the treatment... some institutions believe in giving consolidative chemotherapy after chemo-radiation, some do not... I mean, there is no good data. That is the problem. There is not a lot of good data in terms of consolidated therapy and whether it should or shouldn't be done and what should be given and what shouldn't be given so we all then kind of use our experience and understanding of the disease itself to make decisions (MO4).

It is noteworthy that the use of the word “they” also gives physicians a sense of belonging to the institution where they practice, revealing that each physician’s thoughts are not always based on an individualistic perspective but rather on an institutional perspective or a normative perspective among the practicing team.

...in our centre we are pretty protocol-based... We do have, I think, a fair bit of uniformity in our practice; but I've been in centres where people don't treat IIB's aggressively at all with chemo-radiotherapy, they say it's not worthwhile. I know some people who will say that the tri-modality [approach], for example, is not worthwhile (RO1).

How the physicians use the conclusions drawn from these studies are also important and a large part of the treatment decision-making process. The physicians recognize that the likelihood of a particular benefit of the treatment or its side effect exist in a cloud of uncertainty. The way the physician recognizes this is by taking it a step further by asking the question: Does the patient fit into the population described within that study? Does the patient in front of him/her share similar characteristics with the population described? How much does the patient differ? To what extent is the patient similar? These questions are woven into the treatment decision-making process, where the physicians “cautiously” applies population-based probabilities of treatment side effects and benefits to the patients in front of them, telling the patients how “similar” or “different” they are from the population within the study.

Therefore, physicians carefully extract information from clinical studies that are relevant to the patient in front of them. Treatment decision-making involves viable treatment options, with individualized estimates of benefits and side effects known for each patient, and the goals of ensuring that patients receive the most optimum care that is best *for them*. This is a part of individualizing treatment. Most physicians illuminate the questions: Does

this patient fit the eligibility criteria for this particular trial? How similar is the patient in front of them to the subset of people that are in the trial? This helps set the foundation in explaining to the patient their benefits and side effects to particular treatments, and explaining the uncertainty that lies within both because they do not entirely match the population in the study.

You know, obviously, you always have to take a look at the study and take a look at the patient in front of you and ask yourself, “do the results of these studies apply to this individual patient?” Would this patient, for example, have been eligible to have been enrolled to the clinical trial that shows that this was beneficial? Right? For example, you have a patient who is 83 who had complete resection of a stage II non-small cell lung cancer. Well there weren’t a lot of octogenarians enrolled in the adjuvant chemotherapy trials. Right? Then you have to sort of say, to yourself, “hmmm ...how well does the evidence here apply to this particular 83 year old in front of me?” I have those discussions with patients when I talk to them about the pros and cons of treatment. I say, “well, you know, you are 83, you have nothing else threatening your life right now and the biggest threat to your life in the next little bit is this lung cancer coming back, and this is what we generally recommend to these people. That being said, there weren’t a lot of 80 year olds and I don’t know if 80 year olds benefit from this and now we do know that patients who are very elderly are at higher risk of toxicities to treatment,” and so on, and so on. I also use that myself to help me decide if the 82 or 83 year old in front of me is actually well enough to tolerate these treatments and what their competing risks of mortality are. The way I put it to patients is that the benefit from chemotherapy in the post-operative setting, for example, is to improve your odds of being cured 5 years from now. But the risk, the risk of chemotherapy is today. So if I have a patient who I don’t think is actually going to be alive 5 years from now, not from cancer but from other medical problems...Then, that patient may not live to see the benefit of the chemotherapy and certainly will be exposed to the risk of it. So, in terms of part of your job is to see whether or not the data is actually extrapolatable to the person right in front of you (MO2).

Thus, the way in which a physician interprets the literature and the conclusions he/she comes to – or the institution comes to – will eventually determine what treatment he/she presents as a treatment option or recommends during the treatment decision-making process, ultimately impacting the course of the treatment decision.

Knowledge Translation Tools – The Role of Cancer Care Ontario Guidelines in Non-Small Cell Lung Cancer Management

You have to take into account the social issues sometimes, the wishes of the patient, the lifestyle of the patient – I mean some 80 year olds play tennis every day and some sit in front of the TV and do absolutely nothing. Well they are totally different. [They may have the] same stage disease, [but] they may be radically [different] in how they may be treated even though they seem to be the same age, with the same stage of disease. So in a sense, I would say that guidelines are a reminder to the doc that the doc has to consider them but still has to make a recommendation based on his/her best judgment for that particular patient (SO1).

Physicians reveal that using the best and most recent evidence is a fundamental aspect of the treatment decision-making process. However, the essential skill needed to provide an evidence-based solution to a clinical issue is to be able to critically appraise the evidence and its implications in the context of the patient's specific situation and beliefs (DiCenso, 2003). Along with their own synthesis of the clinical evidence, physicians admit that clinical guidelines (Guideline 7-1-2 [Dec 2006]; Guideline 7-3 [Jan 2006]) relevant to stage II and stage IIIA resected non-small cell lung cancer, and stage IIIA and IIIB non-resected non-small cell lung cancer) play a role in the treatment decision-making process for their non-small cell lung cancer patients.

The clinical guidelines are accessed through rounds, grand rounds, and tumour boards – where they are largely enforced, educational rounds, but often sought independently. Guidelines are considered to be part of an educational process for physicians. All the physicians, including the health care administrators – who were interviewed to gain additional thoughts on the guidelines – are well aware of the guidelines. There is a general consensus among the physicians that guidelines are based on fairly good studies, are of good quality, and are easy to follow. Physicians say that guidelines serve as good educational tools and are based on strong evidence, and many are involved in the physicians' development

process. Physicians also say that guidelines are useful tools for those who do not see the clinical problem that often. The guidelines are also classified as just regular “bread and butter” cases and are based on historical models.

Did the guidelines actually change how I practice? The guideline is how I practiced before the guideline was made... I didn't start adjuvant chemo for lung cancer until [the guideline came out]... And, you know, [as] a group here, we have been doing this approach since 1987/1988. I don't even think the guidelines were even thought of until the 1990s sometime (MO4).

Other physicians speak about the quality of the guidelines, but also say that there can be more than one interpretation of the literature (as explained above):

I mean the evidence for the addition of chemotherapy and specifically cisplatin-based doublets to surgery is quite good. There are a number of randomized trials that have supported that and the second guideline [guideline 7-3] is, I would say, a bit definitive only because it doesn't allow for the possibility of chemo-radiation plus surgery or doesn't seem to. That being said, I don't think it is designed to address that. It's really designed to address the role of what chemotherapy is delivered with the radiation and I think that the guideline again, it supports or illustrates the data that is available showing that cisplatin-based doublets in conjunction with radiation do a good job of maximizing the effect of radiation. There are also other ways you can look at that literature but I think that the guideline is quite good (RO5).

One physician points out that the physicians who are trained or who work in Ontario know and follow the guidelines by default because they are considered standard and form the basis of most recommendations in the treatment decision-making process for patients with stage II or stage IIIA and IIIB non-small cell lung cancer (if they are relevant to the individual patient). If the patients “fit” into the guidelines, the physicians try to treat them according to the guidelines (RO3). Physicians explain that guidelines generally play a role in the treatment decision-making process because there are not that many options for lung cancer (R01), but keeping this in mind, the guidelines also do not necessarily dictate what they physicians do with each “unique” patient in front of them. Ultimately, physicians do not merely use the guidelines to guide their practice; they also use their own interpretation of the

evidence, and their own expertise and experience (RO2). The guidelines are seen as generalizable, but there are caveats to all of them.

I guess the guideline maybe does not address to the same extent T4 high T low N disease, -- so T4 N0 or N1, I don't think the guidelines address that...And I think a centre like ours gets a lot of that and we have surgical expertise to manage that. So the guidelines don't really address that. Everything else though they're pretty good and we do try to practice the guidelines. Where things go sideways is if the patient has comorbidity and can't have the chemo or if the patient doesn't want it or if, and sometimes this happens, the patient can't get enough support to have the treatment (MO1).

Consequently, the guidelines are not able to apply to every type of patient presented.

The generalizability of the guideline recommendations to real world settings has an impact on their perceived utility. The physicians think the data for stage II and stage IIIA non-resected patients is fairly straightforward. However, the data for stage IIIA and IIIB non-resected patients is not. The treatment of stage IIIA patients is considered to be highly controversial.

I think that the studies are as good as they can be. I think that II and IIIA the quality of data are better. I think the IIIA/IIIB is a little more challenging but I completely agree with the conclusions (MO1).

... It's not in the evidence-based guidelines, at least I don't think it is ... there is an opportunity for locally advanced lung cancer patients to have tri-modality treatment which is chemo-radiotherapy and surgery. So sometimes, I mean it's in very few cases that this will be the case, but that is basically a surgical decision. So if a surgeon tells us that they have locally advanced disease and they think they can operate on it, they'd just either (a) just operate on it or (b) ask us to give chemo-radiation prior to their resection (RO2).

Many physicians say that the guidelines have their place in the treatment decision-making process. However, the patient population typically seen may not reflect the patients seen in the studies that underpin guideline recommendations.

Guidelines are meant to be guidelines and are not meant to tell you, "this is how you should practice and if you're not doing it that way, you are doing it wrong..." Well the guidelines don't cover every aspect of every patient's course... The guidelines are specific guidelines for specific situations but there

are no guidelines for every situation... There is an art to medicine. Guidelines are a cookbook and patients don't come as a cookbook (MO4).

Guidelines are seen as the best recommendation for the average patient or the subtypes of patients for which there is data; the guidelines do not speak about the complexity of the range of “real life” patients. The clinical trials from which these clinical guidelines are derived are felt to be only applicable to a small percentage of patients the physicians see. Often the studies that underpin the guidelines include the healthier patients, younger patients, and idealized populations, rather than the average population of patients that exist.

...one has to recognize, and it's not just the guideline and the data, that the studies that the guidelines pull from have highly selected patients who are the fit of the fit and they are -- a lot of those patients we don't see in real life cancer care. They are a much younger, fitter, group of patients (MO6).

When the guidelines are not appropriate for their patients, physicians go to the literature themselves (as mentioned above) to seek clinical evidence that may be more relevant to their patient and help them recommend more optimal treatments, taking into consideration the unique characteristics of their patient – again, individualizing treatment.

So guidelines are great especially when you are unfamiliar with an area or wish to have a consensus opinion, but if you are comfortable interpreting the primary data yourself, you often times can come to a slightly more focused description of the specific problem at hand. So if you know that of the three trials that were included in a guideline, none of them specifically addressed this one patient, whereas this one small trial that is over here in 'boondocks' did address your patient, you are probably serving your patient better by using the data that is most applicable to them as it was to an overall generalized guideline which is probably not wrong but it may not be as perfectly correct for this specific circumstance (RO5).

Physicians raise the issue of the guidelines being restrictive in some cases. Physicians say that they don't hesitate recommending other treatments if they are more relevant to the patient in front of them. Physicians urge that the guidelines are “guides” and should not place restrictions on how they are applied in practice. If the guidelines are not applicable to

the patient in front of them they should present alternative treatments that are more relevant to the patient. This ties in with individualizing treatment and offering the patient a treatment that better fits his/her needs, his/her values, and is appropriate for him/her. For example, one physician shares what is offered to a stage II or stage IIIA resected patient with a low performance level:

Resected stage II and stage IIIA come to us with the pathology, and they're clearly by pathologic criteria, candidates according to the guidelines for treatment. But functionally they are so poor to recover, or slow to recover from their surgery, that we can't follow the guideline because the guidelines don't apply to patients in whom their performance status has dropped off and can't get treatment as a result...In those cases, we don't offer the treatment which is what the guideline would say, we generally offer active surveillance of follow-up (MO6).

Another physician gives an example of an elderly 80 year old patient where implementing the treatment recommended by the guidelines is not appropriate:

I just saw somebody last week and they were not the greatest, they were about 80... I mean, the guidelines say they should have adjuvant therapy but should an 80 year old be getting adjuvant therapy? What is the information? What's the data? That's the other thing. There is no good data. There is not a lot of data on the elderly people because there are not a lot of elderly patients on the randomized trials...Guidelines don't always apply to every patient. They are guidelines. And you have to take patients as individuals and, I think that is the key. A guideline is just a guideline. It can't be prescriptive for everybody and every patient because every patient is different (MO4).

Physicians also recognize that funding decisions are based on the guidelines; and that in oncology, physicians can be restricted by what they can give (MO4).

The datedness of the guidelines is also an issue. Although many physicians acknowledge that the development of guidelines takes time and is a rigorous process, physicians do not want to wait for a guideline because they are dealing with cancer. However, it is important to note that while some physicians do feel the guidelines are dated, they also feel that there is nothing new in the literature:

I think these [guidelines] are old, in the grand scheme of medical care, these are old guidelines. They are five years old now. Having said that, there is really nothing new that has changed in lung cancer management with regards to these two issues. They are very comprehensive...I certainly think that they are a good guideline but they don't replace good clinical judgment either (MO6).

Physicians also point out that the staging of lung cancer recently has been revised, and what is considered stage II now, was a different stage back then. Although this does not limit the role of guidelines in the treatment decision-making process considerably, physicians find that since there is a new staging system it is challenging to decide which staging system to use to interpret the data.

It is noteworthy that for physicians “following guidelines” is defined by physicians as being aware of the guidelines and presenting them as treatment options to the patient in front of them, when the physicians feel, based on their judgement, that the guidelines are relevant to the patient. However, it is important to note that “the presentation of these guidelines” do not mean that the physician always has to mention “CCO guidelines state...” to the patient. Instead, all it means is that physicians make a recommendation that falls within these guidelines. This point is illustrated as physicians speak about the treatment recommendations they “typically” recommend to their resected stage II and stage IIIA, and non-resected stage IIIA and IIIB patients in the interviews (without being asked if they recommend the guidelines). For example, one physician makes this point evident when she speaks about the complexity of stage IIIB patients, and what she typically recommends to these patients. Although what she recommends falls within the Cancer Care Ontario guideline (Guideline 7-3 [Jan 2006]), this is not explicitly said during the discussion.

...If they come back and the final staging is stage III, the discussion is usually around the use of chemotherapy concurrent with radiation (MO4).

When another physician is asked what he typically recommends to his resected stage II and stage IIIA non-small cell lung cancer patients, he answers as follows:

If they have been resected then they should be referred to me by the surgeon for consideration of post-operative chemotherapies since the data shows that generally speaking, for stage II or stage IIIA completely resected non-small cell lung cancer there is a benefit to those patients in giving them post-operative chemotherapy (MO2).

For the purpose of gaining additional insight into the Cancer Care Ontario Guidelines, health care administrators were also interviewed. Their perceptions and the strengths and limitations of the guidelines mirror those of the physicians. All administrators are well aware of the guidelines, and feel that the largest limitation of the implementation of the guidelines and their role in the treatment decision-making process is their relevance to the individual, unique patient. One administrator explains the limitation of guidelines by using an example of what treatment a younger patient might choose in comparison to an older patient. He illuminates that the quality of life may be more important to one person, and less important to another. What is worth to someone radically differs from what is worth to someone else. For some, side effects are worth it, for others not so much.

In fact we are making a conscious decision, and quite frankly not just a conscious decision, but a conscientious decision to deviate from the guideline because of an understanding that the patient in this case may not be able to tolerate the guideline approach... Everyone is going to have a different break point at which they go, "you know what, I'm willing to take that downside for the potential upside"... You know at the age of 20 or 30 you are going to make different decisions than when you are 80 or 90...a 5% difference in survival at five years for someone who is 90 or 80 is very different from someone who is 20 or 30 or 40. But there are break points. It's not a cookie cut...they are guidelines; that's what they are called, 'guidelines'. They are not strict rules. They are not, "this is how you have to do it or else"...(AO3).

Consequently, medicine is seen as an art to physicians. Physicians try to practice the best evidence-based medicine possible; using available guidelines and additional literature deemed relevant to the patient in front of them. Information is provided on the disease,

stimulating the treatment decision-making process between the patient and the physician. The physicians themselves carefully take into consideration and search for the best clinical evidence relevant to the patient's disease and the patient, critically appraising the evidence and considering the benefits and risks for the patient, the patient's values and beliefs, social and personal circumstances, the role of family members, and expert opinions from the team. The clear enumeration and balancing of all aspects are central to the treatment decision-making process and ultimately making a decision that is best for the individual patient.

In summary then, the clinical evidence involves two subgroups that are important to treatment decision-making in (stage II, stage IIIA and stage IIIB) non-small cell lung cancer: a physician's (and the institution he/she is attached to) individual interpretation of clinical evidence and its use; and knowledge translation tools such as Cancer Care Ontario guidelines and their important role relative to the other important factors that inform the treatment decision-making process.

CHAPTER 5: DISCUSSION

The purpose of this research project was to gain a deeper understanding of the treatment decision-making process of stage II, stage IIIA and stage IIIB non-small cell lung cancer patients in Ontario from the physician's perspective, to gain a deeper understanding of the elements involved in making a decision, including the role of guidelines. I chose a grounded theory approach to address the following research question: *How do physicians make treatment decisions with their stage II, stage IIIA and stage IIIB non-small cell lung cancer patients in Ontario?* The sub-question included was: *How do knowledge translation tools, such as Cancer Care Ontario guidelines, influence the decision-making process?* These two questions initially guided the study. The intended outcome of this study was a theoretical perspective on the treatment decision-making process with non-small cell lung cancer patients which was based on the experience of the participants. The theoretical framework that emerged relates to each of these questions.

In the previous chapter, I revealed my understanding of the phenomenon under investigation by putting emphasis on the perspectives of the physicians as they enter the treatment decision-making process with their patients. I discussed five major theoretical categories that arose from the data and served as significant guides in the treatment decision-making process of non-small cell lung cancer patients. In this chapter, I will closely examine each of these categories and link them to research that deals with aspects of these categories. I will also present topical and methodological recommendations.

5.1 Discussion of Findings

Research makes a distinction between that which is concerned with verification and that which is concerned with discovery. In the case of the former, theory serves as a framework to guide verification. In the latter, theory is the “jottings in the margins of ongoing research,” a kind of research in which order is not immediately attained, a messy, puzzling and intriguing kind of research of which the conclusions are not known before the investigations are carried out (Gherardi and Turner, 1987, p.12).

In this project a grounded theory approach was undertaken. Alternative qualitative strategies could have been used. For example, phenomenology asks questions about meaning and the core essence of a lived experience or phenomenon (Richards and Morse, 2007). The benefits of phenomenology are that you gain an in-depth and intimate understanding of the invariant structure and essence of what it is for someone, or several individuals, to experience a particular phenomenon. While a reasonable approach, it was not viewed as the optimal approach. The aim of the study was not to view the treatment decision-making process as a deeply personal experience, and explore what it is like for individual physicians to make treatment decisions, but instead, the aim of the study was to explore more a social phenomenon, seeking patterns of behavior, ideas and experiences among individual physicians, which was an objective more fitting for the grounded theory approach.

Grounded theory emphasises that individuals are “unique living wholes as the researcher focuses on the world as it is experienced by the individual.” (Hallberg, 2006, p.141) Charmaz (2006) explains that the constructivist approach of grounded theory examines how participants construct meaning in particular circumstances, and places an analysis contextually in a particular situation, time, place and culture. Although I could not replicate the experience of my participants, I outlined an interpretative view of the

information the physicians shared with me as they presented narratives about their treatment decision-making experiences with their non-small cell lung cancer patients. I did not approach the data with any hypothesis, but instead did so with as few preconceptions as possible. I used reflexive strategies to write about my understanding and assumptions of the data and how they changed as I conducted a further analysis. Using grounded theory allowed me to have insight into the participants' experiences and helped me delve into a deep introspection of the complex, diverse, and dynamic nature of decision making in non-small cell lung cancer, a phenomenon not yet explored by any other study.

To this end, I strove to maintain the presence of participants' voices throughout my analysis, and revealed that physicians making treatment decisions are a simultaneous interplay between five key cross-cutting guides (or factors): the unique patient, the unique physician, the family, the clinical team, and clinical evidence. Charmaz (2006) notes that a constructivist grounded theorist also remains alert to particular conditions “in which differences and distinctions arise and are maintained” (p. 131). Consequently, the severity and complexity of the patient's disease, together with the institutions at which the physicians practised, presented conditions in which distinctions arose regarding to what extent each guide was involved in the treatment decision-making process. Charmaz (2006) also notes that “certainly a fine-grained analysis of how people construct actions and meanings can lead a grounded theorist to establishing some reasons for it, although occasionally the why, may emerge from the how.” (p.130) *How* physicians were making treatment decisions with their non-small cell lung cancer patients was determined and then translated into *why*. It was revealed that each physician aimed to “personalize the care” of their individual patients. Thus, listening to the participants' accounts allowed me to discover that seamlessly woven into the fabric of

treatment decision-making was a process of personalizing care. There was a continuous flow between the interrelated components of treatment decision-making. The five guides helped physicians navigate their patients through treatment decision-making. In this chapter I connect each guide to the current literature, which strengthens my basis to offer recommendations.

The Unique Patient

The category of the unique patient involved the patient's clinical status, demographics, values and fears, personal and social circumstances, and his/her wishes. Each patient was unique and embodied unique characteristics that helped physicians to individualize treatment. This was the first iterative step in the treatment decision-making process that supported the personalization of the physicians' care. The important aspect of this category was that physicians looked at the patient holistically and as individuals, slowly realizing that they were not merely looking at the colony of disease that had settled in the patient's body, but looked *through* the patient as someone who carried the disease, paying just as close attention to the patient as an individual as to the disease. Weller (2004) defines holism as an inclusive approach to caring for a patient, in body, mind and spirit, when considering all actions and interventions for the patient, while recognizing that each individual is unique and that there may be an influence of internal and external environmental factors on a patient's health. For instance, in the case of two stage IIIA non-small cell lung cancer patients, physicians realized that although to be at a similar stage of the disease, there was no "one-size-fits-all" treatment. Not only did both have unique characteristics as far as their clinical status was concerned (i.e., histology, stage of disease,

metastatic spread, performance status, comorbidities and expected response to treatment), but both also had unique demographics and unique personal and social circumstances coupled with their own wishes. Physicians understood that all these factors meant that they had to individualize treatment and ultimately target their recommendations to fit each unique patient.

Consider, for example, the importance of an individual's comorbidities. One patient's comorbidities may influence his/her treatment decision in a completely different way than someone else's treatment decision; this is clinically logical and has been well supported in the literature (Hurria, 2011; Satariano et al., 1994; Lee et al., 2011). For example, Hurria (2011) states that "data must be placed in the context of an individual patient's risk of cancer recurrence," (p. 4217) and states that when considering each individual's unique comorbidity, it alters "the estimates of risks and benefits of treatment, the potential impact of comorbidity on disease progression, and potential survivorship issues" (p. 4217). The physicians then moved from the importance they put on each individual patient's clinical status to a consideration of demographic issues, or non-clinical factors, such as age, education, culture, socioeconomic status and whether the patient spoke English. Physicians admitted that attention to demographics was important in the treatment decision-making process. In their study, Klebert et al. (1994) discuss the importance of considering demographics and the impact they have on patient choices:

"Older patients assigned significantly more importance to the nature of side effects of treatment than disease related chances of survival, and the baseline of quality of life than younger patients. For patients with lower education level the presence of children, the disease-related chance of survival, and the baseline of quality of life were more important considerations than they were for persons with a higher level of education..." (p. 180).

Socioeconomic status, for example, also affected the treatment modality ultimately employed by patients. Socioeconomic status was defined by the patient's level of education, their poverty level and their income. Howe and Leighl (2008) point out that “lung cancer patients tend to be older, have more comorbid illnesses, [and are of] lower socioeconomic status” (p. 195). Low socioeconomic status meant that patients had fewer resources than the average patient; it meant that some patients sometimes valued keeping their jobs more than undergoing treatment; it meant that they had problems accessing care, getting back and forth to the clinic, having money to pay for their gas, for parking, and their ability to take time off work.

Similarly, age can influence decision making. Age can be a good predictor of risk for toxicities from treatments like chemotherapy. Lung cancer patients tended to be older and over the age of 65 (Edwards et al., 2002), and evidence has demonstrated age can influence choice of cancer therapy (Samet et al., 1986) and the goals of treatment (Greenburg, 1988). For example, Greenburg et al. (1988) discovered that the probability of lung cancer patients undergoing potentially curative surgery was increased by characteristics such as being younger and married.

However, although age was important to the physicians in order to decide whether recommending a particular treatment was optimal, they also emphasized that “age was nothing but a number” and was not the defining factor to determine what they should recommend. It was important for the physicians to enter into discussions with patients and learn more about their lifestyles and who they were.

The talk of age also elicited an important theme that ran through all the physicians' responses: “seeing a patient in person versus seeing a patient on paper.” The physicians

pointed out that when entering into the treatment decision-making process with their non-small cell lung cancer patients, it was important to rid themselves of any stereotypes of what they may think a “typical” 80 year old, or 70 year old, or 60 year old would look like. It was easy to assume things about a person if one saw his/her details “on paper,” but once one actually saw the patient “in person,” things could be completely different. This concept carried through in the discussions of tumour boards (a guide discussed later).

Getting patients to open up about who they were also led to a discussion on creating “bonds” with patients. Physicians put great emphasis on this factor. First, the physicians explained that getting to know one’s patient also provided one with the opportunity to uncover how much the patient knew and understood about his/her disease and treatment information. It was essential for patients to understand their disease and treatment information to participate as informed consumers in the treatment decision-making process. Second, physicians explained that bonding with their patients was an important part of the treatment decision-making process, and that it helped elicit patient preferences and establish trust between the patient and physician, and allowed the patient to feel comfortable and confident that he/she was in good hands.

Physicians also used the information about the patient’s fears, misconceptions, desires, wishes, beliefs, values, personal responsibilities, and social circumstances as part of the decision-making process. For example, in cases where the side effects of cancer treatments would let patients lose their ability to engage in activities they enjoyed or limit their ability to work, patients were reluctant to undergo particular treatments. The physicians explained that in other cases patients simply had fears about cancer and thought that “cancer was a death sentence.” Yet other patients had misconceptions about treatments that

originated from watching movies of “typical chemotherapy patients” or anecdotes of someone they knew who went through cancer treatments that were terrifying and yielded less than optimal results. The literature also cites patients’ misconceptions and fears influencing treatment choices for cancer (Denberg, Melhado and Steiner, 2006).

The physicians explained that the demographics of the patient and the patient’s wishes went hand-in-hand. This statement was also illustrated by the literature. A study done by Pepe et al. (2007) illustrated that platinum-based chemotherapy was perceived as toxic, and older patients were less willing to accept even low levels of toxicity from treatments. The physicians stated that because treatments like chemotherapy and radiation therapy conferred a high likelihood of side effects, often on a patient’s quality of life, patients sought alternative treatments. Conversely, some patients did not mind the side effects and valued the quantity of life above the quality of life. In other cases, physicians explained, some patients wanted aggressive treatments without the recommendation of the physician. This point is also made in the literature: Slevin et al. (1990) study found that patients were ready to undergo treatments and accept toxic side effects for relatively little benefit.

There was variability in patient preferences, based on personal reasons, or based on the clinical appropriateness of alternatives and benefit-risk trade-offs. Uncertainty about the efficacy and outcomes of different treatment options affected patient wishes differently as well. Howe and Leighl (2008) also capture a similar account of variability between lung cancer patients in their responses to adjuvant therapy:

“Those who declined treatment reported greater reliance on family as an information resource...those who declined treatment had less experience with chemotherapy through friends and family, but reported negative experiences. Those who declined therapy were primarily concerned with the potential of severe consequences (e.g.,

prolonged duration of feeling unwell, loss of independence, and poor quality of life in remaining years of advanced age). Those who accepted chemotherapy were more likely to have had exposure to chemotherapy experiences through friends and family, but did not report negative experiences.” (p.195)

Consequently, physicians felt that making a treatment decision that was optimal for the patient was not as easy and straightforward; it was complex and at the core of each decision was the contextual factors explained above. The distinction between patients became apparent in the actual treatment choice. It was important to approach each patient on an individual basis, because each patient was unique. This guide then led to the guide of “the unique physician” who then took all this information and used his/her clinical expertise and judgements, coupled with advice from his/her clinical team and the clinical evidence to make treatment recommendations.

The Unique Physician

Each physician is unique as far as his/her clinical experiences and this can affect the way in which the physician perceives patients. For instance, physicians who were younger in clinical practice shared narratives of giving patients the “benefit of the doubt” and being more eager to suggest aggressive treatments than physicians who were perhaps a little older in clinical practice. Other physicians who were newer in practice explained that they “haven’t been around long enough” to witness certain side effects of patients on particular treatments. Thus, physicians acknowledged and appreciated that the cultivation of sound clinical judgment in the treatment decision-making process evolved and took time. Physicians who differed in their experience and education could come to different conclusions from the same facts is not surprising. Medicine is vast and interacts. Physicians differed in their

judgement, and one could not see them following a precedent in a blind routine. Physicians had their own unique clinical judgement which ultimately influenced the treatment options they would present to their patients and offer as recommendations. The treatment recommendations could vary considerably between individual physicians as they were differentially attuned to what was important in each individual case. It is also noteworthy that physicians' judgements were also affected by the institution at which they practiced. A sense of belonging to an institution and prescribing something to a patient because of institutional policies and normative context surfaced often in physicians' narratives. The "I" in this is what "I" recommend to patients with non-small cell lung cancer was often replaced by "we" recommend this or that (implying a reference to the institution where they practiced).

Each physician acted on his/her perspectives and values – subconsciously or consciously – when presenting treatment options and recommendations, which ultimately also affected the course of the treatment modality chosen. The findings of this study parallel the studies in the literature: in their study Maccormick and Mackinnon (1990) illustrate that the physicians' perspectives and values also plays a role in offering particular treatments. Furthermore, how treatment options were presented varied from physician to physician. This point is also consistent with the literature (Cassileth, Zupkins, Sutton-Smith et al., 1980; Degner et al., 1997; Gattellari, Voigt, Butow et al., 2002; Siminoff and Fetting, 1991).

It is noteworthy that each physician also had his/her unique style in making treatment decisions with his/her patients. Sometimes physicians employed the informed treatment decision making model but most of the time both the physician and the patient collectively entered into a reasonable course of action, allowing the treatment decision to be shared. The literature has shown that cancer patients tend to have stronger preferences for

being involved in the treatment decision-making process (Cassileth, Zupkis, Sutton-Smith et al., 1980). Physicians were seen as navigators, providing the patient with their best clinical judgment and recommendations based on the unique characteristics of the patient, the clinical evidence, and advice from the clinical team, to allow the patient to be the pilot, encouraging the physicians to drive the treatment decision-making process to its ultimate destination of choosing a treatment to be implemented.

The Family

Respect for patient autonomy includes not only taking into consideration patient preferences, but also preferences that involve the family (Pardon et al., 2010). The guide of family involvement is tightly intertwined with the guide of the unique patient, and has an impact on the treatment decision-making process; an additional feature that played into the decision-making process, directly or indirectly, by the physicians. This finding was consistent with the literature. Studies (Pardon et al., 2010; Schafer et al., 2006) found that advanced lung cancer patients wanted family involvement in the treatment decision-making process alongside the involvement of the physician and themselves. Thus, the treatment decision-making process now had not only two active players, but also a third one — the family.

The family can be involved in perpetuating or mitigating patients' fears or misconceptions. Patients' fears and misconceptions were fostered by observing the physical deterioration of a loved one or friend who had endured cancer or another malignant disease. If the patient had a family member who had gone through cancer treatment and died, the physician was left grappling with clearing these misconceptions and explaining to the patient

the variability in outcomes, and that death was not an ultimate conclusion to lung cancer. In their study Zhang and Siminoff (2003) also found that “previous negative experiences had adverse effects on decision making” (p.1027) among lung cancer patients. Conversely, if patients had a family or close friend who survived cancer, physicians explained that this often served as a catalyst for being enthusiastic or motivational to learn more about treatment options and undergo particular treatments. In their study Zhang and Siminoff (2003) also note that family members were empathetic to the patient when they also had their own “personal understanding, knowledge and experiences with death” (p.1027).

Family and friends were also part of patients’ demographics, such as having a support network. Physicians explained that having a support network was very important. Because of the side effects of adjuvant chemotherapy or chemo-radiation, patients sometimes needed a strong support network to help take care of them. The treatment options presented during the treatment decision-making process were often influenced by this factor. Patients who lived alone would have a more difficult time getting through treatment than those who did have someone.

The family’s presence during the consultation influenced the patient’s decision in pursuing treatments. Physicians explained that sometimes family members or friends present during the treatment decision-making process would encourage patients to pursue particular treatments, and at other times discourage them. One study by Zhang and Siminoff (2003) found that it was common in families to disagree about treatment decisions, selection of doctors, care options, caregiving styles, and therapeutic goals for advanced lung cancer patients. However, family also played a larger role in helping physicians make possibly better

suited treatment recommendations for the patients by serving as “windows” onto the patient’s life and exposing details of the patient a physician perhaps could not learn within an hour consultation or a series of consultations.

Family members also served as medical interpreters; again tying in with the unique patient guide, and playing a larger role in the case of patients who did not speak English or understand it that well. Physicians sometimes were able to use family members who spoke the same language as a patient who did not speak English as an avenue to share information and help the patient understand not only the complexity of his/her disease, but also the treatment options and recommendations being made. At other times, physicians were challenged by family as medical interpreters when family members did not want to share particular facts with the patient, or shielded the patients from information being shared by the physician. This posed a challenge, and physicians were left seeking external medical interpreters or understanding why the family member wanted to withhold information from the patient, and getting them to understand why it was important for the patient to understand everything being shared in the treatment decision-making process.

As a result of all of the above, the family’s role in the treatment decision-making process was significant. Four layers of family involvement were revealed: family as support network, family as consultation support, family as medical interpreter, and family as cancer survivor or cancer victim. Each layer not only tied in with the guide of the unique patient, but also served as impacting the treatment decision-making process. It is important to note that Pardon et al. (2010) note that,

“when family is involved in the treatment decision making process, it is important that the physician should regularly re-discuss a patient’s preferred degree of family involvement in the event of loss of competence, or that the physician should tell the patient that a change in preference is not uncommon and can always be communicated to them” (p.1202).

The Clinical Team

Physicians sometimes grappled with complex non-small cell lung cancer patients whose disease management was sometimes unclear, particularly for the very challenging patients with stage IIIB disease where the best decision is difficult to attain. In response, physicians would enter into “informal discussions” with their colleagues on how to handle a case; other times physicians entered into a more “formal discussion” otherwise known as tumour boards (or multidisciplinary cancer conferences). Thus, physicians sought the opinions of their colleagues and added another important element to the treatment decision-making process of non-small cell lung cancer patients: the tumour board.

Tumour boards are meetings that are attended by all the different members of the multidisciplinary lung cancer team – medical oncologists, radiation oncologists, thoracic surgeons, respirologists, pathologists, pulmonologists – which discuss different patient cases and make their judgement known after reviewing a patient’s clinical details. Considering all the viable treatment options, a consensus agreement is then reached (Allum et al., 2002). This decision then flows back to the patient, and additional deliberation takes place until the patient is ready to choose a treatment. Blazeby et al. (2006) state that multidisciplinary teams have been largely introduced in response to increasing complexity of knowledge and specialization. “Multi-disciplinary teams are considered central to the delivery of high quality cancer care and treatment decision-making is a key function.” (Blazeby et al., 2006, p. 458).

Physicians revealed that in the treatment decision-making process of non-small cell lung cancer patients, team work signified a powerful lever for addressing and deciphering not only the diagnosis of the patient and ambiguous information about the stage of the disease, but also for deciding which treatment modalities were optimal to employ in complicated cases.

The literature has also highlighted the importance of multidisciplinary teams:

“The multi-professional composition of teams should increase the likelihood that individual patients are offered the most appropriate treatment for their condition, because management plans would be based on a broad range of expert knowledge from the start, and all aspects that influence treatment options would be considered...This approach is obviously important in more complex cases, where many specialists are involved, especially when the timing and choice of different treatment modalities is complicated. In less complicated cases, teamwork should ensure that care is up-to-date and follows recognized evidence-based guidelines” (Fleissig et al., 2006, p.936).

In another study, Scotland et al. (2005) illustrate the influence of multidisciplinary team meetings on the treatment decision-making process of non-small cell lung cancer patients by comparing the treatment of patients with inoperable non-small cell lung cancer before the introduction of multidisciplinary team meetings in 1997 with the treatment in 2001. They found that after the introduction of multidisciplinary meetings, a significant portion of non-small cell lung cancer patients received chemotherapy, and fewer patients underwent palliative care alone. They also found the median survival of patients in 2001 to be 6.6 months compared to the 3.2 months in 1997 (Forrest et al., 2005).

Consequently, in the treatment of non-small cell lung cancer, treatment decisions were not isolated events. Physicians, patients, and families but also other key professionals with varying degrees of knowledge, skills and experience were involved. It was important to make treatment decisions that were collaborative, especially in the complicated cases (like

stage IIIB non-small cell lung cancer patients). However, physicians revealed that the formal meetings focused significantly on the clinical status of the patient. Perhaps, a more systematic approach to the assessment of not only the clinical characteristics of the patient, but also the inclusion of personal and social characteristics of the patient will allow for tumour boards to be fully informed and to look at patients holistically, thus, optimizing their use in the outpatient consultation and treatment decision-making process. The lack of consideration of all aspects of the patients has also been cited in the literature: for example, in a study it was found that “[multidisciplinary] team decisions were not always implemented because [the multidisciplinary teams] had not fully considered patients’ wishes and once these were discovered at the outpatient consultation a different treatment path was agreed [upon]” (Blazeby et al., 2006, p.459). Thus, it is warranted to explore techniques to optimize the use of decisions made in multidisciplinary meetings in the treatment decision-making process.

The Clinical Evidence

In an era of evidence-based practice, it was not surprising that physicians use clinical evidence in the treatment decision-making process with their non-small cell lung cancer patients. Evidence-based medicine is the practice of a physician combining the best available clinical evidence with his/her own individual clinical expertise (Sackett et al., 1996).

Physicians made treatment recommendations based on the latest up-to-date lung cancer evidence, and made sure that they were aware of any study that could possibly be relevant to the unique characteristics of their patient; even if that meant a small study done down in the “boondox,” as one physician stated. Physicians using studies that were more relevant than the patient in front of them would determine the likelihood of a particular benefit, whether

the individual patient fit into the population described, and whether the individual (as opposed to population average) baseline risks of that event, could be estimated from the characteristics that were known about the patient.

However, an important finding the current study was physicians' use of their individual interpretation of the clinical evidence for non-small cell lung cancer. Physicians stressed that clinical evidence – for example, in the case of stage IIIA non-small cell lung cancer – was sometimes controversial and not that straightforward. This controversy of how to treat stage IIIA non-small cell lung cancer has also been captured by the literature (Santos et al., 2008); for example, the importance of functional status, weight loss, and the like, in determining the most appropriate and safest care option. The unique interpretation of the evidence, by each physician, can be influenced by his or her clinical experience, the normative interpretation of the institutions where he/she practised or the specific practice team with whom he/she worked and the alignment of features between the presenting patient and the patients included in the studies. How patients were being ultimately treated (or what treatments were being recommended in the treatment decision-making process) was partially due to the way in which physicians and their institutions were approaching the clinical literature.

How do knowledge translation tools, such as Cancer Care Ontario guidelines, influence the decision-making process?

Two guidelines were of interest to the following study. Very broadly the guidelines were:

- Patients with stage II and stage IIIA resected non-small cell lung cancer should receive cisplatin-based chemotherapy (7-1-2[Dec 2006]).

- Patients with stage IIIA and stage IIIB non-resected non-small cell lung cancer should receive chemotherapy with a cisplatin-based agent (7-3 [Jan 2006]).
 - Important to note is that guideline 7-3 recommends chemo-radiation for good performance status patients with minimal weight loss. For poor performance status patients palliative radiation or chemotherapy is recommended, and for borderline patients sequential treatment may be considered.

One of the means of disseminating best practice options based on evidence is through the use of clinical guidelines (Walker et al., 2000; Foy, Walker, and Penney, 2001). Guidelines aim to improve patient care by providing “easily accessible information regarding optimal care” (Wollersheim, Burgers, and Grol, 2005, p.188). The current study found that clinical guidelines play an important role in the treatment decision-making process, this role was in the context and influenced by the other important factors that inform the treatment decision-making process. This study confirmed what guidelines are designed to do – to assist in the decision-making process but not to supplant the decision making process as the only important consideration.

Physicians shared their view that stage II non-small cell lung cancer patients were a little more “straightforward,” and while patient factors such as comorbidities or patient preferences sometimes did act as a barrier, the guideline recommending adjuvant chemotherapy (7-1-2[Dec 2006]) for resected stage II non-small cell lung cancer patients was meaningful. The chief barrier to adjuvant chemotherapy seemed to be based on specific details of the patients’ clinical status or patients’ preferences for issues in the “unique patient” guide explained above.

Consequently, all the physicians were aware of the guidelines and stated that they were often emphasized at tumour boards. Although there were constant discussions of the

“datedness” of guidelines the physicians still found the guidelines relevant; with some physicians also expressing no “new” literature in the treatment of stage II and stage IIIA and stage IIIB non-small cell lung cancer patients. The physicians also stated that they generally had confidence in the literature from which the guidelines were derived. However, one has to keep in mind that the clinical literature around the treatment of stage III non-small cell lung cancer patients was seen as controversial, evolving, and only modestly generalizable to the typical patients seen in clinic – causing physicians to recommend various treatment options for their patients. The guidelines were recognized as regular “bread and butter,” and physicians stated that their recommendations were often inclusive of these guidelines when they were deemed appropriate for the individual patient. How often were they appropriate? Most physicians revealed that their lack of uptake in some instances was due to the fact that the patient population – especially stage III non-small cell lung cancer patients – were very heterogeneous, and that the guidelines did not reflect the complexity of this patient population group. While the CCO lung guidelines do provide caveats for individual differences in patient presentation, guidelines provide recommendations for which there are studies to inform that process. Clearly, the diversity of the actual patient population is much greater than the diversity of what a guideline can capture. Further, the stage III non-small cell lung cancer patients were not as “straightforward” nor were “two stage IIIB patients ever alike.” Thus, in this patient population not only did the unique characteristics of the heterogeneous population play a role in determining whether a recommendation was applicable, but also, as explained above, the physicians’ interpretation of the controversial clinical literature. It is noteworthy that clinical evidence ties in heavily with the other guides

in that guidelines such as these must be integrated with each physician’s judgement of whether they are applicable to the individual patient’s clinical state and preferences.

In summary, the role guidelines played in the treatment decision-making process relative to the role of other important factors, and the barriers to their implementation were predominantly for the following reasons:

- The recommendations were not always applicable to the characteristics of the patient population.
- Physicians constantly mentioned that the stage II, stage IIIA and stage IIIB non-small cell lung cancer patients were not as “cookie-cutter” as the guidelines assumed – constantly highlighting the complexity of stage IIIB patients.
- There was a perception based on individual interpretation of the literature that the guidelines would not always lead to the optimal outcome expected by the evidence, particularly for the stage III patients. For example, physicians in one jurisdiction felt that the tri-modality approach has a role in treating patients with stage IIIA non-small cell lung cancer patients whereas, physicians in other locations could possibly favour a bimodality approach.
- Often, because non-small cell lung cancer patients were considered a vulnerable patient group, physicians did feel that sometimes there was an inability to merge recommendations set out by the guidelines with patient preferences. These preferences are outlined in detail in the “unique patient” guide (above).

It is important to note that although these factors served to influence whether the recommendations were used, physicians did not have a lack of motivation to implement recommendations. Many physicians, again, recognized this as something all physicians in Ontario “should know by default”. Some older physicians found that their institutional policies already included these recommendations even before they were coined as “guidelines,” and that they had, in fact, been using these ways to treat patients for a long time. However, one physician also made an interesting analytical point about the people who were more likely to be aware of these treatment recommendations as “guidelines”:

...Guidelines will never be followed 100% of the time and I don't personally believe that they should because then there is no room for judgment... I would guess that probably 80 or 85% adherence to a guideline is probably appropriate and probably as good as you are going to get... it also depends on the physician population age. The older the doc, the less he or she is going, generally speaking and in my opinion, be aware of and/or follow the guideline. The younger guys coming out of school they will know this, or certainly know it better and the people, the bulk of the docs who are in the middle, in the middle of that spectrum I think that they have, especially if they are oncologists of one or another kind and/or work in a cancer centre, they have a responsibility I think as individuals to not only be aware of the guidelines but to bring them up and talk about them when it's appropriate (SO1).

Health care administrators responsible for cancer care programs in the province were also interviewed to gain additional insight into their awareness of the guidelines and their feelings regarding the role they thought guidelines should play in the treatment decision-making process. Foy et al. (2001) state that:

“those with the greatest potential to address barriers range from individual clinicians to national policy makers...For example, developing clinical skills in order to follow guideline recommendations requires support from both local tutors and management to provide protected time and resource training. Ultimately, the priority given to such training is determined by national policy-makers, for example, in establishing frameworks such as clinical governance to ensure that these needs are identified and met. Therefore, strategies to tackle barriers to change need to be multilevel as well as multi-faceted” (p. 172).

The administrators – with clinical backgrounds and without – were all aware of the guidelines, and their responses paralleled those of the physicians. The issue of appropriateness arose, and the administrators predominately acknowledged that a physician choosing with his/her patient the best care option had to consider the extent to which recommendations, the patients in the studies underpinning the recommendations, were similar enough to the presenting patient. Thus, the importance of individualizing and personalizing care was highlighted. Tonelli (1998) makes a valid point: “to the extent [there are] relevant differences between individuals [that] cannot be made explicit and quantified, an epistemological gap between research and practice must remain” (p.1236). There are non-quantifiable individual variations (such as patient values) that are not included in all guidelines. Therefore, “deviating” from the guidelines should not be instantaneously considered suspect unless correct justification is given (Goldman and Shih, 2011).

Ending Remarks

Treatment decision-making is truly an art. And physicians are the artists of medicine, personalizing care by looking directly in front of them and assessing whether the evidence and the efficacy that it claims for particular treatment modalities fit or do not fit the patient sitting in front of them; and taking into account not only their own personal experiences and clinical expertise, but also the biological, social, personal and spiritual makeup of the patient. The study finds that five main guides reflect a dynamic system and inform the treatment-decision process: the unique patient, the unique physician, the family, the clinical team, and the clinical evidence. There was an endless flow between all guides with all the guides playing a role with each other and all affecting the treatment decision-making process to a different

degree, depending on the individual patient sitting in front of the physician. The sheer complexity of all the inter-relating guides (or factors) which come to play in the treatment decision-making process illustrates how difficult it is to attempt to rationalize the decision process, and why a particular treatment is chosen over another one for patients with the same stage of disease. Decisions on whether it was going to be palliative or curative treatment, concurrent or sequential were not separate discussions, but also tied in with the treatment decision-making process and were wrapped around all the factors that affected it. How decisions were made with each patient and the process taken may have been similar, but the ultimate treatment implemented depended on the details of each of these guides. Physicians used his/her knowledge of the disease, the epidemiology of non-small cell lung cancer, the patients' preferences, the patients' social and personal circumstances, family influences, and the advice from his/her clinical team, coupled with his/her own clinical judgement. Truly the artists of medicine, the physicians then sorted all this information out to make sure that he/she could provide the most optimal care for his/her patient, and personalize his/her care. Figure 6-1 is a depiction of the decision-making model of the factors physicians consider when making treatment decisions with their stage II, stage IIIA and stage IIIB non-small cell lung cancer patients:

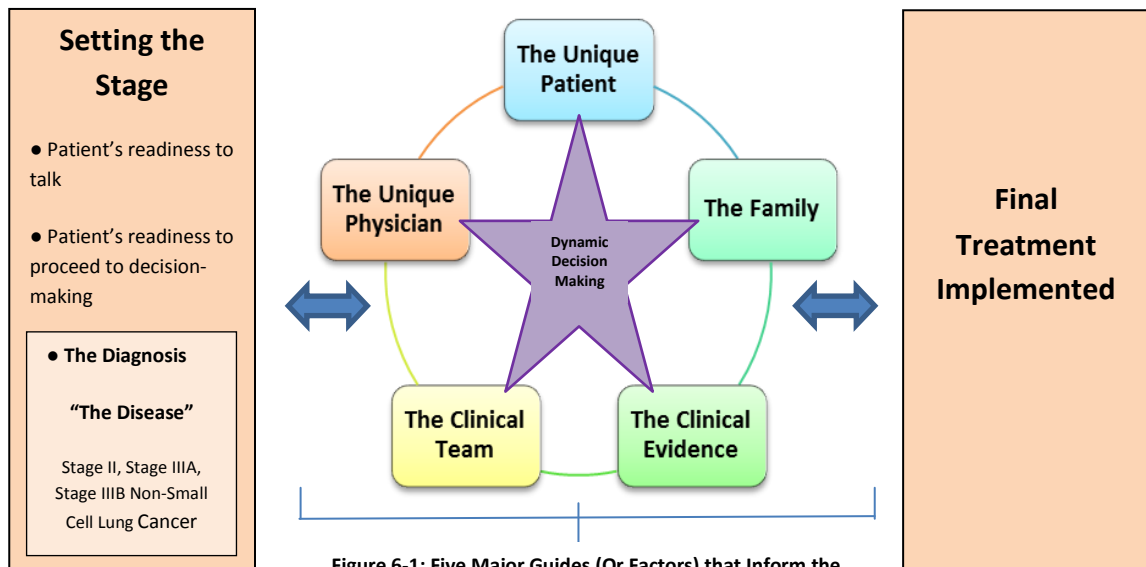


Figure 6-1: Five Major Guides (Or Factors) that Inform the Treatment Decision-Making Process in NSCLC

Figure 6-1: The process of making a treatment decision for an individual case of non-small cell lung cancer involves five major “guides” or factors as illustrated in Fig 6-1. The degree of involvement of each guide varies in the treatment decision-making process due to various conditions, such as the stage of the disease. The circle and star illustrate the connectedness of the guides/factors – that inform the treatment decision-making process – and illustrates that one guide is not isolated from the other. The boxes “Setting the Stage” and the “Final Treatment Implemented” illustrate important stages in the treatment pathway. There may be a reverse flow between the stages of the treatment pathway as shown by the double-headed arrows. Decisions are iterative, rather than linear, where treatments are negotiated and care is personalized. As a result, goals of treatment, radical or palliative, are tightly weaved throughout the decision-making process, and are decided collectively with the guides.

5.2 Unique Contributions of the Study to Current Research: How Findings Fit Current Theory/Conceptualizations in the Literature

Existing literature on the decision-making process in the cancer setting includes studies of patient preferences for participation in decision-making, which emphasize “on the congruence between patients’ preferred and attained levels of involvement” in decision-making (Crichton, Lingler and Happ, 2011, p.33). Literature also focuses predominately on documenting the wide range of patient preferences and the role they play in the treatment decision-making process. Zafar et al. (2009) outline that age, comorbid illness,

socioeconomic factors, and family all play a conscious role in treatment decision-making. The findings of the current study were consistent with these factors. However, the current study presented factors such as the influence of family on the treatment decision-making process and revealed four interacting layers of their involvement: family as support network, family as consultation support, family as medical interpreter, and family as cancer survivor or cancer victim. To my knowledge there are no studies that have broken down the many facets of family involvement and their importance in the treatment decision-making process.

Zafar et al. (2009) also explains that much of the literature on the factors that contribute to both patient and physician cancer decisions are intertwined; such as the example of patient preferences that are also integrated into physician factors (Zafar et al., 2009). The findings of the current study were also consistent with this part of the literature.

A treatment decision-making model originally reviewed by Zafar et al. (2009) details a general treatment decision-making model for cancer patients, but this model is not specific to non-small cell lung cancer patients. This model is an overview of all the factors (i.e., the wide range of patient preferences and values) and the physician's knowledge of factors such as disease, degree of comorbidities, patient age and socioeconomic factors. This decision-making model also "assumes an acceptable balance between the patient and physician in terms of shared decision-making" (Zafar et al., 2009, p.121). While this model includes the findings of the current study, it fails to acknowledge the interplay of clinical evidence and the multidisciplinary teams in the treatment decision-making process and may fall short of the true complexity involved in treatment decision-making. Crighton, Lingler and Happ (2011) note that:

“Most cancer treatment decision-making studies assume that the provision of information combined with an attention to patient preferences about level of involvement in decision making will lead to the ‘right decision’ for each patient. Decisional regret or inappropriate treatment trends to be attributed to errors in information or mismatches between decision-making preferences with little attention to the unique issues or psychological context of decision making in advanced cancer” (p.30).

Thus, although there are some consistencies between the factors that are found within the current study and the existing literature, most studies of decision-making in cancer lack a clear theoretical framework that incorporate all the unique details captured within the current study. The complexity of factors involved in the treatment decision-making process may be evident in the literature. However their representation in a theoretical framework like the one presented in this study is, to my knowledge, lacking in the literature. This study offers the unique details missing in the existing treatment decision-making model (Zafar et al., 2009).

The impetus of the study originated from data showing, perhaps, lower than anticipated use of chemotherapy and chemo-radiation therapy for non-small cell lung cancer patients in Ontario, and variation in practice in the region. This study illustrates the complexity of decision-making. No simple reasons can adequately explain the variation in treatment decisions seen in this data. The coherent framework offered of how decisions are made in the context of non-small cell lung cancer invites us to look deeper into the treatment decision-making process. Decisions are rooted in patients’ values and preferences, the family members’ direct and indirect roles and influences, physicians’ values and clinical judgements, their clinical experiences, the teams’ clinical judgments and the clinical evidence and tools

that represent this evidence as action statements. Thus, treatment decisions for non-small cell lung cancer patients are complex and dynamic.

Consequently, current treatment decision-making models seem limited. For example:

“Shared decision-making models that begin to offer approaches that shift focus away from individual elements of treatment decision-making toward a more comprehensive approach that incorporates contextual elements of treatment decision-making. For example, one model proposes a linear process involving phases: (a) assess the patient’s needs and the role he or she wants to play in the process, (b) advise him or her of the evidence, (c) agree on a course of action that incorporates the patient’s value, and (d) help the patient obtain services and arrange follow up (Sheridan, Harris and Woolf, 2004, in Crighton, Lingler and Happ, 2011, p.34).

However, the theoretical framework/model presented within the current study highlights the fact that decision-making is not confined to a linear path, but instead is iterative and dynamic such as: physicians reaching out to clinical teams for advice, and going back to the patient for additional negotiation, then going back to the team for further advice if it is needed; interpreting individually and as a team how guideline recommendations do or do not generalize to the unique patient; or physicians being impacted by new clinical evidence that forces them to go back to the “drawing board”. The constant interplay of many guides going back and forth along a care trajectory reveal that treatment decisions evolve, and are not just shared between two people — physician and patient — but many physicians, the patient, and family.

Uncovering how treatment decisions are made help reveal factors that are important to clinical practice. It also opens up the multidimensional needs of non-small cell lung cancer patients that seem to be older in age and families throughout the treatment decision-making process. While current literature predominately focuses on patient preferences that explain only an aspect of the decision-making process, the current study, by taking the physician

perspective, aptly describes and sheds light on the full complement of players and contextual complexity that accompanies treatment decision-making in the *real* world.

5.3 Future Directions for Research in This Area & Recommendations

Many studies have attempted to gain insight into the very difficult and complex process of decision-making in cancer management. Future studies can focus on the patient perspective of treatment decision-making in the non-small cell lung cancer setting, and obtain patient-reported data as he/she moves through each step of making a treatment decision to treatment adherence and his/her health status and quality of life throughout this treatment continuum. In fact, an alternative method to conduct the current study would have been to conduct a multiple or single case study of a patient where analysis can illustrate possible areas of gaps and congruence between real life clinical personal experiences and decision-making measurements. Such a study can render a more complete and accurate picture, and perhaps provide insight into why patients actually choose what they do rather than have physicians interpret their reasoning as they do in this study. Because non-small cell lung cancer is also populated with an older patient group, it would also be worthwhile to have studies focus on how older patients differ from younger patients in their reasoning and rationales to pursue particular treatments. Do these rationales lead to lower quality final decisions, and do they have implications for morbidity or mortality?

Clinical decisions in non-small cell lung cancer are approached based on the specifics of patient details, and each physician personalizes care by taking into consideration these patient specific details. Advancements in personalized medicine may help address some of the clinical advancements in matching patients to best care options. However, these

innovations do not take into account other personalized, but non-clinical, features of the patient that this study has shown to be important. This may be an area for further development.

The current study revealed that multidisciplinary team meetings play a significant role in the treatment decision-making process. Studies are needed to further explore the implications of multidisciplinary team meetings and whether the decisions they make match the specific needs of the patient. In the current study, physicians shared their views that patient values are not always discussed or well understood. It seems important to develop standardized methods to allow for the inclusion of not only clinical data, but non-clinical data such as patient values and preferences, to optimize the use of multi-disciplinary expertise in treatment decision-making. It is also warranted to explore if decisions made in these multidisciplinary team meetings actually influence better patient cancer management and ultimately, survival.

Furthermore, because the communication between different disciplinary groups is essential for cancer management, as revealed by the current findings, a study is warranted that examines the impact of having all disciplines under one roof versus multiple roofs on not only the environment of communication between these groups, but also on the effect it has on treatment decision-making models and ultimately the treatment that is implemented. Does it enable a more streamlined approach? Does it optimize the multidisciplinary exchange required in planning treatments for these patients, etc.? And can it evolve to introduce other clinical care specialists whose patients *may also* have cancer and require special considerations. For example, a lung cancer patient who has severe mental health issues that may influence his or her ability to complete treatment

Some physicians also shared the view that lung cancer patients do not seem as motivated as other cancer patients to seek treatment. Could this perhaps be due to the notion linked to smoking and the mentality, “I did this to myself”? It is an issue worth exploring.

Physicians were of the opinion that clinical evidence was not always relevant to the patient in front of them, and that guidelines did not always apply to all the “real-life” patient’s physicians see day-to-day. Perhaps it would be worthwhile for larger clinical studies testing the efficacy of drugs to cast their net wider in selecting a patient population that is not just the “best” and the “fittest” as physicians claimed in this study, but instead select a patient population that is a reflection of the patients physicians see day-to-day (i.e., like older patients). In other words, shifting from an efficacy goal to an effectiveness goal when testing new care options. The trials should also build in a qualitative component that captures these patients’ quality of life.

The Cancer System Quality Index illustrated the practice patterns across Ontario in the management of stage II and stage IIIA resected non-small cell lung cancer, and stage IIIA and stage IIIB non-resected non-small cell lung cancer. In other words, it illustrated a picture of the variation of FINAL treatments being implemented and the variation in this metric. What the Cancer System Quality Index failed to show us was *how* these final treatment decisions were actually reached? The current study aimed to understand this *how* question, which then allowed us to shed light on *why* particular treatments were being implemented in some cases and not in others across the province of Ontario. For example, as the study showed, although clinical practice guidelines played a role in the treatment-decision making process, their role was always considered in combination with other

important factors as well, such as the lack of patient support networks; where sometimes, the lack of patient support networks would contribute more significantly in the final treatment decision than the recommended clinical guideline. Thus, this study helps in taking the first step in illustrating *why* or *why not* the clinical guidelines are being implemented specifically in the stage II and stage IIIA and stage IIIB non-small cell lung cancer context.

It is also noteworthy that the Cancer System Quality Index data is unable to differentiate patients according to key elements in the guideline, such as functional status, weight loss, etc.. Therefore, the conclusion that clinical practice, particularly for the Stage III patients, where treatment is dependent on these clinical characteristics, is inadequate may be misguided. Thus, metrics of adherence to the guideline, as reported by the Cancer System Quality Index, is likely influenced by the complexity of the decision making process, as revealed in this study, as well as data quality issues. Indeed, some of the study participants reported concerns with Cancer System Quality Index data quality and completeness, and challenges with the interpretability of data such as this (although not presented as a central focus in the results).

How might we use the findings of this current study to understand current patterns of treatment of stage II and III non-small cell lung cancer? What are some of the next steps in a program of research designed to understand the data of this study? Unfortunately, the study's current design did not allow one to address the question of why there may be practice variation across regions in Ontario in the treatment of (stage II and stage IIIA and stage IIIB) non-small cell lung cancer. However, the following study serves as a strong prerequisite for addressing such a question. It unfolds the factors involved in the treatment decision-making process that may begin to inform the variation in practice patterns. For example,

varying physicians' clinical judgements can cause differences in what treatments are ultimately recommended to the patient. Thus, is it clinical judgement that is causing variation? The current study also showed that multidisciplinary groups play a large role in the treatment decision making model. Thus, how is the communication and relationship between different disciplinary groups in different hospitals and cancer centres across Ontario? Does the strength of communication between disciplinary groups influence practice variation? Physicians also shared that some patients were fluent in English, had more education and more health literacy than other patients. Do patient characteristics such as English fluency and health literacy contribute to practice pattern variation? Furthermore, to address practice variation, it would be important to ask questions such as these: are there differences in the patient preferences or patient characteristics because of geography and where they live? For example, do patients in some jurisdictions wait longer when potential symptoms present than patients in other regions, perhaps due to poverty, different perceptions of entitlement to health care, or the like? Could these differences translate into patients in some jurisdictions presenting with poor health status thus making them less likely to be appropriate candidates for certain care options than patients in other jurisdictions with better health care status? Where have physicians been trained in the different LHINs? Are they predominately from Ontario, or have they been trained elsewhere and do these differences create a different normative context or different interpretation (or acceptance) of evidence?

In addition, discussions with some physicians “off the recorder” revealed that in Ontario there are different payment models: some physicians get paid a salary while others get paid on a “fee per service”. It would be important to consider payment models and their relation to how cancer patients are treated. Is there a difference between how physicians

make treatment decisions with their patients depending on the method according to which they get paid? Is there a difference in practice because of payment models? Do physicians who get paid a fee per service differ in recommending particular treatments from those who are paid per treatment? Is this, if not consciously but subconsciously, playing a role? Thus, is there a contribution of payment models to the variability in practice?

The current study also highlighted the importance of clinical guidelines and the role they play relative to the other elements involved in the treatment decision-making process. Guidelines can be used within continuing medical education or to answer specific clinical questions, especially for those who are not familiar with the area in which they are prescribed. However, it is warranted to offer disclaimers with these guidelines. Especially for novice physicians, coming out of training, it would be important to mention and be vigilant that it is important to individualize treatment and not blindly offer guidelines but carefully select patients for whom the guidelines are appropriate. This is how guidelines were intended and it is important that these principles are maintained.

Furthermore, because of any disparities in accessibility in certain remote areas of Ontario, a patient diagnosed with a cancer should have the possibility of going online to see what their treatment options should be. If physicians recommend or do not recommend particular treatments (i.e. such as those recommended by the guidelines), patients can raise this with their physicians, and have physicians discuss with them why or why not these treatment options are applicable to them, or why they are not being offered those treatments. This will, in turn, also help facilitate a patient's involvement in the treatment decision-making process and help them ask more questions, be more informed and make good decisions

about their health. This will also help challenge physicians and help facilitate their use of their own clinical judgement of when they think guidelines should or shouldn't be used.

A way to effectively support cancer patients and their families as they contemplate treatment decisions is by conducting more mixed-method studies that can focus on the patient's perspectives. This will advance the understanding of this challenging aspect of clinical oncology – treatment decision-making — and unravel the intricacies of the decisions faced by patients and their families, and help physicians make optimal decisions.

CHAPTER 6: CONCLUSION

In oncology you always have [a treatment] choice. There is a better one, a worse choice but you always have choice, including no treatment. That is not to say that there is no management but no treatment in the sense of active surgery or chemo or radiation or something like that, and then there is palliative care too, which is treatment... And sometimes just the patient coming to see you and talking to you, because it's like a psychological benefit to it even though you may be doing absolutely nothing medically (SO1).

This study has examined the treatment decision-making process of stage II and stage IIIA and stage IIIB non-small cell lung cancer patients from the physician's perspective. Five main factors are found that guide the treatment-decision process: the unique patient, the unique physician, the family, the clinical team, and the clinical evidence. Decision-making roles in lung cancer are complex and nuanced. Patients, for example, seek perspectives from family and friends as well as physicians, who, for their part, use their clinical judgement based on clinical evidence and personal experience, and consult with colleagues. Thus, information from a large number of sources and a wide array of factors, people, emotions, preferences, clinical expertise, experiences, and clinical evidence informs the dynamic process of treatment decision-making.

In this last chapter, I discuss the strengths of the study, its limitations, and implications.

6.1 Strengths of the Study

This study uses grounded theory. The procedures of data collection, data analysis, and theory development are framed according to the grounded theory methodology outlined by Kathy Charmaz (2006). My protocol was designed a priori and executed according to

plan. Grounded theory has offered insights into the nature and complexity of treatment decision-making not apparent in the literature.

The participants in this study represent a variety of disciplines from different (but not all) LHINs. This was intended to assist exploration of professional and administrative factors – whether, that is, differences between disciplinary groups or regional authorities influence decision-making. Introducing these parameters has made the study more robust and reinforces the finding of commonalities in physician experience when making treatment decisions with their non-small cell lung cancer patients.

6.2 Limitations of the Study

Among the main limitations of this study are those related to recall bias, self-reporting, study practicalities (physician location and time for checking), and generalizability. The first limitation is the recall bias that resulted from the interviews being conducted retrospectively. The findings might have been influenced by a number of factors in this respect, including the sheer length of time that had elapsed since a treatment decision and the physician's consequent failure to recall particular elements involved in the decision-making process. It is also important to note that the participants' responses were not exhaustive. Because of time constraints, I was unable to return to them for further discussions. Thus, the information provided may have been the most important to them at the time of the interviews, but they may have had second thoughts since then.

Secondly, although physicians were articulate and reflective about their decision-making experiences with their non-small cell lung cancer patients, the questions were open-ended, meaning that information was self-solicited and selected. This dependency on self-

reported data implies various possible shortcomings, for example a discrepancy between what physicians say they do and what they actually do. Similarly, physicians spoke deeply about patient preferences contributing to the treatment decision-making process, but there may be significant differences between physicians' perceptions of patients' preferences and the actual preferences themselves, including, for example, differences between physicians' perceptions of what patients think are harmful side effects of a treatment and what patients really think about this. How physicians assess patient preference and perception and the (assumed) gap between physician assessment and patient reality warrant further study. Recording consultations between physicians and patients and conducting a content analysis would have been another way to explore the same topic but overcoming this limitation.

Thirdly, there was, unfortunately, a rather limited recruitment of participant physicians serving rural areas (primarily because of their busy schedules). Most of the informants of this study reside in larger urban centres. Although the aim of the research was not to produce statistically generalizable results, we can speculate that physicians practicing in rural areas – where access to both medical facilities and healthcare information is often limited for patients, but consultations proceed at a more relaxed pace – may have provided different insights and observations.

Also, time limitations of the study itself placed a constraint on sending a summary of the findings to participants as a form of member-checking. Such member-checking could have enhanced the dependability of the study.

Lastly, it is important to recognize that the purpose of this study was to explore a deep structural process as experienced by the participants; it was not to develop a theory that would be generalizable to all physicians treating patients with non-small cell lung cancer, and

any effort to do so would go beyond the scope of this investigation. Using the constructivist approach of grounded theory outlines that the researcher does not aim to discover an objective reality, but instead attempts to understand the reality as experienced by the participants, and then, by co-constructing the meaning of the phenomenon studied with the participants by listening to their experiences, develop a characterization of the particular situation. The end product of such a study, Charmaz (2000) explains, is “more like a painting than a photograph” (p. 522).

6.3 Implications

The diagnosis of cancer can result in fear, uncertainty, and commitment to often complex and arduous treatments. The way in which treatment decisions are made, therefore, is an important element in a difficult journey. Treatment decision-making involves more than just the provision of information: it involves physicians in the role also of important contributors who input into, and guide a group process. This process depends on many factors in addition to the provision of clinical information to the patient on treatment options, like discussion of the benefits and risks of these options, and encompasses a heavy reliance on doctor expertise and advice. The treatment decision-making process depends on the patient’s delivery of information to the physician about his or her values, on discussion between physicians (informally and at tumour boards), and on a conversation between the patients and families and physicians and other professionals about which treatment to finally implement (and when to give up on a treatment and/or change treatments).

The current study reveals how contextual factors play a large role in choosing treatments; and how aware clinicians are that there is only this one “Mr. Smith” or “Mrs.

Khan” sitting in front of them. Emphasizing the individual is at the heart of treatment decision-making in non-small cell lung cancer. Thus, although the current study portrays the treatment decision-making process as a uniform experience for the participants, it illuminates also the importance of personalizing care; how one patient may benefit from a particular treatment may not be how another benefits, if it all.

It is important to note that physicians’ responses during the course of this research prompted valuable discussions about treatment variations among the non-small cell lung cancer patients themselves. By uncovering this dynamic process of decision-making, it was very clearly revealed that variation in final treatment decisions and ultimate implementation is not synonymous with error for patients. Such variation results, among other things, from differences in physicians’ judgements and perceptions about what constitutes optimal treatment for their particular “unique” patient, including consideration of that individual’s preferences and values. Treatment variation is a natural and positive result of the dynamic process of treatment decision-making. Physicians do not have one viewpoint, or straightforward answer such as those that clinical guidelines can sometimes prescribe to a patient population that is heterogeneous as the non-small cell lung cancer patient population.

It is noteworthy that the current findings also reveal that most physicians seek to involve patients to the degree they desire. Further studies should thus be aimed at understanding how doctors feel in assessing patient preferences, and how they actually do this. Studies examining the degree to which patients are really involved in the actual decision-making process according to their preferences are also warranted. Additionally, awareness of the fact that treatment preferences may vary across non-small cell lung cancer patients depending on patient characteristics should prompt health care providers in general to

proactively seek to determine patient preferences in order to provide the most appropriate care. This holds especially in the family context, since this is an important part in the treatment decision-making process.

Given the prevalence of non-small cell lung cancer in Canadians, the present study has aimed to produce a rich description of the treatment decision-making process that can provide a unique contribution to the literature. It represents a move toward a better understanding of how treatments come to be made by physicians with their non-small cell lung cancer patients. The findings presented here may suggest interventions that can aid in a stepwise approach to treatment decision-making without overwhelming the physician and patient. The critical data produced can also contribute to tailoring treatment decisions in the future. Knowing *how* physicians are making treatment-decisions, as opposed to merely knowing *what* treatments are being chosen with non-small cell lung cancer patients will help us better understand which factors (i.e. clinical guidelines) do or do not enter the treatment decision-making equation, and *why*. A fuller appreciation of the multiple factors that affect the way patients with non-small cell lung cancer are treated and which of these are most important to oncologists and patients in determining how to treat the illness can help us to better design interventions aimed at facilitating optimum clinical practice and to create improved clinical practice guidelines that assist patients and physicians in making more suitable and concordant decisions. Thus, the implications of this study should also be considered by policy makers as well as institutions such as Cancer Care Ontario to help design interventions (i.e. guidelines) that can be more readily used by physicians to help facilitate healing and provide optimal care.

In this study, participant physicians reported their experiences by gathering information about the individual (i.e. his/her medical status and patient preferences), acknowledging family involvement, using their own unique judgement of the patient, followed by considering team expert opinions, and considering the clinical evidence most relevant to the patient in front of them. A common process, making the best choice for the *individual* patient (and consequently “personalizing care”) was explicated. By embracing the complexity of treatment-decision making and understanding the importance of individualized treatment for any particular patient, we really do have the hope of achieving personalized care and optimizing patient outcomes. The physicians showed in this study that treatment decision-making is not solely a science, but truly is the art in medicine.

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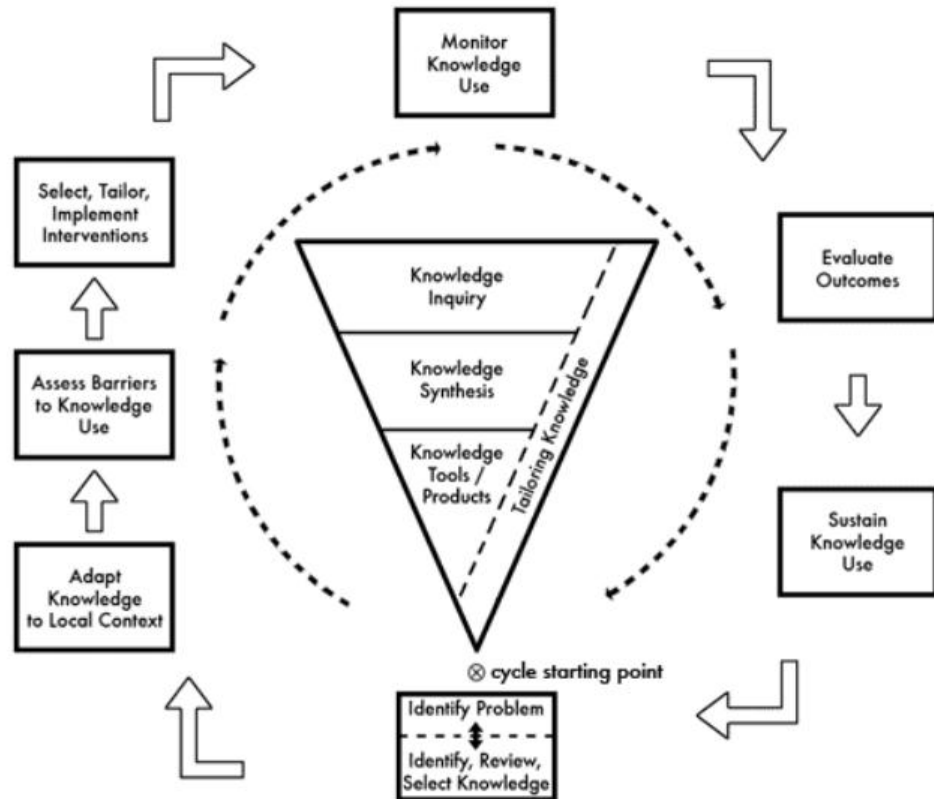
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APPENDIX A

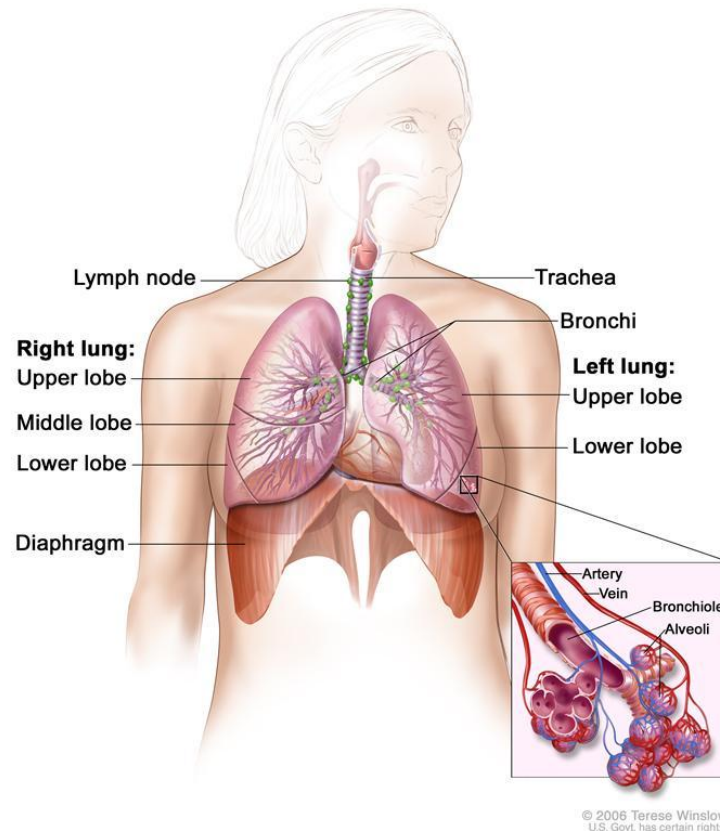
Knowledge to Action Cycle Figure



Source: Straus, E.S. & Holroyd-Leduc, J. (2008). Knowledge-to-action cycle. *Evid Based Med* 13:98-100.

APPENDIX B

The Anatomy of the Respiratory System



“Anatomy of the respiratory system, showing the trachea and both lungs and their lobes and airways. Lymph nodes and the diaphragm are also shown. Oxygen is inhaled into the lungs and passes through the thin membranes of the alveoli and into the bloodstream” (National Cancer Institute. 2012).

Source: National Cancer Institute. (2012). *Non-small cell lung cancer treatment: General information about non-small cell lung cancer*. Retrieved on February 15, 2012 from, <http://www.cancer.gov/cancertopics/pdq/treatment/non-small-cell-lung/Patient/page1>

APPENDIX C

TNM Classification

TNM Classification

Tumor (T)	
Tx	Primary tumor cannot be assessed
T0	No primary tumor
T1	Tumor < 3 cm and not in main bronchus
T2	Any of the following: <ul style="list-style-type: none"> - Tumor > 3 cm - Involving main bronchus but > 2 cm from carina (junction of right and left main bronchi) - Invading the pleura (outer lining of the lung) - Collapse of < one lung
T3	Any of the following: <ul style="list-style-type: none"> - Involvement of main bronchus < 2 cm from carina without involving the carina - Invasion of chest wall, diaphragm, pericardium, or mediastinal pleura (layer lining the organs between the lungs) - Collapse of the entire lung
T4	Any of the following: <ul style="list-style-type: none"> - Involvement of the carina - Invasion of mediastinum (organs between the lungs) including the heart, great vessels, trachea, esophagus, or vertebra - Malignant pleural (fluid around the lung) or pericardial (fluid around the heart) effusion - Additional tumor nodules in same lobe of the lung
Nodes (N)	
Nx	Lymph nodes cannot be assessed
N0	No nodal metastases
N1	Metastasis to lymph nodes within the lung or in the hilum (area where blood vessels enter the lung) on the same side as the tumor
N2	Metastasis to lymph nodes in the mediastinum (area between the lungs) on the same side as the tumor
N3	Metastasis to lymph nodes on the opposite side from the tumor or to lymph nodes above the collar bone
Metastases (M)	
Mx	Cannot assess distant metastases
M0	No distant metastases
M1	Presence of distant metastases

Source: Lin, J., Brown, K.J.R. & Chang, C.A. (2004). *Lung cancer: Who is a candidate for surgery?: An emerging role for PET scanning*. Retrieved on December 27, 2011, from, <http://www.cancernews.com/data/Article/265.asp>

APPENDIX D

Non-Small Cell Lung Cancer Staging (6th Edition of the TNM Staging)

Staging

		<u>Tumor (T)</u>			<u>Mets (M)</u>	
		T1	T2	T3	T4	M1
<u>Nodes (N)</u>	N0	IA	IB	IIB	IIIB	IV
	N1	IIA	IIB	IIIA	IIIB	IV
	N2	IIIA	IIIA	IIIA	IIIB	IV
	N3	IIIB	IIIB	IIIB	IIIB	IV
<u>Mets (M)</u>	M1	IV	IV	IV	IV	IV

The boxed area indicates lung cancers that are potentially resectable.
Abbreviations: Mets, metastases.

Source: Lin, J., Brown, K.J.R. & Chang, C.A. (2004). *Lung cancer: Who is a candidate for surgery?: An emerging role for PET scanning*. Retrieved on December 27, 2011, from, <http://www.cancernews.com/data/Article/265.asp>

APPENDIX E

Models of Treatment Decision-Making (Charles et al., 1999)

Models of treatment decision making ^a

Analytical stages		Models				
		Paternalistic	(in between approaches)	Shared	(in between approaches)	Informed
Information exchange	Flow	One way (largely)		Two way		One way (largely)
	Direction	Physician→patient		Physician↔patient		Physician→patient
	Type	Medical		Medical and personal		Medical
	Amount ^b	Minimum, legally required		All relevant for decision - making		All relevant for decision - making
Deliberation		Physician alone or with other physicians		Physician and patient (plus potential others)		Patient (plus potential others)
Deciding on treatment to implement		Physicians		Physician and patient		Patient

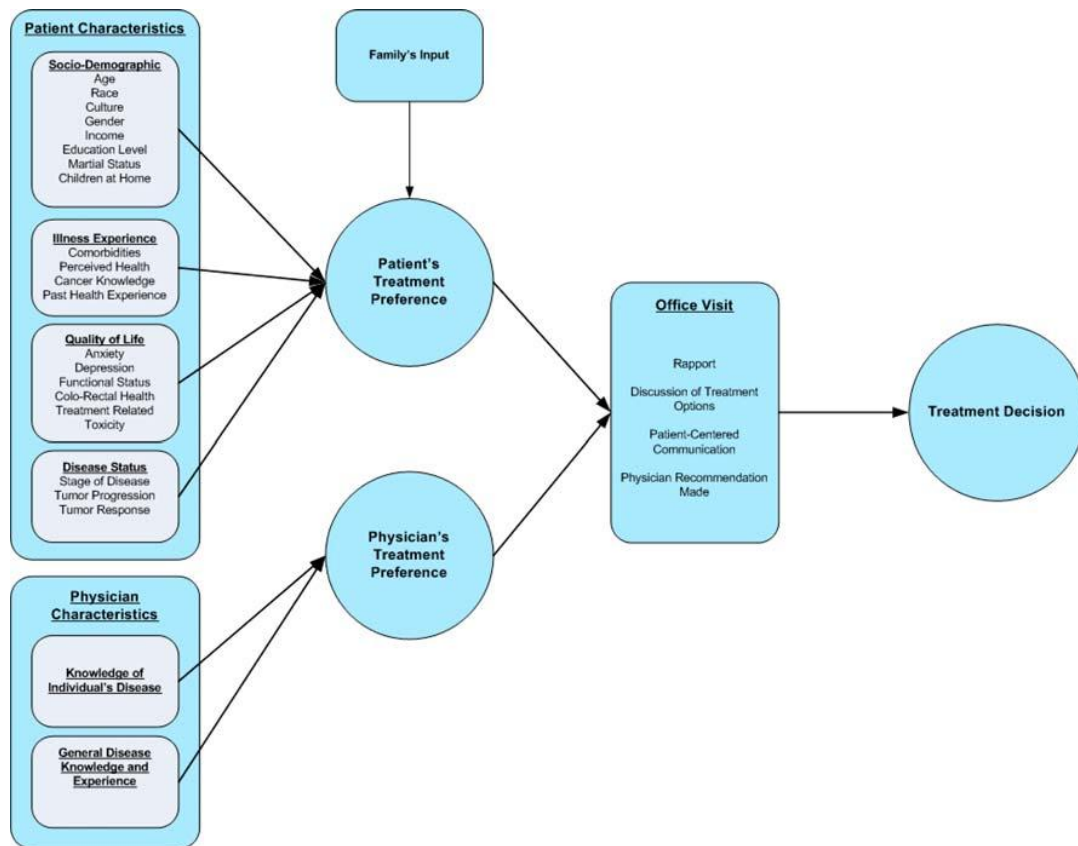
a Illustration for an encounter focusing on the case of a (treating) physician–patient dyad. For more complex cases see text

b Minimum required.

Source: Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine* 49(5):651-661.

APPENDIX F

An Existing Patient and Physician Treatment Decision-Making Model



“Patient and physician treatment decision-making model. Multiple factors are involved in the decision-making process as a treatment plan is developed” (p.122).

Source: Zafar, S.Y, Alexander, C.S., Weinfurt, P.K., Schulman, A.K. & Abernethy, P.A. (2009). Decision making and quality of life in the treatment of cancer: a review. *Support Care Cancer* 17:117-127.

APPENDIX G

Barriers and Enablers Analysis of Guidelines

Barriers and Enablers Analysis of Guidelines Table (M. Brouwers, 2011 [project proposal]).

Domain	Feature	Description
Knowledge	Awareness	Inability to correctly acknowledge existence of evidence and/or guideline.
	Familiarity	Inability to correctly answer questions about recommendation content.
	Forgetting	Inadvertently forgetting the recommendations.
Attitudes evidence	Interpretation of Evidence	Not believing recommendations are supported by evidence.
Attitudes applicability	Characteristics of Patients	Lack of agreement that recommendations apply to the characteristics of patients.
	Clinical Situation	Lack of agreement that recommendations apply to the clinical contexts in which treatment is practiced.
	Support for Reccs	Lack of agreement that CT should be offered to stage II and IIIA resected patients. Lack of agreement that CT-RT should be offered to stage IIIA and IIIB non-resected patients. Lack of agreement that a cisplatin agent is the most appropriate CT drug.
	Cost-benefit	Perception that there will be an increased cost if recommendations are implemented.
	Developers	Lack of confidence in the authors of the guideline. Lack of confidence in CCO advancing a quality agenda to improve lung cancer care in Ontario.
Attitudes general	Cookbook	Lack of agreement with recommendations because they are too artificial (formulaic).
	Challenge to Autonomy	Lack of agreement with recommendations because they threaten professional autonomy.
	Biased Synthesis	Belief that authors of guideline were biased.
	Not Practical	Lack of agreement with recommendations because they are too impractical to follow.
	Lack of Expectancy	Perception that performance following recommendations will not lead to improved patient outcomes.
	Health Care	Perception that performance following

Domain	Feature	Description
	Process	recommendations will not lead to improved health care process.
	Feeling Expectancy	Perception that performance following recommendations might provide difficult feelings or does not take into account current feelings.
	Self-Efficacy	Belief that one cannot implement recommendations.
	Motivation	Lack of motivation to implement recommendations and/or to change one's practice.
Behavior	Patient Preferences	Inability to reconcile recommendations with preferences expressed by patients.
Innovation	Trialability	Perception that recommendations can be experimented with on a trial basis.
	Compatibility	Perception that recommendations are not consistent with one's own approach.
	Observability	Perception that the benefits of implementing recommendations are not visible.
	Uncertainty	Perception that recommendations may increase uncertainty.
	Not modifiable	Perception that recommendations lack flexibility in the process of implementation.
	Time Pressure	Insufficient time to put recommendations into practice (e.g. make referral to cancer centre)
	Lack of resources	Insufficient materials or staff to put recommendations into practice (e.g. nobody to make referral to cancer centre)
	Organizational constraints	Insufficient support from the organization to support implementation of recommendations.
	Lack of Access to Services	Inadequate access to actual health care services (e.g. cancer centre clinicians) to put recommendations into practice.
	Lack of Reimbursement	Insufficient reinforcement for putting recommendations into practice.
	Perceived increase in malpractice liability	

APPENDIX H

Research Ethics Approval Letter



RESEARCH ETHICS BOARD



REB Office, 293 Wellington St. N., Suite 102, Hamilton, ON L8L 8E7
Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8378

Research Ethics Board Membership

Suzette Salama PhD
Interim-Chair/Ethics Representative
Donald Arnold MD, MSc FRCP(C)
Hematology & Thromboembolism
Uma Athale MBBS, MD, M.Sc. FRCP
Pediatric Hematology/Oncology
Mary Bedek CCHRA (C)
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David Clark MD PhD FRCP(C)
Medicine
Jean Crowe MHSc
Rehabilitation Science
Lynn Donohue BA(Hons)
Community Representative
Melanie Griffiths FRCR (UK)
Diagnostic Imaging
Ali Hersi MD, PhD, FRCP
Emergency Medicine
Cindy James BScN
Gastroenterology
David Jewell M S.W, MHSC
Geriatrics
Graham Jones BSc, MSc, PhD, MD,
FRCP, FCCP
Medicine
Peter Kavaak PhD, FCACB, FACC
Laboratory Medicine
Rosanne Kent RN BA MHSc(M)
Cardiology
Oliver Klimek MDiv, MA
Research Ethics Officer
Grigorios Leontiadis MD PhD,
Gastroenterology
Steve Lloyd MD
Family Medicine
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Leslie Murray RT (R), BAppSc (MI)
Medical Radiation
Madhu Natarajan MD, FRCP, FACC
Cardiology
Kesava Reddy MB BS FRCSC FACS
Neurosurgery
Susan Rivers RN MSC (T),
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Administration
Stephen Walter PhD
Clinical Epidemiology & Biostatistics
Kathryn Weibert MD
Transfusion Medicine
Andrew Worster MD
Emergency Medicine
Ed Younglai PhD
Obstetrics/Gynecology

July 22, 2011

PROJECT NUMBER: 11-327

PROJECT TITLE: Analysis and Assessment of Physician Practice Patterns in the Treatment of Non-Small Cell Lung Cancer Patients in Ontario: Working together to optimize the treatment of non-small cell lung cancer patients in Ontario

PRINCIPAL INVESTIGATOR: Dr. Melissa Brouwers

As you are aware your study was presented at the July 19, 2011 Research Ethics Board meeting where it received *final* approval from the full REB. The submission, research proposal version 1.0 dated June 23, 2011 including the Sample letter of invitation to be sent by e-mail, the sample telephone script, Interview Guide and the Sample Questionnaire, all versions 1.0 dated June 24, 2011 was found to be acceptable on both ethical and scientific grounds.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the REB meeting on July 19, 2011. Continuation beyond that date will require further review and renewal of REB approval. Any changes or revisions to the original submission must be submitted on an REB amendment form for review and approval by the Research Ethics Board.

The Hamilton Health Sciences/McMaster Health Sciences Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations.

PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON
ALL FUTURE CORRESPONDENCE

Sincerely,

Suzette Salama, PhD
Interim-Chair, Research Ethics Board

APPENDIX I

Initial Letter of Invitation to Program Heads

The following message is sent on behalf of [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario].

Department of Oncology Henderson Site
905-527-4322
60(G) Wing, 2nd Floor Ext 42832
711 Concession Street Fax 905-526-6775
Hamilton, ON L8V 1C3

[Name of Program Head]

[Program Head of: Surgical Oncology/Radiation Oncology/Systemic Therapy Program]

[Name of Institution]

12th August, 2011

RE: Request For Assistance on a Research Project

Analysis and Assessment of Physician Practice Patterns in the Treatment of Non-Small Cell Lung Cancer Patients in Ontario: Working Together to Optimize the Treatment of Non-Small Cell Lung Cancer Patients in Ontario.

Dear [Name of Program Head],

I hope this note finds you well and that each of you has been able to take at least a wee break during this gorgeous summer. I am writing to you wearing my health services researcher hat. As you know, as part of the Disease Pathway Management (DPM) initiative of Cancer Care Ontario (CCO), the Lung Cancer Team studied lung cancer treatment practice patterns and adherence with PEBC clinical practice guideline (PG) recommendations. The data show significant regional variation and patterns indicating that practice may not be optimal. I have been given funding by CCO to conduct a research study to explore this further and to better understand clinicians' perceptions of these data and of the PGs and how the clinicians

approach the treatment of these patients. This project has received ethics approval from the Hamilton Health Sciences/McMaster University Research Ethics Board (REB# 11-327).

As one step to this project, we would like to conduct Key Informant interviews with surgeons, radiation oncologists, and medical oncologists; ideally, with at least 5 individuals or so from each discipline. I am writing to seek your assistance with this process in two ways. First, I am asking if you would help by identifying up to 10 candidate clinicians within your discipline whom you would recommend we approach. We are looking for clinicians who treat lung cancer, who practice in different regions, and, where relevant, who practice in varying environments (community hospital, cancer centre, academic hospital, etc). Second, and as a means to increase person recognition and participation rates, I am asking if you would consider co-signing with me the letter of invitation to these candidate clinicians. A copy of the draft letter is attached.

I realize that each of you is extremely busy and that your programs receive many requests for assistance. However, I do believe this is an exciting project that could be of benefit to all of us. The project, as a whole, will provide us with useful data regarding the generalizability of PEBC guidelines to practice and will result in a comprehensive analysis of barriers to guideline implementation. The goal will be to use these data to inform the design of strategies and quality improvement initiatives that will lead to better use of evidence in practice.

I would appreciate if in your response you would please copy [Name], my research manager [insert email address]. If you are in agreement with this proposal, she will follow up with you or your identified designate to implement the plan. Thank you for your consideration. I look forward to hearing from you soon.

Warm regards,
[Name]

Director Program in Evidence-based Care Cancer Care Ontario
Associate Professor Head of Health Services Research Department of Oncology, McMaster University

APPENDIX J

Initial Letter of Invitation to Participants

This letter of invitation is being sent on behalf of [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] & [Name of Program Head/Nominating or Referring Physician]

Department of Oncology Juravinski Site
Phone 905-527-4322
60(G) Wing, 2nd Floor Ext 42832
711 Concession Street Fax 905-526-6775
Hamilton, ON L8V 1C3

August 24, 2011

[Participants Name]
[Name of Institution]

RE: Invitation to Participate in Provincial Lung Cancer Research Project

Dear [Name of Participant],

On behalf of the project co-investigators, we request your consideration to participate in the research study titled: “Working Together to Optimize the Treatment of Non-small cell lung cancer Patients in Ontario”.

Your participation would involve participating as a key informant in a telephone or in-person interview to discuss the treatment and care of stage II and IIIA/B non-small cell lung cancer patients in Ontario.

This project is funded by Cancer Care Ontario (CCO) and has received research ethics approval from the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board (REB #11-327). As part of their quality improvement mandate, CCO has requested this study be undertaken to better understand the treatment of patients with lung cancer, the role of CCO clinical practice guidelines in guiding treatment choices, and the barriers and enablers associated with best practice. To that end, the objective of the interview is to ascertain, from the perspectives of clinical leaders and

administrators, issues related to creating an environment that enables best practice with these patients.

Given your experience in treating lung cancer patients and/or your role as a regional cancer program administrative leader in lung cancer, we request your participation. Your participation would involve participating in one interview, which is expected to last one hour. Your participation is completely voluntary and you are free to withdraw at any time during the study by simply notifying us of your intent to withdraw. You will be assigned a unique identifier number, and as such, your responses will remain confidential and will be used for comparative purposes only. All results will be held in a secure database on a password protected computer.

If you wish to participate, simply reply to this email indicating your interest to participate by August 31, 2011. We greatly appreciate your consideration and thank you in advance for your time.

If you have any questions regarding this project, please contact [Name], Program Manager at [insert email address]. If you have any questions regarding your rights as a research participant, you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at (905) 521-2100 x42013 (ethicsoffice@mcmaster.ca).

Yours sincerely,

[Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario]

[Name of Program Head/Referring Physician]

Principal Investigator

[Title of Program Head/Referring Physician]

Associate Professor & Health Services Research Lead,

Cancer Care Ontario

Department of Oncology, McMaster University

APPENDIX K

Letter to Set-Up Interview – To Participants (Physicians)

Department of Oncology Juravinski Site
Phone 905-527-4322
60(G) Wing, 2nd Floor Ext 42832
711 Concession Street Fax 905-526-6775
Hamilton, ON L8V 1C3

[Date]

[Name of Physician]
[Title and Name of Institution]

RE: Interview - Provincial Lung Cancer Research Project

Dear [Name of Physician],

Earlier, you were contacted by [Name] on behalf of the project co-investigators, who requested your consideration to participate in the research study titled, “Working Together to Optimize the Treatment of Non-Small Cell Lung Cancer Patients in Ontario”.

I am writing to schedule an interview date and time, and to introduce myself. My name is Saira Akram, and I am a Master's student in the Health Research and Methodology Program at McMaster University. I am conducting the key informant interviews as part of the requirements of my thesis.

As you might recall, this study is funded by Cancer Care Ontario and [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] is the project's principal investigator. A core objective of the study is to conduct an analysis with the clinical community (i.e. medical oncologists, radiation oncologists, surgical oncologists) in Ontario to better understand the treatment decision-making process with stage II and stage IIIA resected non-small cell lung cancer patients, and stage IIIA and stage IIIB non-resected non-small cell lung cancer patients.

My goal in the interview is to capture a deeper understanding of how physicians are making

treatment decisions with their non-small cell lung cancer patients, the role, if any, the PEBC/CCO clinical practice guidelines (7-1-2 & 7-3) are playing in guiding treatment choices, and the barriers and enablers associated with best practice. The interview will take place at a mutually agreed upon time and place, and should last about 45-60 minutes. The interview will follow a semi-structured format and it will be audio taped so that I can accurately capture and reflect on what is discussed. The recordings will only be reviewed by members of the research team who will transcribe and analyze them. The recordings will then be destroyed. In addition to your participation in the interview, I will also submit to you a summary of my interpretations of the interview discussions for your verification.

As a reminder, your participation is voluntary and you are free to withdraw at any time by simply notifying me. Further, all the information you provide to me is confidential and will be kept in a secure location. Your information will be anonymized and when the results of the study are published or presented at professional meetings, your identity will not be revealed. This study has received ethics approval from the Hamilton Health Sciences/McMaster University Research Ethics Board (REB#11-327).

In terms of next steps, I would ask that you kindly email me your availability by [insert date here] so that we may schedule the interview. I will require a one-hour time slot.

If you have any questions, please contact me at [insert email here] or [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] at [insert email here]. Thank you for your consideration and time. I look forward to hearing from you.

With kind regards,
Saira Akram, MSc (c)

APPENDIX L

Letter to Set-Up Interview – To Participants (Administrators)

Department of Oncology Juravinski Site
Phone 905-527-4322
60(G) Wing, 2nd Floor Ext 42832
711 Concession Street Fax 905-526-6775
Hamilton, ON L8V 1C3

[Date]

[Administrator's Name]

[Institution Name]

RE: Interview - Provincial Lung Cancer Research Project

Dear [Administrator Name],

Earlier, you were contacted by [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] who requested your consideration to participate in the research study titled, "Working Together to Optimize the Treatment of Non-small cell lung cancer Patients in Ontario".

I am writing to schedule an interview date and time, and to introduce myself. My name is Saira Akram, and I am a Master's student in the Health Research and Methodology Program at McMaster University. I am conducting the key informant interviews as part of the requirements of my thesis.

As you might recall, this study is funded by Cancer Care Ontario and [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] is the project's principal investigator. A core objective of the study is to conduct a series of key informant interviews with clinicians who treat patients with non-small cell lung cancer and senior administrative leaders (at a provincial level and a regional level) who are responsible for overall quality issues for their jurisdiction.

The interview will take place at a mutually agreed upon time and place, and should last about

45-60 minutes. The interview will follow a semi-structured format and it will be audio taped so that I can accurately capture and reflect on what is discussed. The recordings will only be reviewed by members of the research team who will transcribe and analyze them. The recordings will then be destroyed.

In addition to your participation in the interview, I will also submit to you a summary of my interpretations of the interview discussions for your verification.

As a reminder, your participation is voluntary and you are free to withdraw at any time by simply notifying me. Further, all the information you provide to me is confidential and will be kept in a secure location. Your information will be anonymized and when the results of the study are published or presented at professional meetings, your identity will not be revealed. This study has received ethics approval from the Hamilton Health Sciences/McMaster University Research Ethics Board (REB#11-327).

In terms of next steps, I would ask that you kindly email me your availability by [insert date here] so that we may schedule the interview. I will require a one-hour time slot.

If you have any questions, please contact me at [insert email here] or [Name of Provincial Director of Program in Evidence-based Care, Cancer Care Ontario] at [insert email here]. Thank you for your consideration and time. I look forward to hearing from you.

With kind regards,
Saira Akram, MSc (c)

APPENDIX M

Interview Information Sheet and Question Guide – For Physicians

Interview Script:

Good morning/ afternoon. I want to thank you for taking the time to meet/talk with me today. My name is Saira and I would like to talk to you about your experiences in treating patients with lung cancer.

More specifically as one of the components of our overall project, our goal is to capture a deeper understanding of how physicians are making treatments decisions with their non-small cell lung cancer patients, the role of PEBC/CCO clinical practice guidelines (7-1-2 & 7-3) are playing in guiding treatment choices, and the barriers and enablers associated with optimum practice. The findings of this study will help design interventions aimed to facilitate optimum clinical practice.

The format of the interview is semi-structured and has a set of questions and a framework of themes that I wish to explore. The interview should take less than an hour. If you don't mind, I will be taping the session because I want to have an accurate record of the information you share with me today. Because we're on tape, please be sure to speak up so that I don't miss your comments. Please note that you will not be identified on this recording, and all responses will be kept strictly confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent.

Are there any questions about what I have just explained? If not, let's begin.

I will start the tape recorder now.

Interview Questions:

Treatment Decision-Making Process

- 1) Could you tell me a little bit about how you generally approach treatment decision-making with your non-small cell lung cancer patient (specifically in stage II and stage IIIA resected; and stage IIIA and stage IIIB non-resected)?
 - a. Probe: How did you approach a recent case? (Give a few examples)
 - b. Probe: Have other cases gone differently?

- c. Probe: What does your treatment decision making process usually involve? (i.e. examples of other patient treatments and their relevance of the patient in front of you, patient preferences, CCO guidelines, standard treatment, personal, social, clinical situation of the patient?)
- d. Probe: What do you typically recommend to your stage II and stage IIIA resected non-small cell lung cancer patients? And what do you typically recommend to your stage IIIA and stage IIIB non-resected non-small cell lung cancer patients?
- e. Probe: Are the discussions with these patients challenging or uncomfortable?

Regarding Data and Guidelines

- 1) Can you please explain to me how familiar you are with the clinical evidence, and with the primary clinical studies regarding the treatment of non-small cell lung cancer patients?
- 2) How are you made aware of these PEBC/CCO clinical guidelines?
 - a. Probe: How are you alerted of this information?
 - b. Probe: How do you access this information? (i.e. larger cancer centres may have CCO representatives, but what about smaller cancer centres? What are the mechanisms in communicating this information: reps, leaders, disease group?)
- 3) What are your thoughts on the PEBC/CCO clinical guidelines and from the evidence they are derived?
 - a. Probe: Do you find the evidence compelling?
 - b. Probe: What is your opinion of the research studies on which these treatment recommendations are based?
- 4) How generalizable, in your opinion are the findings of these research studies?
 - i. Probe: Share an example of one or more cases when treating patients with non-small cell lung cancer (stage II and stage IIIA resected/ and stage IIIA and stage IIIB non-resected) where you had made treatment decisions consistent with the PEBC/CCO guidelines.
 - ii. Probe: Share an example of one or more cases when treatment patients with non-small cell lung cancer (stage II and stage IIIA resected/ and stage IIIA and stage IIIB non-resected) where you had made treatment decisions but deviated from the PEBC/CCO guidelines.
- 5) What are the consequences of these guidelines being transferred into actual care? For the patient? For the physician? For other aspects of care?

- 6) Based on the data and the recommendations, do you perceive a practice gap or quality of care issue?

Regarding Adherence to Guidelines

- 1) Do you think that recommendations should be followed? Are they being followed enough, too much, too little?
- 2) *If the respondent agrees to the above question, and agrees that recommendations should be followed more.* What kinds of things might make these recommendations easier to follow?
 - Probe: What tools and strategies would be acceptable to you?
 - Probe: What is feasible in your practice setting?

Regarding Current Practice

- 1) *Surgeons or community medical oncologists:* Do you refer patients to the Cancer Centre for a consultation? Why or why not?
 - a. Probe: How does the Cancer Centre respond to your referral? (I.e. do they respond in a timely fashion?)
 - b. Probe: Do you see a pattern of patient preference that does not align with PEBC/CCO treatment recommendations?
- 2) Explain any issues around access to treatments for non-small cell lung cancer? (i.e. affordability – so costs of travel for the patient to get to treatment, physical accessibility - the patients are unable to get to treatment centres, acceptability of services, adequacy of supply)

Regarding Support Practice

- 1) How do you provide information or education to your patients?
 - a. Probe: What kinds of information resources do you use most to support your treatment discussions with your patients?
- 2) How do your patients respond to your use of educational information resources?
- 3) Does your clinic support the care and treatment of non-small cell lung cancer patients?

Ending Questions

- 1) So the purpose of this interview was to hear your thoughts about current clinical practice guidelines for non-small cell lung cancer patients, hear more about your current practice patterns, and better understand how physicians are making treatment decisions with their non-small cell lung cancer patients. Is there anything more you

would like to add? What other questions should we be asking about non-small cell lung cancer treatment and the Cancer Care Ontario guidelines?

APPENDIX N

Interview Information Sheet and Question Guide – For Administrators

Good morning/afternoon. I want to thank you for taking the time to meet and talk with me today. My name is Saira, and I'm a graduate student in the Health Research Methodology Program at McMaster University. I'm here to ask questions about your administrative perspective on Program in Evidence-based Care/CCO clinical guidelines in general and their use in the treatment decision-making for lung cancer, specifically non-small cell lung cancer patients in Ontario.

The format of the interview is semi-structured and has a set of questions that I would like to explore. The interview should take less than an hour. If you don't mind, I will be recording the session because I want to have an accurate record of the information you share with me today. Because we're on tape please be sure to speak up so that I do not miss your comments. Please note that you will not be identified on this recording, and all responses will be kept strictly confidential. This means that your interview responses will only be shared with the research team members, and we will ensure that any information we include in our report does not identify you as the respondent.

Are there any questions about what I have just explained? If not, let's begin.

I will start the tape recorder now.

Interview Questions

Regarding PEBC, Data and Guidelines

1. How familiar are you with the Program in Evidence-based Care in general?
2. Are you familiar with their guideline methodology process?
3. Are you familiar with the principles of evidence-informed guideline development?
4. Have you read a PEBC guideline before?
5. Are you aware of when new documents are released?
6. Is there a mechanism by which your region is made aware of a new or updated PEBC guideline
 - a. For example, is someone responsible for disseminating them to you, other administrative leaders, and the clinicians in your region?
 - b. Are there strategies you would like to see developed so that you are made aware of guidelines and the recommendations?
7. Do you use the guidelines to help justify or inform the development or implementation of quality initiatives within your region (OR IF IT'S A PROVINCIAL LEADER – within your provincial program)?

8. Do the clinical leaders in your region use PEBC guidelines to improve quality of care?

DEPENDING ON WHAT THEY ANSWER ABOVE

9. Are you aware of the guidelines related to the treatment of non-small cell lung cancer patients?
10. If yes,
 - a. Are you aware of the recommendations?
 - b. Do you have an opinion about the quality of these guidelines or the quality of the evidence-base underpinning the recommendations?

Performance Data

My project is in response to recent data from the Cancer System Quality Index (CSQI) of practice patterns regarding treatment recommendations for Non-small cell lung cancer Patients [7-1-2 & 7-3]. These recommendations are:

- Patients with stage II and stage IIIA resected non-small cell lung cancer should receive cisplatin-based chemotherapy.
- Patients with stage IIIA and IIIB non-resected non-small cell lung cancer should receive chemo-radiotherapy with a cisplatin-based agent.

SHOW THEM THE GRAPH or DESCRIBE IT

11. So my question is: from an administrator perspective, what is your response to the above presented information?
 - a. Probe: Do you perceive a practice gap or quality of care issue across the province?
 - b. Are you concerned with these patterns?
 - c. Are you concerned about the performance for your region?
 - d. Does this data suggest action is required? Would this be action by you?
 - e. Do you see a role for the PEBC guideline to help address this variation in practice?
 - f. If yes,
 - i. How should that role be operationalize to optimize the value of a PEBC guideline
 - ii. Probe: Whom do we need to communicate to? The individual physicians? The multi-disciplinary groups as a whole? Multidisciplinary cancer conferences? Who should communicate? You, the clinical lead, the PEBC directly?

Ending Questions

12. So the purpose of this interview was to hear your thoughts about current clinical practice guidelines for non-small cell lung cancer patients, hear more about clinical practice patterns, and better understand your administrative perspective on the practice variation we are seeing for stage II and stage III non-small cell lung cancer patients across regions in Ontario. Is there anything more you would like to add? What other questions should we be asking about these recommendations, the treatment decision-making for non-small cell lung cancer patients, and current practice patterns to administrators, or physicians treating these specific patients?

APPENDIX O

PHYSICIAN DEMOGRAPHIC QUESTIONNAIRE

Physician ID No. _____

Today's Date _____

In order to describe the physicians that have agreed to participate within this study, we are asking each of the physicians to answer a few questions about themselves. Please be assured that no names will be used, and only the research teams will have access to the information you provide in this questionnaire.

Personal Details

1. In addition to your clinical responsibilities, do you have other roles in the cancer centre/hospital? (Place a checkmark in the appropriate box)

- Educational duties or roles
- Research duties
- Quality improvement activities, locally, regionally, provincially
- Administrative duties (i.e. division lead, clinician group leader)

2. How old are you? (Place a checkmark in the appropriate box)

- ≤25 years old
- 26-35 years old
- 36-45 years old
- ≥46 years old

3. How many years have you been in medical practice (as a medical oncologist, radiation oncologist or surgeon)? (Place a checkmark in the appropriate box)

- ≤ 10 years in medical practice
- >10 years in medical practice

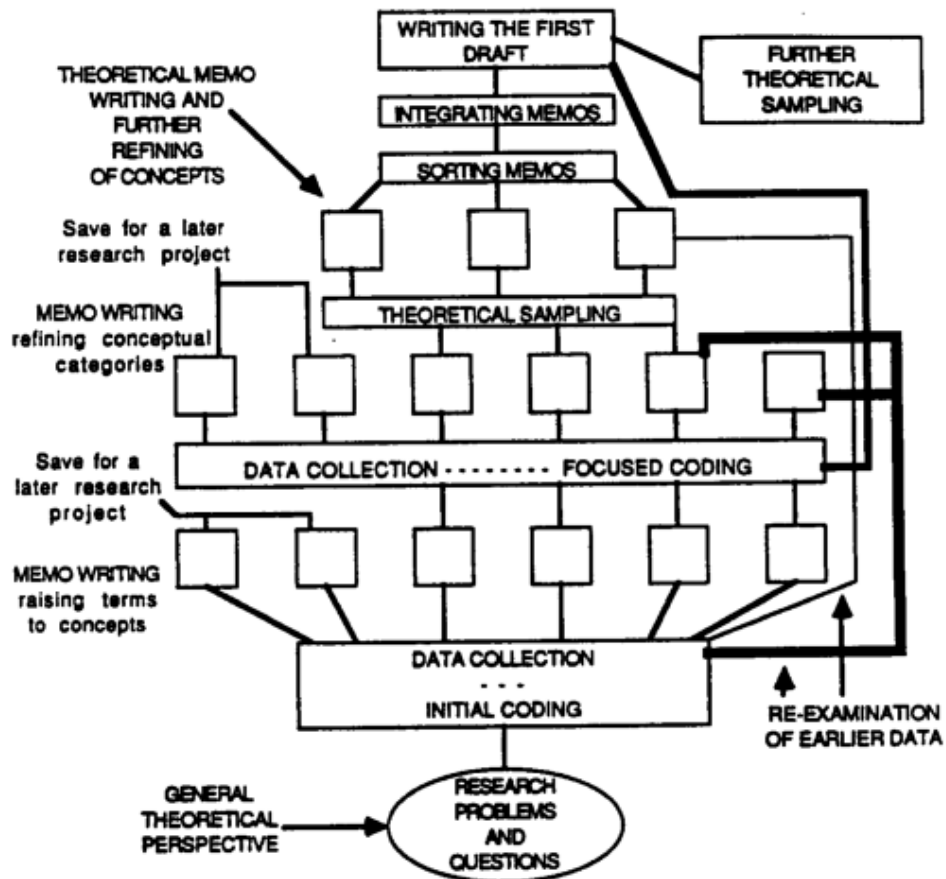
Medical Practice and Treatment Details

4. What is the approximate number of non-small cell lung cancer patients with stage II and stage IIIA resected non-small cell lung cancer and stage IIIA and IIIB non-resected non-small cell lung cancer do you approximately see annually? (Fill in the blank)
-

- 4.1 How many of these patients seen (above) are new patients? (Fill in the blank)
-

APPENDIX P

Overview of Grounded Theory Procedures Employed With the Present Research

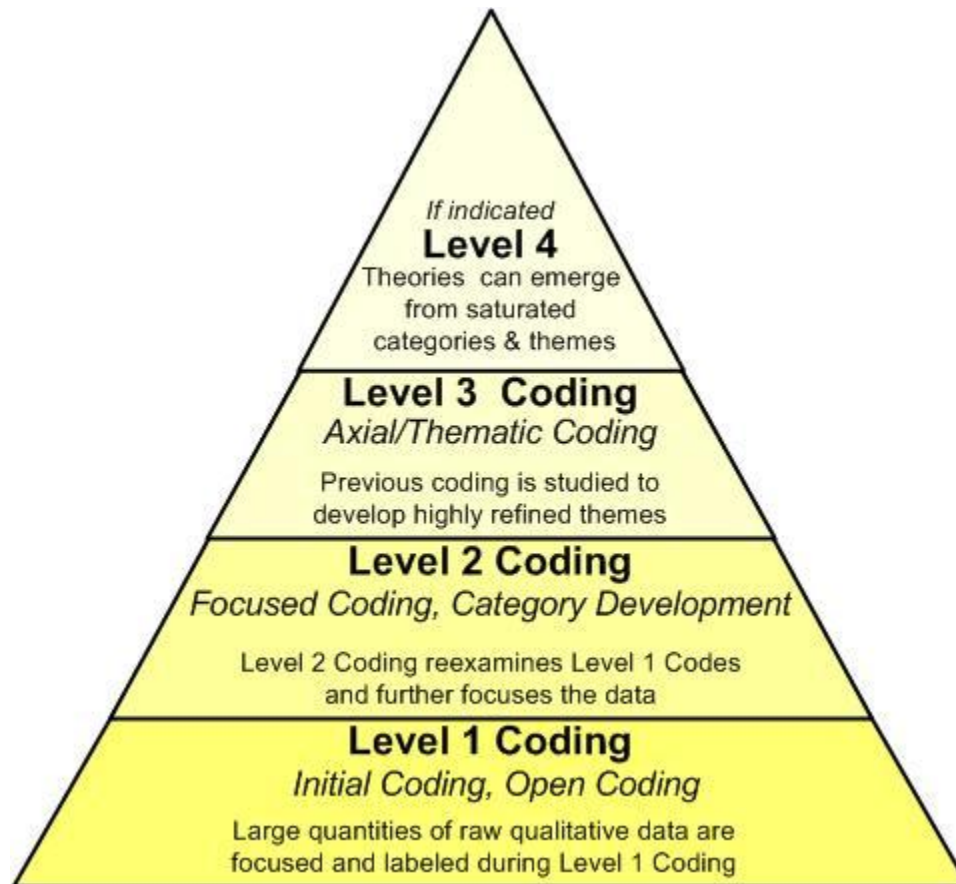


Research levels in the grounded theory method (Charmaz, 1990, p.1166)

Source: Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine* 30(11):1161-1172

APPENDIX Q

Types of Coding and Coding Terminology



“This illustration is best viewed from the bottom up as the data are progressively refined to arrive at categories, themes, and theories. The generalizations in this illustration are meant to broadly describe stages of the coding process while recognizing and upholding the vibrant differences between various qualitative methods” (Hanh, 2012).

Source: Hahn, C. (2012). *Doing qualitative research using your computer a practical guide*. Retrieved on February 16, 2012, from, <http://qtrtips.com/faq/FAQ--code%20terms.htm>

APPENDIX R

Transcriptionist Confidentiality Agreement

This study is a student research project conducted by a Master's of Science student in the Health Research Methodology Graduate Program for McMaster University, Saira Akram, under the supervision of Dr. Melissa Brouwers. The purpose of this study is in response to recent data of practice patterns regarding treatment recommendations for non-small cell lung cancer patients. This thesis aims to better understand the treatment decision-making process in non-small cell lung cancer, and better understand the apparent gap in clinical practice and what is recommended in evidence-based clinical practice guidelines, through conducting semi-structured interviews with physicians and health care administrators from across Ontario Cancer Centre's.

I, _____, the *Transcriptionist*, agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. transcripts, mp3 files) with anyone other than the Researcher(s).
2. Keep all research information in any form or format (i.e. transcripts, mp3 files) to the Researcher(s) when I have completed the research tasks.
3. After consulting with the Researcher(s), erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher(s) (i.e. information stored on my or any computer hard drive).

Transcriptionist

Print Name

Signature

Date

Researcher(s)

Print Name

Signature

Date

If you have any questions or concerns about this research study please contact:

Saira Akram, MSc Student, Health Research Methodology
McMaster University
Phone: 905 616 XXXX/Email: [email address here]

APPENDIX S

ECOG Performance Status Description

ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

ECOG PERFORMANCE STATUS*	
Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.:
 Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: *Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol* 5:649-655, 1982.

The ECOG Performance Status is in the public domain therefore available for public use. To duplicate the scale, please cite the reference above and credit the Eastern Cooperative Oncology Group, Robert Comis M.D., Group Chair.

Source: Eastern Cooperative Oncology Group. (2000). *ECOG Performance Status*. Retrieved on October 31, 2012 from, http://www.ecog.org/general/perf_stat.html

APPENDIX T

Glossary of Terms

Table: Definition of Terms

Term	Definition	Source
Bronchoscopy	a usually flexible endoscope for inspecting or passing instruments into the bronchi (as to obtain tissue for biopsy)	Merriam-Webster, Incorporated. (2012). <i>Bronchoscopy</i> . Retrieved on January 12, 2012 from, http://www.merriam-webster.com/dictionary/bronchoscope
Carcinoma	a malignant tumor of epithelial origin	Merriam-Webster, Incorporated. (2012). <i>Carcinoma</i> . Retrieved on January 12, 2012 from, http://www.merriam-webster.com/dictionary/carcinoma
Chemotherapy	the use of chemical agents in the treatment or control of disease (as cancer) or mental illness	Merriam-Webster, Incorporated. (2012). <i>Chemotherapy</i> . Retrieved on January 12, 2012 from, http://www.merriam-webster.com/dictionary/chemotherapy
Chest X-Ray	A chest x-ray is an x-ray of the chest, lungs, heart, large arteries, ribs, and diaphragm.	Dugdale, C. D. (2012). <i>Chest X-Ray</i> . Retrieved on April 12, 2012 from, http://www.nlm.nih.gov/medlineplus/ency/article/003804.htm
Computed Tomography (CT)	A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, computerized axial tomography scan, and computerized tomography.	National Cancer Institute. (2012). <i>CT Scan</i> . Retrieved on April 12, 2012 from, http://www.cancer.gov/dictionary?cdrid=46033
Data Triangulation	Data triangulation is the use of multiple data sources that have a similar foci to obtain many points of views about a topic for the purpose of validation	Kimchi, J. & Polivka, B. & Stevenson, S.J. (1991). Triangulation: Operational definitions. <i>Nursing Research</i> 40(6):364-366.
Lymph Nodes	A rounded mass of	National Cancer Institute. (2012). <i>Lymph</i>

	<p>lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells). They are located along lymphatic vessels. Also called lymph gland.</p>	<p><i>Nodes</i>. Retrieved on April 12, 2012 from, (http://www.cancer.gov/dictionary?cdrid=46033 http://www.cancer.gov/dictionary?cdrid=45762</p>
Mediastinoscopy	<p>A procedure in which a mediastinoscope is used to examine the organs in the area between the lungs and nearby lymph nodes. A mediastinoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease. The mediastinoscope is inserted into the chest through an incision above the breastbone. This procedure is usually done to get a tissue sample from the lymph nodes on the right side of the chest.</p>	<p>National Cancer Institute. (2012). <i>Mediastinoscopy</i>. Retrieved on April 12, 2012 from, (http://www.cancer.gov/dictionary?cdrid=46033 http://www.cancer.gov/dictionary?CdrID=46287</p>
Member-Checking	<p>Member-checking is when the construction derived from the analysis is taken back to the informants and presented to them for validation</p>	<p>Morse, M.J. (1994). <i>Designing funded qualitative research</i>. In N.K. Denzin, & Y.S.Lincoln, (Eds.) <i>Handbook of Qualitative Research</i>. Thousand Oaks, CA: Sage</p>
Metastasis	<p>The spread of cancer from one part of the body to another. A tumor formed by cells that have spread is called a “metastatic tumor” or a “metastasis.” The metastatic tumor contains cells that are like</p>	<p>National Cancer Institute. (2012). <i>Metastasis</i>. Retrieved on April 12, 2012 from, (http://www.cancer.gov/dictionary?cdrid=46033 http://www.cancer.gov/dictionary?CdrID=46710</p>

	those in the original (primary) tumor. The plural form of metastasis is metastases.	
Palliative treatment	To palliate a disease is to treat it partially and insofar as possible, but not cure it completely. Palliation cloaks a disease. Also sometimes called symptomatic treatment.	MedicineNet, Inc. (2012). <i>Palliative Treatment</i> . Retrieved on April 12, 2012, from, http://www.medterms.com/script/main/art.asp?articlekey=10703
Phenomenon	Any phenomenon represents a suitable point for phenomenological reflection. The very appearance of something makes it a Phenomenon.	Moustakas, C. (1994). <i>Phenomenological research methods</i> . Thousand Oaks, CA: Sage.
Radiation Therapy	The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiotherapy.	National Cancer Institute. (2012). <i>Radiation Therapy</i> . Retrieved on April 12, 2012 from, http://www.cancer.gov/dictionary?CdrID=44971
Radical Treatment	Treatment that aims to completely get rid of a cancer.	Encyclo Online Encyclopedia. (2012). <i>Radical Treatment</i> . Retrieved on April 12, 2012 from, http://www.encyclo.co.uk/define/Radical%20treatment

<p>Reflexivity</p>	<p>Reflexivity is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process.</p> <p>“A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions” (Malterud, 2001, p. 483-484).</p> <p>The perspective or position of the researcher shapes all research - quantitative, qualitative, even laboratory science.</p>	<p>Robert Wood Johnsons Foundation. (2008). <i>Reflexivity</i>. Retrieved on April 12, 2012 from, http://www.qualres.org/HomeRefl-3703.html</p> <p>Malterud, K. (2001). Qualitative research: Standards, challenges and guidelines. <i>The Lancet</i> 358: 483-488.</p>
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*please note that definitions are direct quotations from the sources specified.