PERCEPTIONS OF PHYSICIANS ON THE ADOPTION OF A PALLIATIVE CARE APPROACH IN PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

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Abstract

Models of care released over a decade ago advocate for an early and concurrent adoption of disease-modifying and palliative care approaches to address the needs of patients with a life-limiting illness, such as Chronic Obstructive Pulmonary Disease (COPD). However, research suggests patients with COPD continue to receive insufficient palliative care. While endorsing these models of care is justified, no study has demonstrated their adoption by physicians caring for patients with COPD. The purpose of this study is to examine the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD.

A qualitative design with an exploratory approach was used. Semi-structured interviews conducted over a 5-month period involved 7 residents and 7 attending physicians from internal medicine, respirology, emergency medicine and family medicine. Following verbatim transcription and member checking, the data were inductively analyzed with the aid of the computer software Atlas.ti to identify recurrent themes.

Results showed that interviewed physicians unknowingly practice some elements of a palliative care approach with their patients with COPD. Residents repeatedly describe influences from attending physicians’ practices. Physicians’ misperceptions of palliative care and its role in COPD limit their full adoption of this approach, creating disparity on its timely introduction.

In conclusion, physicians delay the adoption of palliative care simultaneously with disease-modifying therapies, largely due to three barriers: 1) physicians misperceive palliative care as an approach focused on comfort, 2) physicians fear the negative perceptions held by patients about palliative care; and 3) physicians use a reactive approach to palliative care rather than a proactive approach. However, they hold a propensity to concurrently adopt a palliative care approach with disease-modifying therapies, albeit delayed, suggesting a shift in medical culture. Residency education about the role of palliative care in the management of patients with COPD is lacking. This should be complemented by providing targeted education for attending physicians to meet the needs of patients with COPD.
Acknowledgements

When I started my Masters of Education in September 2013, I was inflated with research ideas, and arguably overly ambitious for my two-year deadline. Sometimes we require someone to ground us. My “someone” was Dr. Don Klinger. Thank you Don for appropriately channeling my enthusiasm toward a realistic goal. As my thesis supervisor, Don has provided me with constant guidance and support. Despite his sabbatical leave, he took the time to read my thesis… even during his vacation. I am sincerely grateful for your dedication.

I do believe the success of my thesis results from the collective contributions from my committee members, Drs. Lyn Shulha and Graeme Smith. They positively challenged my thoughts and ideas, and thus helped shape the final product. Thank you for challenging me!

I am very fortunate to experience my oral thesis defence with Drs. Don Klinger, Lyn Shulha, Graeme Smith, Ben Bolden and Rena Upitis: a compassionate group of intellectuals. I am honored to end my journey in the Masters of Education with you.

While my interest for palliative care began in medical school, my passion for this specialty truly surfaced during my first year of residency with the help of key players. Dr. Cori Schroder’s enthusiasm for palliative care was contagious, and surely infected me. Thank you Cori! Dr. Ingrid Harle also inspired me to pursue a career in palliative care. I value the time she spent coaching me on this research project. Ingrid, your mentorship continues to be instrumental to my residency training, and the start of my medical career. Thank you for believing in me.

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# Table of Contents

Abstract ................................................................................................................................. ii
Acknowledgements .................................................................................................................. iii
List of Figures .......................................................................................................................... vi
List of Tables ........................................................................................................................... vii
List of Abbreviations .............................................................................................................. viii
Chapter 1 Introduction: Diagnosing the Problem .................................................................... 1
  Purpose ................................................................................................................................. 6
  Rationale ............................................................................................................................... 6
Chapter 2 Unraveling the History of the Present Problem ...................................................... 8
  Palliative Care’s Evolution: Responding to Shifting Illness Trajectories ......................... 8
  Barriers to Adopting a Palliative Care Approach in Patients with Non-Malignant Diseases ... 11
  Chronic Obstructive Pulmonary Disease ......................................................................... 13
  A Disease-Modifying Approach Versus a Palliative Care Approach in COPD .................. 18
Chapter 3 Investigating the Problem - Methodology .............................................................. 23
  Ethics Approval, Informed Consent, Privacy, and Confidentiality ..................................... 23
  Research Site and Participants ......................................................................................... 24
  Pilot Interview ..................................................................................................................... 25
  Data Collection ................................................................................................................. 26
  Data Analysis and Validation Techniques ........................................................................ 27
  Researcher Role .................................................................................................................. 28
Chapter 4 Results ................................................................................................................... 29
  Participants ......................................................................................................................... 29
  Categorization of the Codes ............................................................................................... 30
  Thematic Representation of the Results ............................................................................ 32
  Theme 1: Physicians Unknowingly Adopt Elements of a Palliative Care Approach in Their Assessment, Management and Communication with Patients with COPD .......... 33
  Theme 2: Physicians Have a Limited Understanding of Palliative Care and its Approach in Patients with COPD ................................................................................................. 35
  Theme 3: There is no Consensus Amongst Physicians on the Timing to Introduce a Palliative Care Approach ................................................................................................................................. 37
  Theme 4: Physicians Experience Difficulties to Engage in Discussions about Prognosis and Illness Trajectory ................................................................................................................................. 39
Theme 5: Resident Physicians are Influenced by Attending Physicians Regarding the Therapeutic Approaches They Adopt when Caring for Patients with COPD .......... 41
Summary of the Results ................................................................................................................. 42
Chapter 5 Assessment and Plan .................................................................................................... 44
The Extent to which Physicians Adopt a Palliative Care Approach ........................................ 44
The Delayed Adoption of a Palliative Care Approach ............................................................... 46
Implications of a Delayed Adoption of a Palliative Care Approach ........................................... 50
The Learning Experience of Resident Physicians ................................................................. 52
Recommendations ......................................................................................................................... 53
Limitations .................................................................................................................................. 54
Significance of the Study .............................................................................................................. 55
Future Research .......................................................................................................................... 56
Final Reflections .......................................................................................................................... 57
References .................................................................................................................................... 58
Appendix ....................................................................................................................................... 62
Appendix A: Ethics Letter of Approval ....................................................................................... 63
Appendix B: Letter of Information ............................................................................................... 64
Appendix C: Consent Form ........................................................................................................... 65
Appendix D: Interview Questions ................................................................................................. 66
Appendix E: Codes ....................................................................................................................... 69
List of Figures

Figure 1: The Typical Illness Trajectory of Patients with Cancer vs Non-Malignant Disease........3
Figure 2: The Older Transition Model of Care ........................................................................... 4
Figure 3: The Newer Model of Care .......................................................................................... 5
Figure 4: The Bow Tie Model of Disease-Modifying and Palliative Care Approaches ..........21
Figure 5: Summarization of the Categories .............................................................................. 32
Figure 6: Physicians' Selection on the Time to Begin to Adopt a Palliative Care Approach .... 38
Figure 7: Model of Care Adopted by the Physicians in the Study for Patients with COPD
Compared to the Recommended Model of Care ..................................................................... 47
List of Tables

Table 1: MRC Dyspnea Scale ........................................................................................................... 14
Table 2: Classification of COPD Severity by Symptoms and by Spirometry .................. 16
Table 3: Demographics of the Participants ..................................................................................... 30
List of Abbreviations

BiPAP – Bilevel positive airway pressure

CHPCA – Canadian Hospice Palliative Care Association

COPD – Chronic Obstructive Pulmonary Disease

CTS – Canadian Thoracic Society

FEV₁ – Forced expiratory volume in one second

FVC – Forced vital capacity

GOLD – Global Initiative for Chronic Lung Diseases

MRC – Medical Research Council

PRN – When necessary (from Latin “pro re nata”)

Chapter 1

Introduction: Diagnosing the Problem

How would you like to die? It is not a question we often ask ourselves. It typically does not surface during a casual dinner conversation amongst family and friends. This important question is presumably often avoided, but I doubt many people would dream of a death full of suffering, while isolated in an unfamiliar environment. I began to understand the importance of this issue when I met Mr. C, an elderly patient with severe chronic obstructive pulmonary disease (COPD). COPD is an irreversible chronic disease characterized by airflow obstruction in the lungs caused by inflammation (National Clinical Guidelines Centre, 2010). Mr. C and I first met while I was managing the medicine wards as a second-year medical resident. He suffered a terrible exacerbation of COPD, and was kept alive with a non-invasive ventilator machine. As he became increasingly confused and dyspneic, his family members, particularly his wife, were becoming increasingly distraught. Bedridden with his body dramatically weakened, his wife finally accepted the inevitable outcome after several days of discussion, and eventually gave permission to remove the life-sustaining mask. Mr. C died within 30 minutes. Mr. C and his wife of over 50 years missed the opportunity for a quality end of life, and were completely ignorant to the terminal nature of COPD. Unfortunately, many patients with COPD experience this somber reality.

The authors of a prospective cohort study involving five teaching hospitals in the United States aimed to compare the illness trajectory and care patterns for patients with advanced stages of non-small cell lung cancer to patients with severe COPD (Claessens et al., 2000). Patients with severe COPD were notably more likely to die in the intensive care unit, on mechanical ventilation, and with dyspnea when compared to patients with lung cancer. Such research
suggests patients with COPD receive insufficient palliative care compared to patients with malignant conditions (Curtis, 2008; Spence et al., 2009).

Researchers have sought to explore this gap in care of patients suffering from non-malignant diseases in general, including COPD. Non-malignant disease is a term coined to include any disease categorized as non-cancerous in nature (e.g. heart failure, COPD, chronic kidney disease, dementia, rheumatic diseases, etc.). One particular recurrent theme expressed by physicians is the difficulty to prognosticate patients suffering from non-malignant conditions, rendering it difficult to estimate a timely introduction for palliative care in their treatment plan (Curtis, 2008; Hanratty et al., 2002; Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012; Spence et al., 2009). The difficulty with prognosticating patients with non-malignant diseases, particularly diseases with an organ system failure, stems from their typical illness trajectory (see Figure 1). The top diagram in Figure 1 illustrates the illness trajectory of patients suffering from cancer while the bottom diagram depicts the trajectory of patients with a non-malignant disease, typically an organ system failure. In contrast to patients living with cancer, where they maintain a rather steady level of function from diagnosis before dramatically deteriorating to the point of death, patients with an organ system failure, such as COPD, experience a steady slow decline in function with periods of exacerbation (Lynn & Adamson, 2003). Every point of exacerbation, illustrated by a dip in the level of function, represents a time of potential death. With current medical treatment, patients can recover from the acute exacerbation but not quite to their previous level of function. They eventually continue to decline over time. Death, in their case, tends to occur suddenly when an exacerbation is refractory to medical treatment.
Figure 1

The Typical Illness Trajectory of Patients with Cancer vs Non-Malignant Disease


The unpredictable timing of sudden death for patients with non-malignant diseases challenges the physicians in deciding when to initiate palliative care. I believe this challenge is a result of medical professionals’ traditional perceptions of a dichotomous continuum from curative to palliative treatment, where “the decision to focus on reducing suffering is made only after life-prolonging treatment has been ineffectual and death is imminent” (Morrison & Meier, 2004, p. 2582). In a study measuring the theoretical knowledge of nurses working in German nursing homes, nearly 50% of the 130 participants thought palliative treatments should never be combined with curative care (Pfister et al., 2013). Lynn and Adamson (2003) depicted an older model of care where curative treatments were suddenly halted, and hospice care ensued (see
Figure 2). The diagram illustrates the traditional school of thought with the approach to care for patients. The model was conceived after physicians recognized in the late 1960s the unsuitability of traditionally aggressive therapies to patients experiencing the dying process (Lynn & Adamson, 2003). The hospice movement, mandated to focus on end-of-life care, soon followed in the 1970s.

Figure 2

The Older Transition Model of Care


The older model dichotomizing curative and palliative approaches is inappropriate for the growing number of patients with chronic non-malignant diseases with unpredictable illness trajectories, because they miss the opportunity for care directed at quality of life, and will suddenly die without any preparations in place (Lynn & Adamson, 2003; Murray, Kendall, Boyd, & Sheikh, 2012). The solution is an early adoption of a palliative care approach in the patient’s illness trajectory, arguably as early as at the time of diagnosis, as recommended by the Canadian Hospice Palliative Care Association (2012). Jean Bacon’s (2012) discussion document prepared for the Canadian Hospice Palliative Care Association (CHPCA) highlighted key reasons for the early integration of a palliative care approach in the course of a patient’s illness, including
improved quality of life, greater patient autonomy, and increased longevity, amongst many other advantages. Historic recognition of these advantages created newer models of care, notably the famous graph by Lynn and Adamson (2003), later adopted by the CHPCA (see Figure 3). Figure 3 illustrates the newer model of care suitable for patients with chronic diseases, demonstrating concurrent disease-modifying and palliative care treatments with palliative care eventually taking precedence near the end of life.

Figure 3

*The Newer Model of Care*


Although the model of care depicted by Lynn and Adamson (2003) has gained popularity in the palliative care community and proven to benefit patients and their families, few studies have actually demonstrated its application amongst primary care physicians and specialists caring for patients with non-malignant diseases, notably COPD. The actual approach adopted by physicians when faced with a patient with COPD remains unknown at this time. Of course, physicians medically treat their patients with COPD, but I question the objectives set out in their minds while providing their treatment. Are they solely focused on disease-modifying therapies? Are they concerned about the patient as a whole?
Purpose

The purpose of my research is to understand the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD. My objective is to answer the following questions:

1. What are the therapeutic approaches resident and attending physicians adopt when caring for patients with COPD?
2. What conditions influence the adoption of a palliative care approach?
3. How do resident and attending physicians perceive a palliative care approach?

To specify, resident physicians, commonly referred to as residents, are graduates of medical school, training in a specific field of medicine before entering independent practice, at which point they would be called attending physicians, or simply, attendings.

Rationale

Medical residents “are the physicians who spend the most time providing direct [end-of-life] care in teaching hospitals” (Schroder et al., 2009, p. 460). No studies have explored their perceptions of palliative care in patients with COPD or other non-malignant diseases. They are in the transition stage of their medical career, bringing into practice their most recent theoretical understanding of medicine from their medical school training while also gaining clinical experience in preparation for independent practice. In my opinion, their preceptors’ practices and views on the treatment of non-malignant diseases influence in turn the residents’ perceptions. Although a resident may feel justified to adopt a palliative care approach, the attending physician can change the treatment course. Therefore, studying the perceptions of resident physicians is highly valuable to identify whether they experience any conflicts when selecting the most appropriate therapeutic approaches, or rather mirror the approaches of their attendings.
While other health professionals, such as nurses, play pivotal roles in the delivery of care to patients, they do not hold the same responsibilities as physicians. Attending physicians are the leaders and decision-makers of direct patient care. In light of their privilege, I am interested in exploring the extent to which they adopt a palliative care approach in patients with COPD. From my experience as a resident, several attending physicians continue to hold a traditional view, dichotomizing disease-modifying and palliative care approaches on a continuum.

Although the main purpose of my study is to understand the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD, the study also serves to identify gaps in knowledge about palliative care. I suspected the presence of important gaps in resident and attending physicians’ understandings of the definition, roles and purposes of palliative care, particularly as it pertains to COPD. Recognition of these gaps is the first step in creating targeted educational objectives for ongoing medical education and practice. The long-term goal is to develop educational interventions to improve the perceptions of palliative care, and promote early adoption of palliative care approaches in patients with non-malignant diseases. These future interventions can be implemented as early as medical school. Early understanding of a palliative care approach in COPD could potentially prevent submitting patients to costly interventions, and compromising their quality of life.

In the following chapters of this thesis, I provide a deeper understanding of palliative care, the management of COPD, and the therapeutic approaches adopted by physicians, marrying palliative care and the management of COPD. Chapter 3 covers the methodology used to respond to the research questions, and Chapter 4 presents the results of the study. Finally, the thesis closes with a discussion of the results, comparing them to the current understanding in the literature of a palliative care approach, and the management of COPD.
Chapter 2

Unraveling the History of the Present Problem

Palliative Care’s Evolution: Responding to Shifting Illness Trajectories

From 1921 to 2011, the average life expectancy in Canada rose nearly 25 years, increasing it to 81.7 years old (Statistics Canada, 2014). The increase in longevity reflects the decline in sudden death from circulatory diseases, infections, accidents, and childbirth (Lynn & Adamson, 2003; Murray, Kendall, Boyd, & Sheikh, 2012). While improved medical treatments and public health are drivers for improved life expectancy, the unanticipated consequence has been a significant increase in disability in the years prior to death. In comparison to the infrequent pre-death disability in the early 1900s, Americans experienced in the year 2000 an average of two years of disability before dying (Lynn & Adamson, 2003). Similar trends are observed amongst Canadians, with Statistics Canada (2014) reporting severe declines in functional health accelerating after the age of 65, and peaking on average at 77 years of age. Living longer has not necessarily translated into living better.

As explained in Chapter 1, the hospice care movement began in the 1970s in recognition of patients experiencing the dying process, rather than suddenly dying or quickly recovering from an illness. The hospice movement later birthed palliative care (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008). Balfour Mount, a Canadian physician, first introduced the term ‘palliative care’ in 1973 when he created a medical unit at Montreal’s Royal Victoria Hospital to treat terminally ill patients (Pastrana et al., 2008). Although he first wanted to use the term ‘hospice’, the equivalent French term was already in use, describing “a nursing home for the poor and the destitute” (p. 222). He therefore chose a term based on its etymological meaning of ‘improving the quality of something’. A few years later, the term ‘palliative care’ was often interchanged with ‘terminal care’ (Pastrana et al., 2008).
Historically, palliative care targeted patients with cancer in the last few months of their life, treating their physical symptoms and addressing their psychosocial needs (Bacon, 2012). However, given the growing number of patients with disabilities in the years prior to death, palliative care is shifting. The Canadian Hospice Palliative Care Association (CHPCA) is advocating for an earlier integration of palliative care in a patient’s course of illness, offering it simultaneously with disease-modifying therapies, and broadening its scope to include patients with non-malignant diseases. This shift has also been reflected in the World Health Organization’s definition of palliative care. In 1986, the WHO’s definition of palliative care was the following:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment (Ahmedzai et al., 2004, p. 2193).

While the first sentence of the definition reflects the older model of care (see Figure 2), the last sentence further stereotypes the role of palliative care solely for cancer patients, disregarding the option of combining it with other treatments benefiting those patients with non-malignant diseases. The WHO revised its definition in 2002, responding to the need of an earlier integration of palliative care across many diseases, both malignant and non-malignant. While many debates take place over the exact definition of palliative care, I will refer in my study to this widely cited definition. The WHO (2013) comprehensively defines palliative care as:

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

Palliative care:

• Provides relief from pain and other distressing symptoms;
• Affirms life and regards dying as a normal process;
• Intends neither to hasten or postpone death;
• Integrates the psychological and spiritual aspects of patient care;
• Offers a support system to help patients live as actively as possible until death;
• Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• Will enhance quality of life, and may also positively influence the course of illness;
• Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (para. 1-2).

Although the current WHO definition acknowledges the inclusivity of all life-threatening illness, many patients with non-malignant diseases are not treated with palliative care.
Barriers to Adopting a Palliative Care Approach in Patients with Non-Malignant Diseases

While the need for palliative care in patients suffering from non-malignant diseases is well justified in the literature, these patients continue to receive insufficient palliative care (Claessens et al., 2000; Curtis, 2008; Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012; Spence et al., 2009). Given this need, there are surprisingly a limited number of studies exploring the barriers in adopting a palliative care approach for patients with various non-malignant diseases, but many health care professionals express recurrent themes.

In response to the fact that “the median survival for heart failure... is worse than for many of the common cancers” (Hanratty et al., 2002, p. 581), researchers designed a qualitative study to examine the need for palliative care and the barriers to providing these services to patients suffering from heart failure, as perceived by doctors (Hanratty et al., 2002). The researchers hosted seven focus groups, which were composed of general practitioners, cardiologists, palliative care physicians, general internists, and geriatricians. The selected physicians either practiced within a teaching hospital, a tertiary referral centre or a district general hospital in the United Kingdom. The three main recurring barriers to palliative care services expressed by the physicians were the uncoordinated organization of the health care system, the challenges of prognosticating the course of heart failure, and the confusing roles of the different doctors involved in the care of a patient with heart failure.

Parallel to the described study on heart failure, a qualitative study was conducted in Northern Ireland to evaluate the perceptions of health and social care professionals on the barriers to delivery of palliative care to patients with advanced COPD (Spence et al., 2009). Twenty-three professionals from varied disciplines, including respiratory, palliative, health and social care volunteered to be interviewed. These professionals all experienced caring for patients with advanced COPD, and had experience working in palliative care. According to them, COPD is often managed during an acute exacerbation, and the acuity of the management overshadows the
patient’s long-term prognosis. Furthermore, as reported by these professionals, the resources and support systems for this patient population actually exist, but patients fail to request the information, possibly due to insufficient time with their care providers. Professionals also recognized the need for palliative care in patients with advanced COPD, but the researchers listed five barriers to accessing these services: (a) disagreement on the exact definition of palliative care, (b) the unpredictable course of COPD putting into question the timing to initiate palliative care, (c) the difficulties in broaching the topic with the patients, (d) the confusing roles of all the health care professionals involved in the delivery of palliative care, and (e) the negative perceptions of the patients on the concept of palliative care, often equating it to death. Unlike the study research by Hanratty et al. (2002), this study included various health and social professionals, but the authors failed to report the nature of these professions.

Limitations in accessing palliative care services have also been witnessed in people afflicted with dementia, a disease that is notorious for an end-of-life “described as lengthy and typified by slow degeneration and decline” (Ryan et al., 2012, p. 879). Researchers designed a qualitative study with the purpose to elicit issues surrounding end-of-life care for patients with dementia, and the experiences of health care professionals working with these patients in acute care hospitals, family medicine clinics, hospices, and palliative care units (Ryan et al., 2012). They hosted eight focus groups and four individual interviews comprised of physicians, nurses, and other allied health professionals. The participants of the study failed to recognize the terminal nature of dementia, and hesitated to provide palliative care services to patients with dementia, perceiving their symptoms as incomparable to those of cancer patients. Furthermore, the lack of collaboration between health professionals was expressed as a significant hindrance to palliative care, creating situations where treatments in acute care settings, such as feeding tubes, could not be adequately maintained in the community, and consultations to mental health specialists were difficult due to their inaccessibility. Good quality end-of-life care is partly challenging to achieve
in patients with dementia because they cannot always communicate their needs, and the health professionals consequently lack confidence in their patient care assessments.

From the previous literature, there is evidence of many barriers to adopting a palliative care approach for patients with heart failure (Hanratty et al., 2002), COPD (Spence et al., 2009), and dementia (Ryan et al., 2012). Several of the listed barriers stem from ineffective communication amongst members of a multi-disciplinary health care team, as well as gaps in knowledge of the definition of palliative care and the natural course of non-malignant diseases. As a result, timely introduction of palliative care in the patient’s treatment plan often proves to be difficult.

Although palliative care has theoretically evolved to integrate all patients with non-malignant diseases, the listed barriers frame an awareness of the practical challenges to providing palliative care to patients with non-malignant diseases. While the barriers to palliative care are not the focus of my research, they underlie the purpose of understanding the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD. The high prevalence of COPD places this disease in the spotlight of an evolving platform for palliative care.

**Chronic Obstructive Pulmonary Disease**

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in Canada, and is projected to be the third on a worldwide scale by 2020 (Curtis, 2008; O’Donnell et al., 2008). The Global Initiative for Chronic Obstructive Lung Disease (GOLD) defines it as a: preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases (Rabe et al., 2007, p. 534).
Airflow limitation during the expiratory phase of breathing is pathognomonic of COPD, and one of the main contributors to the shortness of breath experienced by patients (O’Donnell et al., 2008). During expiration, there is concurrent collapsing of the small airways, resulting in air trapping, and subsequent hyperinflation of the lungs.

While cigarette smoking is reputed to be the greatest risk factor for COPD, the chronic lung changes in COPD are also attributable to other exposures seen in non-smokers, such as occupational dust and chemicals as well as indoor and outdoor air pollution (Rabe et al., 2007). Continuous inhalation over time of these noxious particles risks the development of COPD. This chronic lung disease is diagnosed based on clinical symptoms, and post-bronchodilator spirometry results (O’Donnell et al., 2008; Rabe et al., 2007). Patients will typically experience various degrees of shortness of breath, cough, and sputum production. The severity of dyspnea can be graded using the Medical Research Council (MRC) dyspnea scale (see Table 1).

Table 1

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not troubled by breathlessness except with strenuous exercise</td>
</tr>
<tr>
<td>2</td>
<td>Troubled by shortness of breath when hurrying on the level or walking up a slight hill</td>
</tr>
<tr>
<td>3</td>
<td>Walks slower than people of the same age on the level because of breathlessness or has to stop for breath when walking at own pace on the level</td>
</tr>
<tr>
<td>4</td>
<td>Stops for breath after walking about 100 yards (90 m) or after a few minutes on the level</td>
</tr>
<tr>
<td>5</td>
<td>Too breathless to leave the house or breathless when dressing or undressing</td>
</tr>
</tbody>
</table>


Post-bronchodilator spirometry requires a patient to breathe through a device after inhaling salbutamol, a medication designed to dilate the airways of the lungs (i.e. bronchi). A
sensor installed in the device detects airflow, and measures various components of lung function. Patients with COPD have an obstructive pattern, and will have a forced expiratory volume in one second (FEV$_1$) over forced vital capacity (FVC) ratio of less than 0.70. FEV$_1$ is the volume of air forcefully expired over one second after full inspiration, and FVC is the total volume of air forcefully expired after a full inspiration. With an obstructive disease like COPD, patients would experience great difficulty to forcefully expire large volumes of air in one second compared to a normal individual who can generally blow off most of the inspired air in the first second of expiration. Therefore, the GOLD as well as the Canadian Thoracic Society (CTS) suggest an FEV$_1$/FVC ratio of less than 0.70 to establish the diagnosis of COPD (O’Donnell et al., 2008; Rabe et al., 2007).

Once the diagnosis of COPD has been made, the CTS recommends classifying the patient’s disease severity by symptoms or by impairment of lung function in order to guide management (O’Donnell et al., 2008). While classification by symptoms is mostly based on the MRC dyspnea scale, classification by lung function is determined by post-bronchodilator spirometry measurements of FEV$_1$ (see Table 2).

Classification solely based on spirometry would deprive certain patients from essential treatments. For example, a patient may have an FEV$_1$ of 60%, but remains too breathless to leave the house or has evidence of right-sided heart failure, a sign of chronically high pressures in the lungs. Classifying this patient as moderate would underestimate the severity of their disease, and can prevent access to certain beneficial therapies.

Fortunately, treatment options are available at all stages of COPD, and are typically a combination of pharmacological and non-pharmacological interventions. GOLD establishes four components in the management plan of COPD: (1) disease assessment and monitoring, (2) reduction of risk factors, (3) management of stable COPD, and (4) management of COPD exacerbations (Rabe et al., 2007). The overarching goals in the management of COPD include:
• preventing disease progression;
• treating exacerbations, and reducing their frequency and severity;
• relieving symptoms, particularly dyspnea;
• improving exercise tolerance;
• treating disease complications;
• improving health status; and
• reducing mortality (O’Donnell et al., 2008; Rabe et al., 2007).

Table 2

Classification of COPD Severity by Symptoms and by Spirometry

<table>
<thead>
<tr>
<th>COPD Stage</th>
<th>Symptoms</th>
<th>Spirometry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>MRC 2</td>
<td>$\text{FEV}_1 \geq 80%$ predicted</td>
</tr>
<tr>
<td>Moderate</td>
<td>MRC 3 to 4</td>
<td>$50% \leq \text{FEV}_1 &lt; 80%$ predicted</td>
</tr>
<tr>
<td>Severe</td>
<td>MRC 5, or the presence of chronic respiratory failure or clinical signs of right-sided heart failure</td>
<td>$30% \leq \text{FEV}_1 &lt; 50%$ predicted</td>
</tr>
<tr>
<td>Very Severe</td>
<td>(Not defined)</td>
<td>$\text{FEV}_1 &lt; 30%$ predicted</td>
</tr>
</tbody>
</table>


The first component in the management of COPD incorporates ongoing assessment of the patient’s disease severity, identification of any arising comorbidities, and measurement of arterial blood gases if clinically indicated. While identifying risk factors is part of the disease assessment, it certainly becomes more relevant in the second component of management, according to GOLD. Interventions include smoking cessation through counseling and/or pharmacotherapy, and reducing environmental exposure to occupational dusts and chemicals, as well as indoor and outdoor air pollution. Although the management of stable COPD varies from patient to patient to meet their particular needs, it broadly involves patient education, a cocktail of inhalers, routine
influenza and pneumococcal vaccines, exercise training programs such as pulmonary rehabilitation, and administration of continuous oxygen therapy if indicated. The management of COPD exacerbation, the final GOLD management component, is of critical importance because of the negative prognostic effects of an exacerbation. Therefore, the best intervention is to prevent exacerbations by optimizing adherence to the management of stable COPD. A COPD exacerbation is defined as “an event in the natural course of the disease characterized by a change in the patient’s baseline dyspnea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication” (Rabe et al., 2007, p. 544). Many of the therapies available to treat an exacerbation are pharmacological in nature, including inhalers, systemic corticosteroids, and antibiotics, but also largely comprise of addressing abnormal arterial blood gases and dyspnea with oxygen therapy and/or non-invasive positive pressure ventilation, a high pressured mask worn over the mouth and nose. While infections most commonly trigger an exacerbation, other conditions, such as a pulmonary embolism (i.e. a lung clot), can acutely exacerbate a COPD patient. Therefore, investigating for underlying causes of an acute exacerbation and appropriately treating them are crucial elements of the management. After the exacerbation resolves, patients should receive education on strategies to prevent a recurrent exacerbation.

At least 700,000 people are affected with COPD in Canada (O’Donnell et al., 2008). The disease prevalence is rising, resulting as well in increasing health care costs. According to GOLD, the care provided to patients during an acute exacerbation of COPD accounts for the greatest costs in the health care system in developed countries, with “a striking direct relationship between the severity of COPD and the cost of care” (Rabe et al., 2007, p. 536). Most of the direct costs of severe COPD are associated with pharmaceuticals and hospitalizations (Jansson et al., 2002). With the rising prevalence, more patients will progress to the advanced stages of COPD, and undergo aggressive medical care. Beyond the costs associated with severe COPD, 20% to 50% of
patients with COPD experience anxiety and depression, and this prevalence increases with advanced disease. Adopting a palliative care approach can potentially streamline care in the more severe stages of disease, alleviating healthcare costs, but more importantly, in my opinion, addressing the patients’ distressing symptoms of dyspnea, anxiety, and depression.

Although one of the objectives in the management of COPD includes prevention and treatment of complications and exacerbations, the characteristic airflow limitations of the disease are progressive in nature, regardless of the quality of care provided to patients, and eventually can lead to death (Rabe et al., 2007). Therefore, there must be a role for palliative care.

**A Disease-Modifying Approach Versus a Palliative Care Approach in COPD**

The purpose of my research is to understand the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD. One of my objectives is to decipher the therapeutic approaches adopted by physicians when caring for patients with COPD. The typically two competing approaches are disease-modifying and palliative care.

According to a review article published in 2009 in the Journal of Chronic Obstructive Pulmonary Disease, disease modification is defined as “an improvement in, or stabilization of, structural or functional parameters as a result of reduction in the rate of progression of these parameters which occurs whilst an intervention is applied and may persist even if the intervention is withdrawn” (Halpin & Tashkin, 2009, p. 222). This working definition sprung from discussions between respiratory physicians and scientists from North America and Europe. The need for these experts to convene was triggered by the lack of a clear definition for disease modification, especially in the context of COPD. The absence of a coherent definition resulted in ambiguity and debates on whether certain interventions and medications for COPD were considered disease-modifying. Therefore, after creating a definition by consensus, Halpin and Tashkin (2009) reviewed the literature and sought to determine potential markers of disease modification in
COPD. They proposed five markers: (1) FEV\textsubscript{1}, (2) exacerbation rates, (3) breathlessness, (4) exercise tolerance, and (5) health-related quality of life.

Many interventions and treatments for COPD can potentially be considered disease-modifying, but their relationship with some of the proposed markers remains to be studied. For example, while no pharmacologic interventions to date have shown any improvement in the rate of decline of FEV\textsubscript{1}, smoking cessation has been proven to reduce this rate (Halpin & Tashkin, 2009; O'Donnell et al., 2008). Therefore, quitting smoking can be considered a disease-modifying intervention. Certain inhalers, notably bronchodilators, and pulmonary rehabilitation have been shown to improve exacerbation rates, breathlessness, exercise tolerance, and health-related quality of life (Halpin & Tashkin, 2009; O'Donnell et al., 2008). Therefore, they can also be considered disease-modifying therapies. However, with the exception of FEV\textsubscript{1}, the markers proposed by Halpin and Tashkin (2009) were identified as patient-centered outcomes. Patient-centeredness is the essence of a palliative care approach.

A palliative care approach “focuses on person and family, and on their quality of life throughout the illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care – and strives to give patients and families a greater sense of control” (Bacon, 2012, p. 8). In the early stages of illness, a palliative care approach aims to:

1. openly communicate to patients and their families their prognosis and illness trajectory;
2. discuss advance care planning by establishing the patient’s goals of care and providing them with all the options for treatment;
3. offer psychosocial and spiritual support as they cope with the illness; and
4. alleviate any symptoms.
In the latter stages of disease, the goals are similar, but often involve ongoing discussions about goals of care as these may change over time (Bacon, 2012). However, engaging specialized palliative care providers can become more pressing as complex psychological and physical symptoms arise with disease progression. Any physician can adopt a palliative care approach, no matter their specialty or area of expertise. When faced with specific challenges in delivering palliative care, such as relieving physical and psychological symptoms or enhancing a patient’s quality of life, a referral to a palliative care specialist is warranted. Therefore, referrals to specialized palliative care providers will only occur in the first place if the primary care physicians treating patients with COPD adopt a palliative care approach, and recognize an unmet need.

A simplistic fictional case can help illustrate the interacting dynamics of disease-modifying and palliative care approaches. Mrs. G, a 72 year-old woman diagnosed with COPD six years ago, presents to her family doctor’s office for follow-up management of COPD. Her family doctor, Dr. Fam, has previously succeeded in counselling Mrs. G to quit smoking five years ago. Spirometry tests one year ago showed an FEV$_1$ of 40% predicted and FEV$_1$/FVC of 0.60. As Dr. Fam questions Mrs. G, he discovers that increasing breathlessness is limiting her ability to function well at home. Despite the appropriate use of prescribed inhalers, she continues to feel unwell. Dr. Fam decides to refer her to Dr. Resp, a specialist in respirology. Dr. Resp changes some of Mrs. G’s inhalers, and provides her with oxygen at home after an arterial blood test reveals significantly low levels of oxygen during times of mild exertion. Mrs. G’s symptoms improve for some time, but then continue to worsen one year after her initial visit with Dr. Resp. She is now experiencing significant anxiety along with the shortness of breath. Recognizing her MRC dyspnea scale of 5, and having optimized her inhalers after ruling out any other causes for her breathlessness, Dr. Resp decides to refer Mrs. G to Dr. Pall, a palliative care specialist. Dr. Pall addresses Mrs. G’s symptoms, notably the shortness of breath and anxiety, with both
pharmacological and non-pharmacological interventions. She also reviews her goals of care, which were previously discussed with both Dr. Fam and Dr. Resp. Dr. Pall and Dr. Resp collaborate on monitoring Mrs. G’s progression while she attends pulmonary rehabilitation. Mrs. G’s quality of life remains steady despite her limitations in function. She eventually dies peacefully from a COPD exacerbation two years after her initial visit with Dr. Pall.

The initial intervention by Dr. Fam in encouraging Mrs. G to quit smoking is most definitely a disease-modifying approach. However, the introduction of inhalers and oxygen can both be considered disease-modifying and palliative care approaches. Reviewing Mrs. G’s goals of care throughout her disease progression falls under the palliative care realm. Most importantly, all three physicians involved in the care of Mrs. G adopted elements of a palliative care approach.

Figure 3 depicts the interaction of the approaches described in this fictional case. Other more recent depictions modeling an early integration of a palliative care approach highlight the possibility of survivorship (Hawley, 2014). The bow tie model (see Figure 4) purposes to hold a more universal application in various clinical settings, because the duality of the approach “prepares patients for the worst (death) but still allows hope for the best (cure)” (p. 3). The blue triangle of “Disease Management” intersects with the pink triangle of “Palliative Care”. The top diagram in Figure 4 lists the possible interventions targeted at disease management, while the lower diagram lists terminology under the umbrella of palliative care. In the palliative care triangle, at the top right, the outcome is survivorship, and at the lower right, the outcome is death and family bereavement.

As opposed to the model of care by Lynn and Adamson (2003) shown in Figure 3, where the only outcome of an early integration of palliative care is eventual death, followed by family bereavement, Hawley’s bow tie model (2014) illustrates findings in the literature where survivorship is a possible outcome with concurrent palliative and disease-modifying care. The bow tie model may arguably serve as a better tool to communicate with patients and health care
providers the benefits of integrating palliative care early on in the patient’s course of illness. These benefits include greater patient autonomy, better patient engagement in deciding the orientation of care, improved quality of life, decreased hospitalizations, decreased health care costs, better symptom control, and greater longevity (Bacon, 2012).

Figure 4

*The Bow Tie Model of Disease-Modifying and Palliative Care Approaches*

![Diagram](Image)


Although it may be compelling to adopt a palliative care approach in light of the evidence, there is no study evaluating the extent to which physicians adopt a palliative care approach, particularly for patients with COPD. Essentially, I am trying to understand how physicians draw the relationship between a disease-modifying approach and a palliative care approach. In comparison to Figures 2, 3, and 4, where do they draw the line?
Chapter 3

Investigating the Problem - Methodology

A qualitative approach was chosen for this research as it was considered the most suitable to understand the extent to which resident and attending physicians adopt a palliative care approach. Furthermore, such an approach enabled me to explore in greater depth the language used by physicians to describe their therapeutic approaches for patients with COPD. While the novelty of this topic renders it an appropriate study to be approached from a qualitative point of view, the nature of the research questions is a more compelling reason to support the selected methods. The questions explore the experience of physicians with patients with COPD, particularly in adopting palliative care in their practice. Therefore, the exploratory nature of the research is best studied in a qualitative manner.

Ethics Approval, Informed Consent, Privacy, and Confidentiality

Ethics clearance from Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board was obtained on August 12th, 2014 to complete the research study (see Appendix A). A letter of information and consent form were created to ensure informed consent of the participants (see Appendices B and C). These forms partially explained the purpose of the study, described the length of their participation, and included a statement on the assurance of confidentiality, as suggested by McMillan and Schumacher (2010). Though anonymity was not achievable given the nature of the data collection, confidentiality was maintained to the extent possible through the development of a coding system serving to mask participants’ identities. The interview transcripts did not include the names of the participants. To further protect participants’ identities, a pseudonym replaced their names on all data files and in any dissemination of findings. After transcription and analysis were completed, the recordings were destroyed. All electronic files were password protected. Paper and audio data were secured
in a locked cabinet, and were made accessible only to the principal investigator and committee members. I will maintain copies of the transcripts for a minimum of 5 years and may use the data (using pseudonyms) in subsequent research or presentations.

**Research Site and Participants**

My research study took place in Kingston, Ontario, the city in which I am currently training as an Internal Medicine resident. The location was selected based on my familiarity with the environment, and to ease the process of data collection. Most of the interviews were conducted in a room booked in one of the buildings of Queen’s University or in the offices of the participants, but two interviews took place at the homes of the participants.

There were two types of participants included in the study: attending and resident physicians. To specify, resident physicians, commonly referred to as residents, are graduates of medical school, training in a specific field of medicine before entering independent practice, at which point they would be called attending physicians, or simply, attendings. The selection method was a maximum variation sampling in order to capture differing views based on field of practice and years of medical experience (McMillan & Schumacher, 2010).

The attending physician group was further subdivided into four: respirologists, general internists, general practitioners (i.e. family doctors), and emergency physicians. All of these attendings were directly involved in the care of patients with COPD, albeit from different perspectives. General practitioners, commonly known as family doctors, will usually make the first diagnosis, and follow the patients until the end of life. Respirologists, who are physicians with an expertise in lung pathologies, will often be consulted by other physicians for diagnostic confirmation and expertise in disease-modifying treatments of COPD. General internists, referring specifically to specialists of general internal medicine, will typically treat patients with COPD when they are admitted to the hospital with an acute exacerbation. Finally, emergency
physicians are often the first responders at the hospital when a patient arrives with a COPD exacerbation.

The attending physicians were recruited by email and/or face-to-face invitation. I communicated with the Administrative Assistants of the Departments of Medicine, Family Medicine and Emergency Medicine at Queen’s University to facilitate email distribution to the respirologists, general internists, general practitioners and emergency physicians. The plan was to recruit participants within each specialty-type listed to a total maximum of eight participants, assuming such a sample size would provide saturation of data collection.

The resident physicians represented the second group of participants. These residents were further divided into three subgroups: internal medicine, family medicine and emergency medicine residents. Aside from Respirology residents, these are the only three groups of residents who would deliver care to patients with COPD on a frequent basis. Residents in Respirology were not a targeted group because there are only four residents in the program at Queen’s University, of whom one participated in the pilot interview, and two were focused on studying for their licensing exam at the time of the study. The remaining resident could potentially be easily identified. In addition to reaching residents by email, I also recruited participants via a face-to-face invitation. I also planned to collect interview data from this group until saturation was reached or a maximum of eight residents were interviewed. Residents were from various levels of training, from first-year junior residents to senior fifth-year residents.

**Pilot Interview**

Prior to recruitment, the interview process was piloted with a fifth year respirology resident on September 17th, 2014. The pilot served to review the consent process, and test the interview questions. I selected her because she was less than a year away from becoming an attending physician, had extensive seniority as a resident, and her specialty focuses in part on the management of the disease under study: COPD. During the pilot interview, an additional
interview question was posed to better understand her approach when encountering patients with COPD. The additional question related to naming the approach taken when caring for patients with COPD. It was added to the final version of the interview questions. Following the pilot interview, the interview questions were reordered in such a way as to only mention the word *palliative care* towards the end of the interview. In fact, the word palliative care was omitted from the letter of information and consent form, as per suggestions obtained during the pilot, to minimize potential bias. The omission served to capture the participants’ candid thoughts on their approach to patients with COPD during the interviews, and prevent any influence from the word palliative care. The data collected from the pilot interview were not included in the data analysis.

**Data Collection**

Similar to the studies conducted by Hanratty et al. (2002), Spence et al. (2009), and Ryan et al. (2011), data were collected through interviews. On average, the interviews required 45 minutes to complete. They were semi-structured one-on-one interviews with attending and resident physicians because coordinating focus groups with physicians, particularly attendings, would have been an arduous task in light of their busy schedules. The interview-guided approach was the most efficient method to collect data in a time-sensitive framework while also allowing the participants to share their thoughts and experiences in a meaningful manner (Patton, 2002).

The interview questions (see Appendix D) were structured in a strategic manner. After the participants were invited to talk about themselves, they were presented with two straightforward and fictional case scenarios of a patient with COPD. The first case is in the outpatient (i.e. clinic) setting and the second case takes place in the Emergency Room with the patient presenting with a COPD exacerbation. The first case was not presented to emergency medicine physicians, because they do not treat patients in a clinic setting. They were therefore given a more completed version of the second case. Participants were asked to describe their management of patients with COPD in each of the scenarios, and summarize their thought
processes. This led to the next question in which participants were then asked to name their approaches to patients with COPD. This “naming” was intended to provide me with further insights into their therapeutic approach to patients with COPD. The remaining interview questions focused on elements specific to a palliative care approach, beginning more subtly with (1) prognosis and illness trajectory, (2) goals of care, and (3) patient and family support. Participants were then given a graph illustrating the typical trajectory of a patient with COPD, and asked to mark the point at which they would begin to adopt a palliative care approach. The graph served as a starting ground for discussions about palliative care, a palliative care approach, and the role of palliative care in COPD. The interviews always concluded with an invitation for the participants to share any final thoughts.

Data collection began October 27th, 2014 and ended on January 26th, 2015. Interested participants received a communication by email with further explanations of the purpose of the study, and reflective questions to consider prior to the interview. The prompting questions were aimed at preparing the interviewees for the recorded encounters, and providing them with sufficient time to thoughtfully consider the topic of interest. All participants were offered a gift card to Tim Hortons as a sign of gratitude for their participation.

Data Analysis and Validation Techniques

The interviews were audio recorded, and subsequently transcribed verbatim to enhance the validity of the qualitative design (McMillan & Schumacher, 2010), similar to studies by Hanratty et al. (2002), Spence et al. (2009), and Ryan et al. (2012). I transcribed the first five interviews, including the pilot interview. A transcriptionist was hired to complete the transcription of the remaining interviews. Unlike the three listed studies, member checking was also used as a validation technique to ensure accurate representation of the participants’ responses. Therefore, as soon as the interview was transcribed, a summary of the transcription
was sent by email to the participants to give them the opportunity to review their responses. Their additional comments were included in the data analysis.

Inductive analysis was conducted with the aid of Atlas.ti, a computer software program for coding purposes. Adopting an open-coding method was most suitable in this study in light of the novelty of the topic and the exploratory nature of the research questions concerning the physicians’ adoption of a palliative care approach in patients with COPD. Following data coding, the results were synthesized in a thematic approach to best inform the research questions. Predominant themes for the perceptions of the physicians were supported by the analyzed codes and direct quotations from the participants.

**Researcher Role**

My research study was created in the context of a thesis for a Master’s degree in Education. As a result, I held several roles. I firstly developed an interview framework serving to inform the study’s objectives. I initiated recruitment of the participants, and I also personally performed the interviews. I transcribed the first five interviews to provide me with some insight into the process of transcription, and gain further familiarity with the data. Although a transcriptionist transcribed the subsequent interviews, I reviewed all the transcriptions with the original audio recordings, and summarized each interview. Summarizing the interviews provided me the opportunity to thoughtfully synthesize each transcript to the main factual observations. Finally, I analyzed the data with a coding system, and consolidated them into themes presented in Chapter 4.
Chapter 4

Results

The purpose of the study was to examine the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD. A qualitative approach with one-on-one interviews was determined to be the most suitable and effective method to inform the purpose of the research. Recruitment took place over a five-month period during which time several physicians volunteered to take part in the study. The demographics of the participants introduce the results of this chapter. The data collected from the interview transcripts were then inductively analyzed to produce codes and categories. These categories are described in detail, followed by a separate discussion for each of the resulting themes. A summary of the results concludes the chapter and sets the stage for Chapter 5.

Participants

A total of 14 physicians volunteered to be interviewed for the study, of whom half were residents and half were attendings. Most of the physicians participating in the study originate from my own specialty: Internal Medicine. They were an easier group to recruit in light of our familiarity. Nonetheless, I gained representation from all the specialties from both resident and attending physicians. The demographics of the physicians in the study are presented in Table 3.

All participating physicians received by email a one to two-page summary of their interview. Although 13 physicians confirmed receipt of the summary, only the two attending physicians in respirology made additional comments, elaborating on some of the responses they made during the interview. Their comments were included in the data analyses.
Table 3

Demographics of the Physicians in the Study (n = 14)

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Residents (n = 7)</th>
<th>Attendings (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respirology</td>
<td>N/A</td>
<td>2</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Family Medicine</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Emergency Medicine</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Categorization of the Codes

Through the initial inductive analysis of the data, 50 codes emerged. The codes were reviewed to identify similarities and differences, resulting in 5 main categories and 8 subcategories. Each category was judged for its “internal homogeneity and external heterogeneity” (Patton, 2002, p. 465):

1. assessment of the patient with COPD;
2. management of the patient with COPD;
3. communication with the patient with COPD;
4. training in COPD and palliative care; and
5. perceptions of COPD and palliative care.

My personal experience as a physician helped me formulate the categories from the data, having experienced a physician’s methodical approach in the general care of a patient. The first three categories represent a physician’s usual sequence of interactions with patients. First and foremost, physicians in the study spoke about their assessment of patients with COPD. They gathered background information and prognosticated the patient, whether in the short- or long-term, the most likely course of illness. The assessment of the patient led into the management of the patient’s disease: COPD. Physicians in the study included non-pharmacological and pharmacological interventions in their management. The chain of interventions was prioritized.
based on their initial assessment. Participating residents and attendings also highlighted the goals of treatment of a patient with COPD during their management plan. Some of the physicians in the study mentioned the involvement of allied health care providers as a key component in their management. Finally, physicians communicated to their patients their findings, treatment plans, and expectations. They also took the opportunity to counsel patients, and educated them about their disease and the proposed interventions. Some of the participating physicians would also include the patient’s family members in these discussions.

The assessment, management, and communication stages were heavily influenced by the two last categories listed earlier: training and perceptions. While the physician’s background training and sources of education oriented their patient interactions, their inherit perceptions of COPD and palliative care equally impacted their assessment, management, and communication with patients with COPD.

The categories are graphically summarized in Figure 5. Training and perceptions are seen encircling the first three categories because they influence them. The methodical approach begins with the assessment of the patient with COPD, comprising the sub-categories Information Gathering and Prognosticating. The bottom arrow connects assessment to the next step in care: management. There are four sub-categories listed under Management of the Patient with COPD. The top arrow leads into communication with the patient with COPD, the final step in care encompassing two sub-categories: Discussions with Patients with COPD and Patient Education. The full list of codes supporting each category and sub-category can be found in Appendix E.
Thematic Representation of the Results

Using the primary purpose of the study as a foundation for analysis, five themes emerged from the data, describing relationships across the categories shown in Figure 5. Each of the themes are further described and supported by direct quotations from the participating resident and attending physicians. Participants were assigned a pseudonym to protect their identity, but for the following quotations, participants are numbered from 2 to 15, and identified as either a resident (R) or an attending (A). Number 1 was assigned to the resident for the pilot interview, whose data were not included in the analysis.
Theme 1: Physicians Unknowingly Adopt Elements of a Palliative Care Approach in Their Assessment, Management and Communication with Patients with COPD

The physician’s assessment of a patient with COPD began with information gathering, and was typically “strictly clinical” (R9). Gathered information mostly revolved around the patient’s medical history, smoking status, medication history, the presence of COPD comorbidities, the frequency and severity of previous COPD exacerbations, as well as the environmental and underlying triggers for an exacerbation. However, both residents and attendings seemed also interested in gathering information considered relevant to the palliative care approach. For example, one attending mentioned screening patients for depression, a condition he felt “people with chronic diseases are prone to” (A8). Four physicians were concerned about a patient’s physical safety prior to discharging them home from an emergency room visit or a hospital admission, expressing interest “to understand what their life is like before you can figure out if they’re safe for discharge” (R5).

Participants also assessed the MRC dyspnea scale of the patient presented in the fictional case during the interview, but the three attending physicians with a largely outpatient practice were particularly more interested in probing patients on the daily severity of their dyspnea, because patients “are very likely to underreport their symptoms, especially in milder disease” (A7). The underreporting of symptoms by patients underestimated their actual MRC dyspnea scale. Symptom burden was thought to affect a patient’s level of function, a point included in the assessment of patients by some of the physicians. However, some further made the link between level of function and quality of life, describing functionality as “what affects quality of life” (A14).

While some elements of the palliative care approach were described in the patient assessment, the approach was also demonstrated in the management proposed by the participating physicians. They listed non-pharmacological interventions aligned with the goals of palliative
care, such as pulmonary rehabilitation. One attending physician shared an exemplary explanation of the benefits of referring patients to pulmonary rehabilitation:

Pulmonary rehab is the best intervention we have to maximize symptom control, improve exercise capacity, improve their empowerment and self-efficacy so that they are more likely to do consistent, regular, home-based activities: so an invaluable intervention for these sort of patients (A7).

All participants incorporated aspects of medication review and optimization in their pharmacological management of patients with COPD. One particular pharmacological intervention commonly associated specifically with the palliative care approach was the use of opioids, because a patient may “benefit from a low dose opioid just to help… for the sensation of breathlessness” (R5), and one attending noted this intervention “would be palliative” (A11). Interviewed physicians listed other common pharmacological interventions in COPD, but not necessarily associating them with the palliative care approach. However, the palliative care approach unknowingly emanated from the goals of both their pharmacological and non-pharmacological management, such as to “improve quality of life” (A6), “optimize symptoms” (A7), “relieve morbidity” (A8), and “improve function” (R5). A few participants also touched upon “a multi-disciplinary approach for more advanced disease” (A7), engaging other health care professionals as part of the treating team. While “a competent case manager” (A7) can assist patients in managing their disease, “a nurse practitioner” (R9) can educate patients on proper inhaler use as well as participate in discussions regarding goals of care, end of life, and prognosis. Nonetheless, some physicians incorporated these topics of discussion pertaining to the palliative care approach within their own patient interactions. As one junior resident explained, “I’m learning more that goals of care and advanced directive discussions also come up quite a bit with COPD” (R10). Interviewed physicians across all disciplines discussed to various degrees goals of care as well as patient and family support with their patients. They would also educate patients
and their families about the definition and pathology of COPD, treatment options, and methods to use medication.

The educational component appeared to be a cornerstone in patient care, because, as one attending explained, “I think that’s what we do, really. The algorithms, sure they help, but whether the patient wants it or not, if you educate them, they may tell you no. They may tell you yes” (A8). Other physicians also shared this value of patient and family centeredness throughout their assessment, management and communication with patients with COPD. Patient centeredness is inherently part of the palliative care approach. However, as highlighted in this theme, most physicians unknowingly practice elements of palliative care, rather perceiving their general interactions with patients with COPD as the “standard approach to COPD” (A11). Their unknowingness was made obvious within their perceptions of palliative care and its approach.

**Theme 2: Physicians Have a Limited Understanding of Palliative Care and its Approach in Patients with COPD**

At first glance, interviewed physicians appeared to align their understanding of palliative care with the WHO definition stated in Chapter 2. A few of them spoke of it as a “holistic approach” (A8), primarily “focusing on patients” (A4). Most recognized the aspects of “symptom management” (R15), describing an approach to alleviate symptoms not only at the end of life, but also “in conjunction with active management for diseases” (R5). Some expressed palliative care as an intervention “to improve quality of life” (A6), and stated, “palliative isn’t end of life care” (A7).

However, the limited understanding of palliative care surfaced when the physicians applied it specifically to patients with COPD. As one attending physician explained:

I and many other people in my generation are not as attuned to thinking about that in the same way. Even though logically, I know, someone with chronic heart disease has got a much worse prognosis than many cancer patients. You know, still an awful lot of
referrals that I use in the hospital are cancer related, probably more so than other chronic medical conditions (A4).

There appeared to be a hesitancy to think about palliative care in patients with chronic medical conditions. Some physicians hesitated to institute a palliative care approach until “it looks like there is no recovery” (R2) for their patient with COPD. In an acute setting, they judged the reversibility of a condition, and held off adopting a palliative care approach until they perceived a “futility of treatment” (R2), or patients expressing “they don’t want to keep going” (A11). In fact, according to many physicians, “patient input” (A14) was required to adopt a palliative care approach, even qualifying the trigger for the approach as being “patient driven” (R3). Some physicians would wait until a patient’s “functionality has significantly declined” (R3), because palliative care “is that switch of maximizing function to maximizing comfort” (A14). Focusing on the patient’s comfort was a perception shared amongst several physicians as being a goal of palliative care. Another described the objective of palliative care as an approach to optimize symptoms, but physicians usually waited until a patient experienced significant symptom burden before adopting this approach. Otherwise, they also judged the “severity of exacerbation” (A6) experienced most recently by the patient, where patients with mild COPD exacerbations were not necessarily treated with a palliative care approach. In fact, when a patient presented to the hospital with a COPD exacerbation, many residents and attendings felt compelled to respond and treat the exacerbation and withhold palliative care, because “to initiate a palliative approach too early on is not giving patients a fair chance” (A11).

Part of the misconceptions of palliative care arose from the perceived connotation and regular use of the word palliative, especially in an inpatient setting. A patient who was qualified as “palliative” (R5) was understood to “not [receive] active management for their disease” (R5), or essentially be “dying very soon” (A8). As one attending physician commented in alignment with the views of others, “patients don’t like the term palliative care unless they’re clear that
they’re dying” (A11). Therefore, according to these residents and attendings, the general public appeared to hold a negative connotation of the term palliative care. This perceived negativity created discomfort in some of the interviewed physicians, because they experienced a “fear of patients’ preconceived notions” (R9) or wanted to prevent making patients “too depressed by thinking we’re talking palliative care” (A13). The misperceptions about the role and meaning of palliative care in COPD created diverging responses on the most appropriate time to adopt a palliative care approach, and resulted in a lack of consensus amongst physicians.

**Theme 3: There is no Consensus Amongst Physicians on the Timing to Introduce a Palliative Care Approach**

Near the end of each interview, participants were given a graph illustrating the illness trajectory of patients with chronic non-malignant diseases, as shown in the bottom of Figure 1. They were asked to mark the point at which they would begin to adopt a palliative care approach for a patient with COPD. Most physicians experienced great difficulty in deciding the most appropriate time. While two physicians (one attending and one resident) marked two points on the graph, one attending physician did not mark a point on the timeline because she required “patient input” (A14). All of the marked points were collated on a single graph shown in Figure 6, with the white points depicting selections made by attending physicians and the black points representing those chosen by the resident physicians. The graph clearly illustrates the lack of consensus amongst these physicians regarding the most appropriate time to begin adopting a palliative care approach, with selections made from the time of diagnosis right up to the time just before the straight dip to death. The only physician who confidently selected a point on the timeline was the attending who marked right at the time of diagnosis. This physician explained the terminal nature of COPD, perceiving the goal of all the interventions in COPD, from the time of diagnosis to death, as methods to improve symptoms, and hence qualifying them as “palliative measures” (A8).
A lack of consensus on the timing of goals of care discussions was also observed amongst the interviewed physicians, therefore reflecting the multiple divergent points in Figure 6. Many physicians were using the goals of care discussion as a reference point for the start of a palliative care approach. Some physicians preferred having the discussion after a patient recovered from a COPD exacerbation and prior to hospital discharge, because it was “easier to broach that topic once things have settled” (R3). However, others described having the discussion at the time of presentation to the hospital with a COPD exacerbation because of the potential for clinical deterioration, and the need to establish whether or not the patient would be amenable to intubation. On the other hand, some physicians would first assess whether a patient responded to the initial interventions of a COPD exacerbation, and if the patient was “not responding to therapy” (R9), then a goals of care discussion would ensue. Such discussions in an acute care setting were described as “challenging” (R9) and “difficult” (A13), because patients in respiratory
distress were perceived to “say ‘yes’ to everything” (R2). Therefore, other physicians argued the best time to have a discussion on goals of care was in the outpatient setting to provide patients with a “realistic goal” (A8). In fact, one resident described making notes to the family doctor to follow up on these discussions. From the point of view of the interviewed attending in family medicine, goals of care discussions were expected to have taken place in hospital when a patient presented with a COPD exacerbation. The discussion would be revisited if necessary at the subsequent clinic visit, but would typically be reviewed at the annual general assessment by the family doctor, and not necessarily during a routine COPD follow up visit. However, another physician with a primarily outpatient practice would not have the discussion because of lack of time during a clinic visit, or would only address it with patients with “very advanced disease” (A6), time-permitting. Patients who were judged to be “relatively well with a chronic condition” (A4) would not necessarily participate in this discussion early in the illness trajectory, because they are perceived to lack comprehension about COPD and its management. Other physicians though recognized the necessity for “ongoing discussions” (A7) about goals of care throughout the illness trajectory.

While interviewed physicians generally valued the discussion about goals of care, there was no consensus on its ideal timing. Similarly, resident and attending physicians could not agree on the best time to begin a palliative care approach in patients with COPD, largely as a result of their misperceptions of palliative care in COPD. Introducing palliative care in a timely manner requires a solid understanding of COPD and its prognosis.

**Theme 4: Physicians Experience Difficulties to Engage in Discussions about Prognosis and Illness Trajectory**

Engaging patients in discussions about prognosis is an important element in the palliative care approach. Only a proportion of physicians felt competent to discuss with patients about prognosis and illness trajectory, but the majority of them were attending physicians. Some of the attendings seemed to recognize the characteristic trajectory of COPD as a “slow chronic decline
with exacerbations along the way” (A11), and shared their understanding with patients, because “patients actually welcome this” (A7). The attending physicians also seemed to value explaining to patients their short-term prognosis during an acute exacerbation of COPD, providing them with realistic expectations. Another attending noted he often discussed prognosis with his patients in front of residents because he “[found] that’s something residents often don’t know” (A4).

The lack of understanding of the prognosis of a patient with COPD appeared to be a barrier for resident physicians to engage in those conversations. As one resident stated, “most of us don’t seem to understand the natural progression of COPD” (R9), a reality shared amongst several residents. Another more junior resident held false impressions about COPD, thinking some patients with COPD could be cured from their disease.

In reality, prognostication is not an exact science. Besides some deferring this latter topic of discussion to “other people to do that” (A13), other attendings shared the difficulty in predicting outcomes and recalled instances where they wrongly predicted a patient’s course of events, whether positively or negatively, as told by this attending physician:

It's hard to know on any given presentation for an exacerbation whether this will be one exacerbation that they sail through like they did the last time or whether they’ll be in hospital for four months or whether this will be the one that actually kills them (A11).

Another attending noted, “physicians are notoriously bad at predicting prognosis” (A4). The understanding of COPD and its prognosis partly rests on the training individuals have received about the disease. The sources of the physicians’ training play an instrumental role on their clinical practices.
Theme 5: Resident Physicians are Influenced by Attending Physicians Regarding the Therapeutic Approaches They Adopt when Caring for Patients with COPD

During the interviews, physicians were asked to justify the rationale for their approach to patients with COPD, and identify the sources of their thought processes. Nearly all the physicians referred to variable extents the impact of “clinical experience” (R3) on their therapeutic approach to patients with COPD. However, resident physicians consistently verbalized the influences from attending physicians. They have observed “what other staff physicians [did]” (R12), and subsequently incorporated these into their own daily practice. Certain management steps in the care of patients with COPD have been “drilled in” (R2) by attending physicians.

Remarkably, the influences by attending physicians were seldom noted in resident physicians’ understanding and application of palliative care. The family medicine resident physician was an exception because “one of [his] preceptors [was] a palliative care doctor” (R15). Otherwise, most resident physicians relied on their clinical experience, particularly patient encounters. Residents in internal medicine spoke about their one-month rotation in palliative care as being a source of their learning about palliative care. A senior resident physician noted the palliative care rotation in her first year of residency training was “absolutely essential” (R9), but became increasingly forgetful of the basic concepts as she progressed in residency. She spoke of her declining knowledge base, approach and understanding of palliative care, because “there [were] no frequent reminders” (R9). An attending physician who recalled rotating through palliative care during his residency training pointed out another problem. While the palliative care rotation gave him “a sense of what palliative care [was]” (A8) for inpatients, it inadvertently provided a narrowed view of palliative care, because it did not sufficiently expose him to outpatient palliative care practices, and most of the inpatient consults pertained to end-of-life care.

In light of the impact of attending physicians on the practices of resident physicians in patients with COPD, it is equally valuable to describe their sources of training. From the
perspectives of attendings, their approach to patients with COPD seemed highly influenced by “guidelines” (A11). They spoke very little of their residency training or previous preceptors. Complementing guidelines, many relied on their clinical experience over the years to orient their approach. Their perspectives of palliative care were similarly influenced by their own experience with patient encounters and interactions with “palliative care physicians offering their services to [their] patients” (A6). They also recalled attending a “lecture” (A14), but a few staff physicians admitted “never [having had] palliative care rotations” (A4).

Summary of the Results

Codes drawn from the interview transcripts involving 14 resident and attending physicians from various medical specialties were analyzed and grouped into five categories. First, three categories describe the interviewed physicians’ methodical care for patients with COPD: 1) assessment, 2) management, and 3) communication. The remaining two categories, the physicians’ training and perceptions of COPD and palliative care, influence their methodical approach. Relationships amongst these categories were translated into five themes informing the purpose to understand the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD:

1. Physicians unknowingly adopt elements of a palliative care approach in their assessment, management and communication with patients with COPD;
2. Physicians have a limited understanding of palliative care and its approach in patients with COPD;
3. There is no consensus amongst physicians on the timing to introduce a palliative care approach;
4. Physicians experience difficulties to engage in discussions about prognosis and illness trajectory; and
5. Resident physicians are influenced by attending physicians regarding the therapeutic approaches they adopt when caring for patients with COPD. Observations across the themes are discussed in Chapter 5, and related to the current understanding in the literature of COPD and the palliative care approach.
Chapter 5
Assessment and Plan

A model of patient care released over a decade ago advocates for an early adoption of a palliative care approach concurrently with disease-modifying therapies to address the needs of patients with a life-limiting illness such as Chronic Obstructive Pulmonary Disease (COPD) (Lynn & Adamson, 2003). While the value of this model of care is justified (see Figure 3), no study has demonstrated the extent of its adoption by physicians caring for patients with COPD, a disease with a high mortality rate (O’Donnell et al., 2008). Overall, patients with COPD continue to receive insufficient palliative care as a result of multiple barriers (Curtis, 2008; Spence et al., 2009). This current research study endeavoured to better understand the ways in which physicians consider palliative care while dealing with patients with COPD. Specifically, the primary purpose of this study was to examine the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD.

A qualitative design with an exploratory approach was used to inform the objectives of the research. Semi-structured interviews conducted over a 5-month period involved seven residents and seven attending physicians from internal medicine, respirology, emergency medicine and family medicine. Following verbatim transcription and member checking, the data were inductively analyzed to identify recurrent themes, which were presented in the previous chapter. This chapter examines the implications of these research findings for subsequent medical practice, education and research.

The Extent to which Physicians Adopt a Palliative Care Approach

The purpose of this research was to examine the extent to which resident and attending physicians adopt a palliative care approach in patients with COPD. The objective was to answer the following questions:
1. What are the therapeutic approaches resident and attending physicians adopt when caring for patients with COPD?

2. What conditions influence the adoption of a palliative care approach?

3. How do resident and attending physicians perceive a palliative care approach?

According to the Canadian Hospice Palliative Care Association (CHPCA), the goals of a palliative care approach in the early stages of illness are to:

1. openly communicate to patients and their families their prognosis and illness trajectory;

2. discuss advance care planning by establishing the patient’s goals of care and providing them with all the options for treatment;

3. offer psychosocial and spiritual support as they cope with the illness; and

4. alleviate any symptoms (Bacon, 2012).

In undertaking this research, I was under the impression physicians lacked an understanding of the definition, role and purpose of palliative care in general. Surprisingly, the resident and attending physicians in the study identified some of the characteristics of palliative care in alignment with recommendations in the literature. For example, they recognized its role in symptom control not only at the end of life, but in conjunction with disease-modifying therapies. Their responses in the interview also partly demonstrated the adoption of a palliative care approach when caring for patients with non-malignant diseases, such as COPD. Their adoption of the approach particularly pertained to the alleviation of symptoms. They assessed the severity of the patients’ symptoms, and would intervene with both pharmacological and non-pharmacological therapies, such as optimizing the patients’ use of inhalers and referring patients to pulmonary rehabilitation. The physicians’ goals of management in COPD also seemed to be in line with the overarching aim of the palliative care approach: to “[focus] on person and family, and on their quality of life throughout the illness, not just at the end of life” (Bacon, 2012, p. 8).
Nevertheless, these physicians’ understandings of the application of palliative care in patients with COPD were shown to be limited. As a result, they did not seem to adopt a palliative care approach early in their patients’ disease trajectory. For instance, few openly communicated to patients and their families their long-term prognosis and the illness trajectory. Although discussions about goals of care generally occurred, albeit to varying degrees, they were not consistently completed in a timely manner early in the disease trajectory. Finally, very few physicians offered any psychosocial or spiritual support to their patients to help them cope with their illness.

The Delayed Adoption of a Palliative Care Approach

The misunderstandings about the application of palliative care in patients with COPD are further made evident by the disparity depicted in Figure 6. This figure captures the different points at which physicians in the study would begin to adopt a palliative care approach. During the interview with the physicians, the figure was primarily used as a platform to discuss the palliative care approach in patients with COPD. Physicians may have held different perceptions of the illustrated trajectory and the meaning behind starting the palliative care approach, which were not captured by their responses in Figure 6. With the exception of only one attending physician who began this approach at the time of diagnosis, the physicians delayed the adoption of a palliative care approach, suggesting a different model of care from Lynn and Adamson (2003). Their model of care shown in Figure 3 is depicted again in Figure 7B, contrasting it to the model of care drawn from the findings of the study. In both models of care, the proportion of total treatment distributed between disease-modifying and palliative care approaches is represented on the vertical axis while time is represented on the horizontal axis. In Figure 7A, at the time of diagnosis, treatment is solely based on modifying the disease course. The dotted line represents the time at which physicians would introduce a palliative care approach concurrently with disease-modifying therapies. Gradually over a variable timeline, the palliative care approach
takes more precedence until the time of death. While the gradual increase in the proportion of the palliative care approach begins at the dotted line in Figure 7A, it begins at the time of diagnosis in Figure 7B.

Figure 7

*Model of Care Adopted by the Physicians in the Study for Patients with COPD Compared to the Recommended Model of Care*

![Diagram A](image)

![Diagram B](image)

On a positive note, the older transition model of care, dichotomizing curative and palliative care approaches, was not adopted by most of the physicians in the study. Few suggested halting disease-modifying therapies when introducing palliative care. Only the two physicians (one resident and one attending) who marked in Figure 6 the point just before the dip to death dichotomized disease-modifying and palliative care approaches.

Most of the physicians held a general concept aligned with Figure 7B, but its adoption was delayed. Three main reasons may explain the delayed effect observed in Figure 7A, all of which pertain to perceptions held by the resident and attending physicians in the study:

1. they perceived palliative care as an approach focused on comfort;
2. they feared the negative perceptions held by patients about palliative care; and
3. they perceived the palliative care approach as a reactive rather than proactive approach.

Early application of a palliative care approach appeared to be a foreign concept for most of the participating physicians because they perceived the approach as a shift in focus, where a patient’s comfort was prioritized. They equated palliative care primarily as a measure to maximize comfort. Hence they hesitated to adopt an approach where a focus on comfort would compromise function, with one physician stating, “some of the things we might use for comfort actually are harmful” (A14) for patients if used too early in the illness trajectory. This physician is most likely referring to medications such as opioids, a class of drug used to control pain and shortness of breath. Admittedly, opioids can harm patients if inappropriately administered at any time in the disease trajectory, but a similar phenomenon would occur for every medication. For example, prednisone, a steroid commonly used in the treatment of COPD, particularly during an exacerbation, carries significant harmful adverse effects. Regardless of the timing of their use over the disease trajectory, the administration of opioids and prednisone require close monitoring to minimize harm to patients. Furthermore, receiving vaccinations, engaging in physiotherapy,
and undergoing surgery to remove a painful tumour are examples of therapies considered to be uncomfortable, but they serve to improve a patient’s quality of life. Nonetheless, insinuating palliative care focuses on comfort is not an accurate premise. In fact, in the 183 words of the WHO definition of palliative care (see Chapter 2), the word or a derivative of the word “comfort” is never mentioned. The misperceived nature of palliative care as an approach focused on comfort may have contributed to the interview comments and the dispersed effect observed in Figure 6. Overall, associating palliative care with a shift towards providing comfort appears to be a barrier for an earlier adoption of a palliative care approach in patients with COPD.

Another barrier indicated by comments from the physicians in the study relates to their perceptions of the patients’ understanding of the term “palliative care.” According to these resident and attending physicians, patients negatively perceive the term “palliative care.” As an example of these concerns, one resident explained her “fear of patients’ preconceived notions” (R9). Rooted in this fear is likely an inability to respond to patients’ concerns regarding palliative care due to the physicians’ lack of confidence on their own knowledge of the role of palliative care in COPD. As demonstrated in Chapter 4, under the second theme entitled “Physicians have a limited understanding of palliative care and its approach in patients with COPD”, participating physicians hesitated to think about palliative care in patients with chronic medical conditions, such as COPD. Their hesitancy is a sign of decreased confidence, and translates from a preconceived fear of patients’ understanding of palliative care. As a result, physicians avoided the term “palliative care” in their clinical practices because they perceived patients to associate the term with death, a phenomenon also shown in the study by Spence et al. (2009).

While resident and attending physicians’ fears of patients’ perceptions may have contributed to a delayed adoption of a palliative care approach, their tendency to use a reactive approach to palliative care rather than a proactive approach also influenced the effect observed in Figure 6. These physicians listed conditions influencing their decision to begin the adoption of a
palliative care approach. These physicians would often wait until there was a decline in function, an increase in symptom burden, a severe COPD exacerbation, a lack of reversibility of an exacerbation, and/or a request from a patient in order to initiate the palliative care approach. The manifestation of these conditions can be difficult to place on a timeline due to their subjective and unpredictable nature. Hence, not only would it be difficult to judge a timely introduction of a palliative care approach based on these conditions, but it would also delay its introduction.

The conditions listed by the resident and attending physicians also do not align with the World Health Organization’s definition of palliative care. The only suggested indication to receive palliative care is a diagnosis of a “life-threatening illness” (WHO, 2013, para. 1). The definition also highlights palliative care as an “approach that improves the quality of life of patients and their families… through the prevention and relief of suffering by means of early identification” (WHO, 2013, para. 1). Rather than waiting for further compromise in a patient’s health, as suggested by the physicians in the study, the WHO recommends proactively addressing the anticipated compromise, stating palliative care “is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life” (WHO, 2013, para. 2). The Canadian Hospice Palliative Care Association (2014) also supports the earlier integration of palliative care in the patient’s course of illness.

Implications of a Delayed Adoption of a Palliative Care Approach

The delayed adoption of a palliative care approach highlighted in Figure 7A was shown to be caused by physicians:

1. misperceiving palliative care as an approach focused on comfort;
2. fearing the negative perceptions held by patients about palliative care; and
3. using a reactive approach to palliative care rather than a proactive approach.

This delay results in the very problem explained in Chapter 1; patients with COPD continue to receive insufficient palliative care (Curtis, 2008; Spence et al., 2009). Patients with a chronic non-
malignant condition, such as COPD, experience an illness trajectory characterized by a steady slow decline in function with periods of exacerbation (Lynn & Adamson, 2003). Every exacerbation represents a time of potential death. Patients with COPD could die from their disease during an exacerbation that is refractory to medical treatment. However, their death is unpredictable, because they survive many of their exacerbations as a result of current advances in medical treatment. Therefore, each patient’s last COPD exacerbation remains a mystery. Many of the conditions associated with the adoption of a palliative care approach listed by the participating physicians coincide with events occurring around the time of an exacerbation. For example, a decline in function, a severe COPD exacerbation and a lack of reversibility of an exacerbation occur only when a patient experiences this COPD exacerbation. The unpredictability of death in COPD renders these conditions inappropriate to base a decision to begin to adopt a palliative care approach, because patients risk suddenly dying. They would therefore miss the opportunity to be treated with a palliative care approach.

The unpredictability of death in patients with COPD demands an earlier integration of a palliative care approach. Nevertheless, the identification of some practices associated with palliative care, albeit unknowingly to the interviewed physicians, is promising. As one participant noted, “I think it’s more important to do the right thing and have the right approach, and not necessarily label it as palliative care” (A11). However, mislabeling physicians’ practices carries significant implications as well.

Avoidance of the term palliative care continues to stereotype it as simply an intervention for end-of-life care. Patients continue to have an ongoing impression of a switch of care from disease-modifying to palliative care when they near death, when in reality, very few interventions in COPD have demonstrated any disease modification (Halpin & Tashkin, 2009; O'Donnell et al., 2008; Rabe et al., 2007). Smoking cessation and initiation of home oxygen for qualified patients are the only two interventions in COPD management proven to delay mortality (O'Donnell et al.,
Avoidance of the term early in the illness trajectory also affects the training of residents. As found across the interviews, physicians culturally used the term “palliative” to describe a dying patient, further driving its stereotype. The switch of care from disease-modifying to palliative care therefore risks remaining as the prevailing model of care in their minds. Resident physicians inadvertently believe patients with COPD may potentially improve over time with disease-modifying interventions, because the palliative care approach comes later when patients near death. Resident physicians in the study were in fact less inclined to engage in discussions surrounding prognosis and illness trajectory, largely due to their lack of knowledge of the natural progression of COPD. Their false impressions blinded them from the actual illness trajectory of COPD, and the patient’s experience of living with a life-limiting disease. To disregard the term palliative care is to disregard a framework of care centered on patients and their families. There is a wealth of literature outlining the treatment of patients with a palliative care approach. If residents are not explicitly informed about the “palliative care” nature of certain interventions, they will not be prompted to access literature on caring for patients with a palliative care approach, therefore limiting their learning potentials.

The Learning Experience of Resident Physicians

While misperceptions of palliative care were observed in both resident and attending physicians, resident physicians seemed to mirror their attending physicians in their therapeutic approaches to patients with COPD. Residents did not allude to any conflicts with their preceptors when caring for patients with COPD. Rather, they often learned from their attending physicians. However, as described in Chapter 4 under the fifth theme entitled “Resident physicians are influenced by attending physicians on the therapeutic approaches they adopt when caring for patients with COPD”, residents seldom regarded attending physicians, specifically those regularly treating patients with COPD, as a source of learning about the palliative care approach. The resident physicians who participated in the study nonetheless also carried two other limitations
for further understanding the palliative care approach in patients with COPD: 1) their primarily inpatient practice, and 2) their limited years of experience.

Internal medicine and emergency medicine residents, who form the bulk of the resident physician demographics in the study, primarily practice within the framework of a hospital. As opposed to many of the attending physicians who have weekly outpatient clinics, these resident physicians rarely treat patients in an outpatient setting. Therefore, their medical training tends to focus on acute care, from presentation in the ER to discharge from hospital. In the illness trajectory of the patient with COPD, they would tend to encounter these patients during a COPD exacerbation, thus providing them with a narrow view of the patient’s illness experience. This could contribute to their difficulty in prognosticating patients with COPD in the long term, because they do not follow patients over a prolonged period of time. Residents seemed unaware of the disease course for patients with COPD. Similarly, the health professionals participating in Spence et al.’s study (2009) often managed COPD during an acute exacerbation, and the acuity of the management overshadowed their patient’s prognosis. The challenges in prognostication may also arise from the residents’ limited years of clinical experience compared to attending physicians. Along with guidelines, attending physicians in the study relied heavily on their clinical experience to guide their current approaches to patients with COPD. Therefore, they have developed a better sense of the illness trajectory of a patient with COPD.

**Recommendations**

The need for education was evident by the common misperceptions held by the physicians on the adoption of a palliative care approach in patients with COPD. Physicians’ use of palliative care as a reactive rather than proactive approach delays the integration of palliative care simultaneously with disease-modifying therapies. As such, I first recommend efforts be implemented to encourage physicians to stop relying on particular conditions to trigger a palliative care approach. The diagnosis of a life-limiting illness should be sufficient to adopt the
palliative care approach. However, to further assist physicians in their adoption of the palliative care approach, more efforts are required to ensure physicians are more familiar with the current definition of palliative care. Personally, I have not come across the WHO definition of palliative care throughout my medical training until I started this project… and I have been an enthusiast of palliative care for a number of years.

Attending physicians use guidelines to justify their interventions in the management of patients with COPD. These physicians in turn influence resident physicians. I would therefore suggest revisiting treatment guidelines, specifically those pertaining to COPD. Although the terminal nature of COPD is already recognized in the literature, guidelines in COPD management do not make any recommendations regarding an earlier adoption of a palliative care approach. Detailing the practical steps in adopting a palliative care approach early in the illness trajectory of a patient with COPD could be highly valuable. Further comments and research can be made regarding balancing disease-modifying and palliative care approaches in this particular patient population.

Beyond the scope of this study, a more proactive approach would be to further expand the education of palliative care to medical students. I personally recall receiving minimal training in palliative care. The training received often pertained to end-of-life care, a phenomenon also experienced by many interviewed residents during their rotation in palliative care in their first year of residency. In medical school, lecturers on non-malignant diseases have the opportunity to introduce the term “palliative care” to demonstrate its early integration across many diseases and disciplines in medicine. Offering both medical students and residents exposure to palliative care clinics could also help them understand the broad scope of the palliative care approach.

**Limitations**

Although important findings have emerged from the study, the size and nature of the sample of physicians make it difficult to generalize the findings. Data were collected from a small
sample of resident and attending physicians from a single medical institution. Most of the resident physicians participating in the study practiced in inpatient acute care settings. Certainly, the involvement of more residents from the department of family medicine, who are exposed to more outpatient settings, may have altered some of the findings. However, family medicine residents receive significant training in inpatient settings during their two-year residency training. Therefore, differences may not have been observable. In spite of the study’s limitation, the findings have been consistent with previous research, suggesting that the early adoption of palliative care for patients with non-malignant diseases remains a challenge.

A second limitation of the study is the use of a single researcher to analyze the interview data. There were no attempts to include a second reviewer of the interview data to provide cross-validation of my interpretations. Given my initial perspectives about the implementation of palliative care, these biases may have possibly influenced my interpretations of the interview data. Regardless, the data obtained using the illness trajectory (see Figure 6) provides support for my interpretations of the interview data.

**Significance of the Study**

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in Canada, and is projected to be the third on a worldwide scale by 2020 (Curtis, 2008; O'Donnell et al., 2008). Addressing the needs of patients with COPD therefore remains a high priority. Patients with COPD continue to receive insufficient palliative care (Curtis, 2008; Spence et al., 2009) despite advocacy for models of care suggesting the concurrent adoption of the palliative care approach with disease-modifying therapies in patients with non-malignant diseases (Bacon 2012; Hawley, 2014; Lynn & Adamson, 2003). While advocating these models of care is well justified, no study has demonstrated their adoption by primary care physicians and specialists caring for patients with non-malignant diseases, notably COPD.
The current study provides a first-time insight into the therapeutic approaches adopted by resident and attending physicians when treating patients with COPD. Interviewed physicians unknowingly described some practices of a palliative care approach, but as shown in Figure 7, they delayed the adoption of a palliative care approach simultaneously with a disease-modifying approach. Although they delayed its adoption, most of the physicians seemed to acknowledge the concurrent practice of the palliative care approach with a disease-modifying approach. They in fact did not dichotomize these approaches, as was done traditionally (Lynn & Adamson, 2003). Therefore, the propensity of the interviewed physicians to concurrently adopt a palliative care approach with disease-modifying therapies, albeit delayed, suggests a possible shift in medical culture.

While it was not the primary objective of the study to examine the barriers to adopt a palliative care approach in patients with COPD, three barriers were evident:

1. physicians misperceive palliative care as an approach focused on comfort;
2. physicians fear the negative perceptions held by patients about palliative care; and
3. physicians use a reactive approach to palliative care rather than a proactive approach.

The second barrier was also shown in the study by Spence et al. (2009), but the two other barriers have been demonstrated in this study for the first time.

**Future Research**

Further research to understand the needs and barriers of physicians in proactively adopting a palliative care approach in patients with COPD would be helpful, especially if such research examines physicians’ approaches to palliative care in different contexts. Moreover, it would be valuable to obtain a broader survey of physicians across many centers in Canada to provide statistical evidence on their perceptions of palliative care in treating patients with COPD and other non-malignant diseases.
While the study showed a delay in the adoption of a palliative care approach, it also demonstrated the propensity of physicians to concurrently adopt a palliative care approach with disease-modifying therapies, suggesting a possible shift in medical culture. Further exploring the etiology of this shift could inform ways to encourage a proactive approach to palliative care.

Finally, it would be valuable to study the public’s view of palliative care. While a need for palliative care has been established in patients with non-malignant diseases, their perceptions of the palliative care approach remains unknown. Such research can clarify gaps in knowledge and identify the sources of people’s fears. As a result, we can progress and appropriately focus patient education on the role of palliative care in non-malignant diseases, such as COPD.

**Final Reflections**

Patients are at the center of medical care. Our role as physicians is to provide them with the best possible care, and learn from our past mistakes. I believe the medical community committed a mistake in depriving Mr. C and his wife from a palliative care approach early in his illness experience, resulting in his distressing death. The early integration of a palliative care approach may have fortuned him with a more peaceful ending of his life. However, palliative care could also have improved this man’s quality of life while living with a diagnosis of COPD. We are all patients at some point in our lives. When you will face a life-limiting illness, how would you like to live?
References


http://hpcintegration.ca/resources/discussion-papers/palliative-approach-to-care.aspx


Appendix
Appendix A: Ethics Letter of Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD-DELEGATED REVIEW
August 12, 2014

Dr. Mino Mitri
Faculty of Education
Queen’s University

Dear Dr. Mitri

Study Title: EDUC-011-14 Perceptions of Physicians on the Adoption of a Palliative Care Approach in Patients with Chronic Obstructive Pulmonary Disease
File # 6013359
Co-Investigators: Dr. D. Klinger

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and interview questions for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of ethics requirements you must fulfill over the course of your study:

Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # 6013359 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher)

Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information. Serious Adverse Event forms are located with your post-review file 6013359 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher)

Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair’s signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert L. Clark.

Chair, Health Sciences Research Ethics Board
August 12, 2014

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete
Appendix B: Letter of Information

Physicians’ Approach to Patients With Chronic Obstructive Pulmonary Disease

This research is being conducted by Mino Mitri (Masters of Education, 2015 Candidate) under the supervision of Dr. Don Klinger in the Faculty of Education and Dr. Ingrid Harle at the Faculty of Health Sciences at Queen’s University in Kingston, Ontario. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines and Queen’s policies.

You are invited to participate in a project entitled “Physicians’ Approach to Patients With Chronic Obstructive Pulmonary Disease”. This letter provides you with the background information on the project.

What is this study about? Chronic Obstructive Pulmonary Disease (COPD) is projected to be the third leading cause of death worldwide by 2020 (Curtis, 2008). There are limited studies exploring the approach adopted by physicians in treating patients with various non-malignant diseases, notably COPD. I am interested in understanding the approach adopted by resident and attending physicians in treating patients with COPD.

What will this study require? If you agree to participate in this research, you will be invited to a 45-minute interview, which will be audio-recorded. You will be contacted by email to arrange a mutually convenient time. Although all resident and attending physicians in the Departments of Family Medicine and Emergency Medicine as well as in the Divisions of Internal Medicine and Respirology will be invited to participate, only a limited number of interviews will be conducted. After transcription of the interviews, you will electronically receive a summary of the interview, which will allow you to ensure that I have accurately captured your thoughts. You have the option to electronically send me any additional comments regarding the summarized transcripts, with the knowledge that these comments would be included as part of the data.

Is participation voluntary? Your participation is completely voluntary and choosing not to participate will not result in any adverse consequences. There are no known physical, psychological, economic, or social risks associated with this study. Further, you are free to choose, without reason or consequence, to refuse to answer any questions during the interview. You may withdraw from the study at any time with no negative consequences. If you withdraw from the study, you may choose to have your data removed.

What will happen to my responses? The interview recording will be transcribed and then the recording will be destroyed. All electronic files will be password protected. Paper and audio data will be secured in a locked cabinet, and made available only to the principal and co-investigators. To protect your identity, a pseudonym will replace your name on all data files and in any dissemination of findings. Hence your confidentiality will be protected to the extent possible. This research may result in publications of various types, including journal articles or other professional publications. I will maintain copies of the transcripts for a minimum of 5 years and may use the data (with pseudonyms) in subsequent research or presentations.

What if I have concerns? Any questions about study participation or a request to withdraw from the study may be directed to Mino Mitri at mino.mitri@queensu.ca or my supervisor Don Klinger at klingerd@queensu.ca. Any ethical concerns about the study may be directed to Dr. Albert Clark, Chair of Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, at (613) 533-6081 or clarkaf@queensu.ca.
Appendix C: Consent Form

Physicians’ Approach to Patients With Chronic Obstructive Pulmonary Disease

Name (please print clearly): ____________________________________________________

1. I have read and retained the Letter of Information and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study called Physicians’ Approach to Patients With Chronic Obstructive Pulmonary Disease (COPD). I understand the purpose of this research is to understand the approach adopted by physicians in treating patients with COPD. I understand that participation in this study will entail a 45-minute audio-recorded interview, and any additional time I choose to put in reviewing my summarized transcript as well as communicating by email any comments to the researcher. I understand that any additional comments pertaining to the summarized transcripts will be considered as data for the study.

3. I understand that my participation in this study is voluntary and I may withdraw at any time without adverse consequences. I understand that if I withdraw from the study, I may choose to have my data removed. I understand that the data may also be published in professional journals or presented at academic conferences. I understand that every effort will be made to maintain confidentiality to the extent possible now and in the future.

4. I understand that this study involves no greater risk than those ordinarily occurring in daily life, and that it is not possible to identify all potential risks in any research, but that all responsible safeguards have been taken to minimize any potential risk.

5. I am aware that any questions about study participation or a request to withdraw from the study may be directed to Mino Mitri at mino.mitri@queensu.ca or my supervisor Don Klinger at klingerd@queensu.ca. Any ethical concerns about the study may be directed to Dr. Albert Clark, Chair of Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, at (613) 533-6081 or clarkaf@queensu.ca.

Please sign one copy of this Consent Form and return to the researcher. Retain the second copy for your records.

I have read the above statements and had any questions answered. I freely consent to participate in this study.

Participant’s Signature: ____________________________

Date: ____________________________ E-mail address: ____________________________
Appendix D: Interview Questions

Prompting Questions Prior to Interview (Sent by Email)

1. When you encounter a patient with COPD, what are your priorities in patient management? How would these priorities change in a patient with severe or very severe COPD?

2. What has influenced your approach to patients with COPD?

Questions for the Interview

1. Can you please describe your career path and areas of expertise?

2. Case scenarios.
   a. Case 1: How would you manage this patient? What is leading you to think in that manner? What factors shape your understanding of the situation?
   b. Case 2: How would you manage this patient? What is leading you to think in that manner? What factors shape your understanding of the situation?

3. How would you name your approach with patients with COPD? Describe your approach. What is your objective in mind with this approach? What has led you to adopt this approach?

4. What is the nature of your discussions with patients with COPD? What has led you to include these elements in your discussions?
   a. To what extent do you discuss issues related to ...
      i. Prognosis and illness trajectory
      ii. Goals of care
      iii. Patient and family support

5. In the following graph illustrating the typical trajectory of a patient with COPD, mark with an “X” the point at which you would begin to adopt a palliative care approach. Explain your answer. What factors influence your decision to adopt a palliative care approach? How did you come to this conclusion?

6. How would you define palliative care? What has shaped your definition of palliative care?

7. What is a palliative care approach? How did you come to this understanding?

8. Do you have any additional comments?
CASE 1

Mr. C is a 72 year-old man presenting to clinic for follow-up management of his COPD. He was diagnosed with COPD six years ago. Besides hypertension and a 45 pack-year history of smoking, he has no other co-morbidities. He quit smoking six years ago at the time of his diagnosis. He has had two COPD exacerbations since his diagnosis, with the most recent one occurring six-months ago. His last exacerbation required BiPAP for the first time.

Further history reveals that Mr. C often stops to catch his breath after walking about 100 meters. He doesn’t complain of cough. He lives with his 66 year-old wife in a bungalow. Although occasionally limited by breathlessness, he can generally function independently at home.

Pulmonary function tests one year ago showed an FEV₁ of 40% predicted and FEV₁/FVC of 0.65. Arterial blood gas drawn one month ago showed mild chronic CO₂ retention with no hypoxemia.

Mr. C is currently compliant with his medications, which include Advair Diskus 250mcg/50mcg BID, Spiriva 18mcg daily, as well as Ventolin and Atrovent PRN. He uses both Ventolin and Atrovent on average 3-4 times per day.

CASE 2

Five months after the clinic visit, Mr. C presents to the hospital ER with a three-day history of worsening shortness of breath, as well as increasing cough and green-coloured sputum production.

Vitals are the following: BP 141/73, HR 93 regular, RR 20 (laboured breathing), SpO₂ 82% on room air, Temp 37.2 °C. On auscultation, there are expiratory wheezing and decreased breath sounds at the bases bilaterally.

Arterial blood gas on room air shows the following: pH 7.25, pCO₂ 71 mmHg, pO₂ 70mmHg, HCO₃ 36 mmol/L

Chest X-Ray has not changed from previous x-ray.

Mr. C required up to 6L of oxygen by nasal prong, but continued to desaturate to 85% three hours later despite oxygen by NP.

ER CASE

Mr. C is a 72 year-old man presenting to the hospital ER with a three-day history of worsening shortness of breath, as well as increasing cough and green-coloured sputum production.

He was diagnosed with COPD six years ago. Besides hypertension and a 45 pack-year history of smoking, he has no other co-morbidities. He quit smoking six years ago at the time of his diagnosis. He has had two COPD exacerbations since his diagnosis, with the most recent one occurring 11-months ago. His last exacerbation required BiPAP for the first time.

Further history reveals that Mr. C often stops to catch his breath after walking about 100 meters. He doesn’t complain of cough. He lives with his 66 year-old wife in a bungalow. Although occasionally limited by breathlessness, he can generally function independently at home.

Pulmonary function tests one year ago showed an FEV₁ of 40% predicted and FEV₁/FVC of 0.65. Arterial blood gas drawn six months ago showed mild chronic CO₂ retention with no hypoxemia.

Mr. C is currently compliant with his medications, which include Advair Diskus 250mcg/50mcg BID, Spiriva 18mcg daily, as well as Ventolin and Atrovent PRN. He uses both Ventolin and Atrovent on average 3-4 times per day.
Vitals are the following: BP 141/73, HR 93 regular, RR 20 (laboured breathing), SpO₂ 82% on room air, Temp 37.2 °C. On auscultation, there are expiratory wheezing and decreased breath sounds at the bases bilaterally.

Arterial blood gas on room air shows the following: pH 7.25, pCO₂ 71 mmHg, pO₂ 70mmHg, HCO₃ 36 mmol/L

Chest X-Ray has not changed from previous x-ray.

Mr. C required up to 6L of oxygen by nasal prong, but continued to desaturate to 85% three hours later despite oxygen by NP.

**Graph for Interview**

![Graph showing three trajectories of illness](image)

(Lynn & Adamson, 2003)
### Appendix E: Codes

<table>
<thead>
<tr>
<th>Categories and Sub-Categories</th>
<th>Codes</th>
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| **Assessment of the Patient with COPD** | Quality of life measures  
Patient safety  
Assessing risks for exacerbations |
| **Information Gathering** | Assessing patient symptoms  
COPD comorbidities  
Gathering patient history  
Functional status  
Smoking status |
| **Prognosticating** | Reversibility  
Prognostication  
Indicators for patient deterioration |
| **Management of the Patient with COPD** | Pulmonary rehab  
Home oxygen  
Vaccinations  
Follow up |
| **Non-Pharmacological Management of COPD** | Non-pharmacological management of COPD exacerbation  
Acutely optimizing ventilation / oxygenation  
Referral to experts  
Optimizing function  
Investigations |
| **Pharmacological Management of COPD** | Medication review  
Medication compliance  
Pharmacological treatment for COPD exacerbation  
Pharmacological treatment for stable COPD |
| **Framing the Approach to COPD** | Goals of COPD management  
Factors influencing COPD management  
Goals of management for a COPD exacerbation  
Framework of the approach to a patient with COPD  
Patient and family centeredness |
| Allied Health Care Providers in COPD Management | Role of case manager  
Multi-disciplinary approach to COPD management  
Involvement of nurse practitioner |
|-----------------------------------------------|-----------------------------------------------------------------|
| **Communication with the Patient with COPD** | Sharing treatment plans with patients  
Prognosis and illness trajectory discussion  
Patient counselling  
Patient and family support discussions  
Goals of care discussion |
| **Discussions with Patients with COPD** | Patient education on treatments  
Patient education on COPD |
| **Patient Education** | Training in COPD management  
Training on goals of care discussion  
Learning about discussions about pt and family support  
Learning about palliative care approach / palliative care |
| **Training in COPD and Palliative Care** | Communicating the term palliative care  
Trigger to begin a palliative care approach  
Triggers to involve palliative care experts  
Perception of the role of palliative care  
Perception of COPD patients  
Perception of a palliative care approach  
Understanding COPD |