Negotiating Uncertainty: Advance Care Planning in Advanced Chronic Obstructive
Pulmonary Disease (COPD)

by

Anna Catherine Simpson

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The undersigned hereby certify that they have read and recommend to the Faculty of Graduate Studies for acceptance a thesis entitled "Negotiating Uncertainty: Advance Care Planning in Advanced Chronic Obstructive Pulmonary Disease (COPD)" by Anna Catherine Simpson in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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External Examiner: _____

Research Supervisor: _____

Examining Committee: _____

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   _____

   _____

Departmental Representative: _____

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DEDICATION

For all those living with the daily challenges of advanced COPD, particularly those who welcomed me into their homes and so graciously shared their hope, courage, and experience. And for those who care for them, at home and within the healthcare system. My hope is that this work will in some way improve that care now and at the end of life.

Hope: An Owner's Manual*

Look, you might as well know, this thing
is going to take endless repair: rubber bands,
crazy glue, tapioca, the square of the hypotenuse.
Nineteenth century novels. Heartstrings, sunrise:
all of these are useful. Also, feathers.

To keep it humming, sometimes you have to stand
on an incline, where everything looks possible;
on the line you drew yourself. Or in
the grocery line, making faces at a toddler
secretly, over his mother's shoulder.

You might have to pop the clutch and run
past all the evidence. Past everyone who is
laughing or praying for you. Definitely you don't
want to go directly to jail, but still, here you go,
passing time, passing strange. Don't pass this up.

In the worst of times, you will have to pass it off.
Park it and fly by the seat of your pants. With nothing
in the bank, you'll still want to take the express.
Tiptoe past the dogs of the apocalypse that are sleeping
in the shade of your future. Pay at the window.
Pass your hope like a bad check.
You might still have just enough time. To make a deposit.

Barbara Kingsolver

*My friend and long-time spiritual guru, the Very Rev. Paul Smith, sent me this poem when my doctoral journey had become bogged down and hope seemed hard to come by.

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Abstract

Physical and psychosocial symptoms in advanced chronic obstructive pulmonary disease (COPD) are cumulative and profound; global financial and human costs are huge. COPD in late stages runs an unpredictable downward course of increasing, potentially fatal exacerbations. Nevertheless many physicians avoid advance care planning in this context, a choice that tends to promote last minute crisis decision-making. To explore a more ethically sound proactive approach to end-of-life care decision-making I conducted a qualitative study informed by the question: "What is required for meaningful and effective advance care planning in the context of advanced COPD?"

Fifteen participants (eight patients with advanced COPD plus seven intimate others) participated in two in-home advance care planning discussions that incorporated patient-centred care principles. Session transcripts were analyzed using "interpretive description." Despite initial wariness, participants were able to discuss their care-related hopes and preferences and reported that the process was a positive one. Interpretation of the positive feedback suggested participants experienced the process as a chance to: a) talk with an attentive clinician, b) learn, c) consider care-related goals and preferences, and, d) have intimate others hear about these goals/preferences. Interpretation of the process that led to this positive assessment is described in terms of a thematic network.

The overarching global theme of this network was "advance care planning as collaborative care," which involved three organizing themes--partnering, negotiating ambiguity, and being a resource--and a cluster of basic themes related to each of these. The "collaborative care" approach is discussed as a guide to advance care planning in advanced COPD. Like other advance care planning models, the study approach included a skilled clinician facilitator, provision of targeted information, and attention to readiness. There were four new elements: focus on caring, engaging hope, facilitator reflective praxis, and contextual sensitivity. While potentially enhancing the "care" dimension in advance care planning, the study approach may incidentally improve resource allocation and satisfaction with outcomes. Done well it may enhance decision-making and care planning, and, just as importantly, be experienced as care itself at a time and by those often neglected in this regard.

List of Abbreviations Used

ALS	amyotrophic lateral sclerosis – Lou Gehrig's Disease
BMI	body mass index
C	intimate other (participant - patient's informal carer/family member/friend)
CCM	Chronic Care Model
CDHA	Capital District Health Authority
CHF	congestive heart failure
CMA	Canadian Medical Association
COPD	chronic obstructive pulmonary disease
CPE	Clinical Pastoral Education
CRF	chronic renal failure
CTS	Canadian Thoracic Society
DMII	diabetes mellitus type II
EMP	Extramural Program (St. John Region 2, New Brunswick)
ER	emergency room/department
F	family (participant)
FEV_1	forced expiratory volume in one second
ICU	intensive care unit
INSPIRED	CDHA community-based outreach program for advanced COPD
MS	multiple sclerosis
P	patient (participant)
PCC	patient-centered care
QEII	Queen Elizabeth II Health Sciences Centre (a CDHA hospital)
R	researcher/facilitator
REB	research ethics board

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Chapter One: Introduction

Chronic obstructive pulmonary disease (COPD) is a source of increasing morbidity worldwide, and is projected to be the third leading cause of death globally by 2020 (Buist, et al., 2007; Mannino & Buist, 2007). As COPD progresses along its unpredictable downward trajectory, patients in advanced stages often experience frightening exacerbations, profound breathlessness (dyspnea), and increasingly frequent Emergency Room (ER) visits and/or hospital/Intensive Care Unit (ICU) admissions (Gardiner, et al., 2009; Hasson, et al., 2008; Rocker, Young, & Simpson, 2009). Symptom burden in late stage COPD may include severe breathlessness, fatigue, anxiety, depression, isolation, loneliness, and/or grief due to ongoing losses related to mobility, independence, spontaneity, and a sense of control (Goodridge, 2006; Gysels, Bausewein, & Higginson, 2007; Gysels & Higginson, 2009, 2010; Hansen-Flaschen, 2004; Hardin, Meyers, & Louie, 2008; Hasson, et al., 2008; Hasson, et al., 2009; Simpson & Rocker, 2008b).

Formal healthcare for COPD continues to follow an episodic acute care "disease" treatment model. While physical suffering tends to be well served by this biomedical model, it has less capacity to address psychosocial and/or spiritual suffering engendered by the chronicity of the illness (Heyland, et al., 2010). Increasingly frequent episodes of exacerbation and sometimes terrifying breathlessness raise concerns about the potential for worse suffering and death (Bailey, 2001, 2004b). Clinicians know that these worsening symptoms raise the risk of respiratory failure and death, and yet many still hesitate to discuss these implications with patients and their intimate others (Reinke, et al., 2011). Thus many patients remain unaware that COPD is potentially life threatening, viewing it instead as simply a "way of life" and part of normal aging (Gardiner, et al., 2009; Habraken, Pols, Bindels, & Willems, 2008; Pinnock, et al., 2011). Patients seldom hear about their prognosis or have opportunities to discuss their illness-related experiences, hopes, uncertainties, fears, or end-of-life care preferences with clinicians (Reinke, et al., 2011). The crisis end-of-life decision-making that can result raises the potential for significant dissatisfaction and distress for all concerned (Goodridge, Duggleby, Gjevre, & Rennie, 2008; Heyland, et al., 2006). This is despite the

professional code of ethics imploring clinicians to ascertain their patients' end-of-life care preferences in a timely, respectful manner (CMA, 2004).

Many institutions have ethics guidelines and institutional policies regarding the responsible use of life-sustaining interventions and advance care planning to document the patient's preferences regarding these life-sustaining interventions. Despite this, a lack of timely, adequate advance care planning continues to fuel the gap related to end-of-life care decision-making and care for patients, their intimate others, and clinicians. This gap increases the risk that patients will experience unwanted interventions that may unintentionally and unnecessarily add to or prolong suffering. Often advance care planning approaches have been grounded in a bioethics-focused goal that has fueled a documentation of care preferences as a way of extending respect for a person's decision-making autonomy into some potential time of cognitive incapacity (Barnard, 2002).

This traditional approach has enjoyed questionable success of in terms of closing the gap, decreasing dilemmas, and increasing patient, intimate others, and clinician satisfaction related to setting care and decision-making goals. Such inadequacy suggests that advance care planning as currently configured is in need of meaningful revision, ongoing research, and more consistent application. The system-wide goal of more patient/family-centered care mandates a more effective approach to advance care planning discussion for patients, their intimate others, and clinicians that includes sensitive, timely advance care planning for those living with chronic life-threatening conditions of which COPD is an exemplar. A meaningful, feasible approach would aim to improve end-of-life decision-making, outcomes, and satisfaction with care by addressing patients' and their intimate others' needs as well as overcoming the communication obstacles identified by their clinicians. Effective patient/family-centered advance care planning is fostered by ongoing dialogue involving the patient, clinician, and the patient's intimate other(s) (Briggs, 2004; Briggs, Kirchoff, Hammes, Song, & Colvin, 2004; Detering, Hancock, Reade, & Silvester, 2010; Parker, et al., 2007; Westley & Briggs, 2004). To be effective, the focus needs to be on the patient's values, goals, and preferences for talking about/planning care including end-of-life care. Theory also holds that evolving illness experience and uncertainties that impact individual readiness to discuss hopes and care priorities mandate that the dialogue be recurrent (Barnes, Jones,

Tookman, & King, 2007; Briggs, 2004; Briggs, et al., 2004; Fried, Bullock, Iannone, & O'Leary, 2009; Hines, 2001; Parker, et al., 2007; Sudore, et al., 2008; Wittink, et al., 2008). While not every patient/family will choose the same level of involvement in such a process, all should have an opportunity to collaborate to the degree they choose (Epstein, 2006; Godolphin, 2009; Gravel, Legare, & Graham, 2006; Heyland, et al., 2010; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Mazur, Hickam, Mazur, & Mazur, 2005; Woolf, et al., 2005).

Because these gaps in advance care planning have potentially serious implications for patients and their intimate others living with advanced COPD, clinicians, and the struggling healthcare system, I decided to explore the issue. I chose a qualitative design, "interpretive description," for the study. This approach was most appropriate for addressing the study research question: *What is required for meaningful and effective advance care planning in the context of advanced COPD?* The resulting study had a three-fold purpose: a) using a skilled facilitator to engage patients and their chosen intimate other jointly in advance care planning discussion and solicit their feedback, b) to understand the content and process of that discussion, and c) to develop a model based on these findings to guide advance care planning efforts and related research in this clinical context. This purpose led to four objectives: a) to explore participants' experience of advanced COPD especially in terms of hope, fear, and uncertainty, b) to gain insight into the dialectic of living and dying with COPD, c) to provide an opportunity for participants to consider, discuss, and/or document their end-of-life goals of care values/preferences, and d) to solicit participant feedback on this process.

The study approach to advance care planning was based on tenets drawn from patient-centred care and relational care ethics philosophies as well as insights from advance care planning communication research done in the context of chronic illness. Ultimately my hope was that this research would provide new insight into difficulties associated with a lack of timely, appropriate advance care planning for individuals and their families living with COPD. I anticipated that findings from the study might help individual clinicians and teams working in this context conduct more timely and meaningful advance care planning interactions with patients and families.

The background, method, findings, discussion and related conclusions are presented in the next four chapters. Chapter two provides a summary of the background literature and theory related to the end-of-life context in advanced COPD and to the field of advance care planning more generally. The third chapter includes a description of interpretive description methodology as well as details of the method as designed and implemented in the study sessions. Chapter four provides an overview of the results of the analysis illustrated with excerpts from the study transcripts. In the fifth chapter these findings are discussed in terms of current literature, the study question, and a proposed model based on these insights. The model is discussed and compared with others in the literature and the implications for clinical practice. The chapter finishes with a short consideration of study limitations, directions for future research, and conclusions.

Chapter Two: Literature Review

What is required for meaningful and effective advance care planning in the context of advanced COPD?

The study question includes two primary themes—advanced COPD and advance care planning. The first section of this chapter outlines the more commonly experienced physical, psychosocial, and spiritual effects of COPD, unique features of this illness, and associated end-of-life implications. In the next section, advance care planning is defined and discussed in terms of ethics, legalities, relational, and communication considerations. Two popular patient-centred models from the literature are described. The chapter concludes with a summary of implications pertinent to conducting these discussions in the context of advanced COPD.

COPD: Chronic Terminal Illness Exemplar

COPD is an umbrella term that includes emphysema and chronic bronchitis. It exemplifies the sort of chronic terminal life-shortening illness currently challenging a healthcare system largely organized around the treatment of acute, finite, potentially curable diseases. Meanwhile many incurable, progressive conditions are associated with substantial personal, institutional, societal, and economic burden. Examples include diabetes mellitus type II (DMII), congestive heart failure (CHF), chronic renal failure (CRF), and neurodegenerative disorders such as multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS). Significant gaps in care have been identified for those living with chronic terminal conditions, especially in the later stages (Arnold, Ranchor, Koeter, deJongste, & Sanderman, 2005; Fitzsimons, et al., 2007; Foley, 2004; Hauptman & Havranek, 2005; Jennings, Callahan, & Caplan, 1988; Lynn, 2005; Selman, et al., 2007; Walke, Gallo, Tinetti, & Fried, 2004).

Lynn (2005) summarized three primary illness trajectories: 1) *cancer* in which there tends to be a long maintenance of good function followed by a sharp decline toward death; 2) *organ system failure* in which there is a slow functional decline punctuated by severe exacerbations with death arriving suddenly and often unexpectedly; 3) *dementia/ frailty* in which there is a long, gradual dwindling of function leading slowly to death over many years. COPD can fall within the pattern described by trajectory 2 or 3. The

acknowledged specialized needs of patients in the first trajectory have led to the development of comprehensive palliative approaches that include appropriate attention to advance care planning. However, patients in the second and third groups, despite the recognition that they are "very sick over a substantial time before death . . . routinely [with] more than one illness," (Lynn, 2005, pp. S15-16) tend to be cared for in acute care systems ill-equipped to respond adequately to their specific and wide-ranging needs (Ironside, et al., 2003; Jennings, et al., 1988; Kennedy, 2006; Machado, 2005). COPD is a prime example of a condition that falls into Lynn's second and third categories, *organ system failure* and *frailty*.

COPD, currently the fourth leading cause of death globally, is predicted to be third by the year 2020 (Buist, et al., 2007; Hoyert, Heron, Murphy, & Kung, 2006; Jemal, Ward, Hao, & Thun, 2005; Mannino & Buist, 2007). It is seventh globally as a cause of disability (Hardin, et al., 2008). COPD is unique among the leading causes of death in Western society because it is the only chronic condition in which the prevalence, associated morbidity, and attributable mortality continue to rise (Mannino & Buist, 2007). By 2018, COPD will cause more than 20,000 deaths per year in Canada ((CIHI), 2001; Lacasse, Brooks, & Goldstein, 1999) and women with this diagnosis will outnumber men (LungAssociation, 2006; Public Health Agency, 2008). The resulting physical, psychosocial, spiritual, and financial costs are high for those living with COPD and personnel and institutions that care for them (Chapman, Bourbeau, & Rance, 2003; Langa, 2002; Mittman, et al., 2008; Simpson & Rocker, 2008a; Skilbeck, et al., 1998). The societal trend toward longevity brings with it the likelihood of increasing numbers of individuals living with "end-stage" COPD (Uronis, Currow, & Abernethy, 2006). This will increasingly challenge our understanding and delivery of care consistent with patients' values and goals in advanced stages.

The characteristic long downward trajectory in COPD is punctuated by increasingly frequent exacerbations, hospitalizations, and occasional ICU admissions (Bergs, 2002; Carling-Elofsson & Ohlen, 2004; Goodridge, et al., 2008; Kanervisto, Kaistila, & Paavilainen, 2007; Low & Gutman, 2003; Rocker, Sinuff, Horton, & Hernandez, 2007; Seamark, Blake, Seamark, & Halpin, 2004; Seamark, Seamark, & Halpin, 2007; Uronis, et al., 2006; Yohannes, 2007). Index hospital admission mortality

in COPD is 2.5-12% (Lynn, et al., 2000; Patil, Krishnan, Lechtzin, & Diette, 2003) with a 36-50% mortality rate two years after admission for acute exacerbation (Spence, et al., 2009). Many patients who survive a hospitalization after an acute exacerbation of COPD experience breathlessness (dyspnea) for the rest of their lives (Lynn, et al., 2000). Compared to patients who have cancer:

- COPD patients spend more time in hospital as their disease progresses (Au, Udris, Fihn, McDonell, & Curtis, 2006)

- often experience a greater symptom burden (Gore, Brophy, & Greenstone, 2000; Solano, Gomes, & Higginson, 2006)

- have poorly controlled dyspnea as a predominant (Claessens, et al., 2000) and incapacitating symptom (Bailey, 2004b; Edmonds, 2001; Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005; Elkington, White, Addington-Hall, Higgs, & Pettinari, 2004; Jones, 2004; Uronis, et al., 2006).

They have less access to palliative care services and high quality symptom-focused interventional strategies (Grbich, et al., 2005; Kite, Jones, & Tookman, 1999; Luddington, Cox, Higginson, & Livesley, 2001; Solano, et al., 2006) and the advance care planning aspect of these services. The formal care focus in COPD has been predominantly short-term, rooted in preventing and treating episodic crises and acute exacerbations (Blackler, Mooney, & Jones, 2004; Curtis & Rocker, 2006; Goodridge, 2006; O'Donnell, et al., 2004). Thus the bulk of care for those diagnosed with COPD is done informally at home by the patient her/himself with or without help from a spouse, family member, and/or friend(s) (Boyle, 2009; Caress, Luker, Chalmers, & Salmon, 2009; Ek, Ternestedt, Andershed, & Sahlberg-Blom, 2011; Goodridge, 2006; Goodridge, et al., 2008; Kapella, Larson, Patel, Covey, & Berry, 2006; Simpson & Rocker, 2008a; Simpson, Young, Donahue, & Rocker, 2010). For many COPD patients, increasing dyspnea slowly erodes the capacity to perform many of the activities of daily living and thus their ability to live independently.

Dyspnea.

Dyspnea is the predominant symptom and the root of illness-related need for care (Gysels, et al., 2007; Gysels & Higginson, 2009; Solano, et al., 2006). The American Thoracic Society has defined dyspnea as:

a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioral responses. (Uronis, et al., 2006, p. 291)

Three domains of dyspnea have been identified: depth and frequency of breathing; perceived urge or need to breathe; and, difficulty breathing and phase of respiration (Uronis, et al., 2006). Patients describe it using terms such as "increased work or effort" to breathe and "air hunger" (Schwartzstein, 1998). Dyspnea is a hallmark symptom in COPD and in advanced stages often becomes refractory, that is, difficult to relieve effectively and consistently despite optimal conventional treatment (Booth, Bausewein, & Rocker, 2011; Uronis, et al., 2006; Williams, 2006). "Breathlessness is the most disabling symptom of advanced lung disease and can be called the pain of non-malignant disease" (Booth, et al., 2011).

Dyspnea, like pain, is a complex, multi-dimensional, and highly individualized symptom (Booth, et al., 2011; Lansing, Gracely, & Banzett, 2009). Each person experiencing dyspnea perceives, interprets, and reacts from within her/his own framework of history, experience, values, and beliefs. Thus a broad range of symptoms affecting physical, emotional, social, and/or spiritual domains tend to be associated with the sensation (Booth, et al., 2011; Rocker, et al., 2009). Because the dyspnea experience has unique aspects for each person, its effect on quality of life also tends to be unique and not infrequently appears out of proportion to an individual's reported level of functioning (Uronis, et al., 2006). Traditional physiological measures also tend to show inconsistent correlation with an individual's descriptions of dyspnea and resulting quality of life (Schon, Dahme, & von Leupoldt, 2008; von Leupoldt, et al., 2009). Thus not only is the illness trajectory of COPD a source of uncertainty, its hallmark symptom is difficult to measure and tends to become refractory to treatment (Booth, et al., 2011; Goodridge, 2006; Gysels & Higginson, 2010; Hardin, et al., 2008; Spence, et al., 2009; Uronis, et al., 2006).

Living with advanced COPD.

This illness in advanced stages is associated with a wide range of physical, social, emotional, and spiritual effects that vary uniquely depending on the individual's context.

Physical Effects.

Of the physical manifestations other than dyspnea, fatigue is a particularly common and distressing symptom in COPD (Baghai-Ravary, et al., 2009; Hasson, et al., 2008; Kapella, et al., 2006; Parnell, 2001; Reardon, Lareau, & ZuWallack, 2006). Fatigue is poorly understood and thought to have a significant subjective component, one that has been strongly associated with dyspnea although the nature of the relationship remains unclear (Baghai-Ravary, et al., 2009; Kapella, et al., 2006). As a subjective concept, fatigue has been defined as "the multidimensional sensation of tiredness that the individual experiences when perceiving the reduced capacity to function normally" and it varies with respect to daily pattern, triggers or contributing factors, and responsiveness to interventions (Kapella, et al., 2006). The fact that anxiety, depression, and disturbances in sleep patterns often co-occur in COPD may partially explain the fatigue, as all three of these factors have been implicated in fatigue in studies of other types of chronic illness (Kapella, et al., 2006). Reciprocally though, fatigue also contributes to depression in COPD (Baghai-Ravary, et al., 2009). As for sleep disturbance and poor quality sleep, both have been well documented in advanced COPD (Hill, Geist, Goldstein, & Lacasse, 2008; Krachman, Ninai, & Scharf, 2008). Although the pathophysiology of pulmonary dysfunction with hyperinflation is considered the root of COPD as a disease entity, the severity of fatigue and poor health-related quality of life often do not correlate well with the standard physiological measures used to assess airway obstruction and lung capacity (Engstrom, Persson, Larsson, & Sullivan, 2001; Hesselink, et al., 2006; Reardon, et al., 2006; Ries, 2006).

These physical manifestations tend to be complicated by symptoms of co-morbid conditions such as cardiovascular disease, muscle wasting, diabetes, infections, and asthma that frequently co-occur with COPD (Chatila, Thomashow, Minai, Criner, & Make, 2008; Mannino & Buist, 2007; van der Molen, 2010). However, when asked about

their health-related quality of life, patients tend to report less quantifiable symptoms like dyspnea, fatigue, environmental, psychosocial, and spiritual effects as most troublesome (Ng, et al., 2007; Nicolson & Anderson, 2003; Seamark, et al., 2004; Seamark, et al., 2007).

Psychosocial Effects.

The influence of physical limitations along with their unpredictability leads to considerable psychosocial distress for those living with advanced COPD. This takes the form of anxiety, panic, strong dependence on interventions such as bronchodilators and oxygen, and an increasing need for planning, pacing, and prioritizing behaviours (Nicolson & Anderson, 2003). Reciprocally, anxiety and depression can compound the physical aspects of the disease (Bailey, 2004b; Hill, et al., 2008; Kunik, et al., 2005). Thus, impairments related to energy levels, emotional functioning, sleep and rest, mobility, social interaction, activities of daily living, recreation, work, finance, and satisfaction with life, as well as increased somatic preoccupation all may find expression to some degree within the psychosocial domain (Burgess, Kunik, & Stanley, 2005; Crockett, Cranston, Moss, & Alpers, 2002; Cully, et al., 2006). Psychological distress is often strongly related to patients' subjective perception of quality of life (Andenaes, Kalfoss, & Wahl, 2004). Patients living with COPD tend to report worse psychological functioning and greater psychiatric distress than that reported in many other chronic illnesses (Nguyen & Carrieri-Kohlman, 2005; Singer, Ruchinskas, Riley, Broshek, & Barth, 2001).

Fear is a major emotional consequence of COPD. It has been associated with increasing dyspnea, dependency, respiratory crises, as well as dying and death (Barnett, 2005; Booth, Silvester, & Todd, 2003; Gysels, et al., 2007; Gysels & Higginson, 2010; Hasson, et al., 2008; Nicolson & Anderson, 2003; Seamark, et al., 2004). Severe exacerbations of COPD often leave patients and their caregivers/family with a sense of profound vulnerability (Bailey, 2001, 2004a, 2004b; Booker, 2003; Ek, et al., 2011). Latent anxieties about outcomes such as being institutionalized for the rest of one's life and/or ending up respirator dependent represent a more generalized sense of vulnerability rooted in loss of independence and quality of life (Ring & Danielson, 1997). In an effort to cope with their illness-related fear and uncertainty, patients and their intimate others

often employ "day at a time" thinking (Booth, et al., 2003; Ek, et al., 2011; Simpson & Rocker, 2008a; Simpson, et al., 2010).

Anxiety, panic disorder, and depression are common psychological issues in COPD (Kozora, et al., 2008; van der Molen, 2010) and all tend to be under-diagnosed and undertreated, especially in the context of co-morbidities (Crockett, et al., 2002; Maurer, et al., 2008; Nicolson & Anderson, 2003; van der Molen, 2010; Wagena, Arrindell, Wouters, & van Schayck, 2005). It is important to note that they significantly affect quality of life and functional status more than predicted by measures of medical burden and COPD severity (Cully, et al., 2006). There is an increasing body of research to suggest that anxiety is even more significant than depression in COPD, not surprisingly given the fear engendered by disabling dyspnea worsened during acute episodes of exacerbation (Cully, et al., 2006). Anxiety disorders, especially generalized anxiety disorder (GAD) and panic disorder, have been found at higher rates among COPD patients than among the general population (Brenes, 2003; Cully, et al., 2006; Gudmundsson, et al., 2005; Hill, et al., 2008). Rates of panic disorder in COPD range from 8% to 67% (Hill, et al., 2008) depending on the study, and panic disorder is a leading cause of ER visits for these patients (Burgess, et al., 2005) making it a significant factor in terms of both the human and economic burden of COPD.

Anxiety has been found to negatively affect quality of life and functional status, including general health, physical roles, social functioning, bodily pain, mental health function, vitality, and disability levels (Brenes, 2003). That anxiety would be a common experience for COPD sufferers makes sense given the fear-invoking nature, sense of powerlessness, and unpredictability related to breathlessness and exacerbations (Bailey, 2001, 2004b; Burgess, et al., 2005; Gudmundsson, et al., 2005). Patients vividly describe the uncertainty, profound anxiety, and fear of death they associate with exacerbations and episodes of markedly worsening dyspnea, and the sense of heightened emotional vulnerability that is the legacy of these events.

Despite the centrality of anxiety in COPD, depression has been the primary focus of related psychology research. It has been suggested that depression rates among patients with severe COPD are two to four times higher than those of the general population (Burgess, et al., 2005; Kunik, et al., 2005; Nguyen & Carrieri-Kohlman, 2005;

Schane, Woodruff, Dinno, Covinsky, & Walter, 2008). COPD-related depression has been associated with decreased health-related quality of life, health and functional status, and coping, increased COPD symptoms, and failure of treatment for exacerbations (Cully, et al., 2006; Nguyen & Carrieri-Kohlman, 2005; van der Molen, 2010; Yohannes, Baldwin, & Connolly, 2003). Further, in one study the authors reported a significant increase in mortality rates for depressed patients hospitalized with a COPD exacerbation compared to those who were not depressed (Nguyen & Carrieri-Kohlman, 2005). Negative health perceptions, sustained and persistent feelings of frustration, hopelessness, helplessness, indecisiveness, less self-confidence, slowed thinking, as well as decreasing energy levels are not uncommon companions of depression in COPD. This pattern may lead to a negative downward spiral—worsening medical symptoms follow declining activity levels accompanied by escalating negative psychosocial impact (Burgess, et al., 2005; Dowson, Town, Frampton, & Mulder, 2004). Depression has been shown to negatively affect adherence to treatment regimens in COPD as well, yet, like anxiety, it continues to be under-diagnosed and undertreated, particularly in elderly COPD patients (Dowson, et al., 2004; van der Molen, 2010; Yohannes, et al., 2003). This is despite evidence that COPD patients with anxiety and/or depression have a higher risk of cognitive decline, functional decline, lower self-efficacy, and more serious life events than those without these mental health concerns (Dowson, et al., 2004; Maurer, et al., 2008). Depression has also been shown to affect end-of-life decision-making and care preferences for patients with COPD (Stapleton, Nielsen, Engelberg, Patrick, & Curtis, 2005; Yohannes, et al., 2003). Thus depression has a direct bearing on any efforts at advance care planning with these patients.

The physical and psychological effects of COPD also have significant social implications that are experienced on multiple levels by both patients and their intimate others. The patient's gradual physical incapacitation brings increasing dependence on intimate others, often a spouse or partner if s/he has one; otherwise another family member or friend (Bergs, 2002; Kanervisto, et al., 2007; Low & Gutman, 2003; Nicolson & Anderson, 2003; Seamark, et al., 2004). While COPD patients have expressed quite clearly their desire to not burden loved ones, research suggests that by its very nature caring for someone with advanced COPD tends to be an intense, constraining,

increasingly time-consuming, debilitating process (Bailey, 2001, 2004b; Bergs, 2002; Booth, et al., 2003; Boyle, 2009; Caress, et al., 2009; Guthrie, Hill, & Muers, 2001; Gysels & Higginson, 2009; Hasson, et al., 2009; Heyland, et al., 2006; Seamark, et al., 2004; Simpson & Rocker, 2008a; Simpson, et al., 2010). Its potential to engender feelings of isolation, abandonment, vulnerability, anxiety, helplessness, powerlessness, and a certain loss of freedom have already been mentioned (Booth, et al., 2011; Booth, et al., 2003). Over time, COPD can erode the intimacy in a relationship as well (Ek & Ternestedt, 2008; Simpson & Rocker, 2008a), "particularly among younger respondents where expectations and perceptions of partners' expectations have been shattered" (Nicolson & Anderson, 2003, p. 262). Increasing frustration, irritability, belligerence, emotional lability, and other mood problems also affect relationships with intimate others, as well as healthcare professionals involved in the patient's care (Bailey, 2004b; Bergs, 2002; Low & Gutman, 2003; Nicolson & Anderson, 2003; Seamark, et al., 2004; Simpson & Rocker, 2008a). These results imply significant needs on the part of intimate others, but also reflect an important source of psychosocial suffering for patients as well.

Perhaps the growing social isolation that develops as COPD gradually renders many virtually housebound is the most profound effect for patients and intimate others (Habraken, et al., 2008; Simpson & Rocker, 2008a; Simpson, et al., 2010). Increasing immobility, a common desire to avoid outside environments that induce dyspnea along with the pervasive cultural ethos of blame so common in this illness result in a virtual "house arrest" situation for patients and consequently their informal caregivers (Nicolson & Anderson, 2003; Seamark, et al., 2004; Simpson & Rocker, 2008a; Simpson, et al., 2010). Elkington (2004) reported that 41% of patients left home rarely or never during their final year of COPD.

Guilt, self-blame, and social stigma are themes common to those diagnosed with COPD because of its association with smoking with its negative connotations within healthcare circles and Western society more generally (Delmar, et al., 2006; Endicott, Corsello, Prinzi, Tinkelman, & Schwartz, 2003; Kanervisto, et al., 2007; Nicolson & Anderson, 2003; Odencrants, Ehnfors, & Grobe, 2005). Further to this theme, if a patient is not on oxygen therapy the incapacitating nature of COPD-related dyspnea is seldom visible to outsiders. The invisibility of such profound disability can have significant

negative emotional impact for sufferers (Habraken, et al., 2008). Despite their desire to maintain some semblance of independence, patients with advanced COPD also need and want social support, and higher levels of positive social support have been associated with lower levels of depression and anxiety and better quality of life in this group (Kanervisto, et al., 2007; McCathie, Spence, & Tate, 2002; Parnell, 2001). Yet relative isolation remains the norm.

Balancing the need for support is the patient's desire to preserve a sense of self-efficacy or mastery (Arnold, et al., 2005; Carrieri-Kohlman, Gormley, & Mahler, 1998; Harver, 1998; Kohler, Fish, & Greene, 2002). Several studies have demonstrated the gradual, significant erosion of self-efficacy, described as the belief that one is (or is not) able to accomplish desired functional activities (Cicutto, Brooks, & Henderson, 2004; Kohler, et al., 2002; Monninkhof, et al., 2004; Nicolson & Anderson, 2003; Oliver, 1999). Self-efficacy is known to be an important variable in psychosocial adjustment to COPD, such that higher levels of symptom management-related self-efficacy are associated with improved depression, anxiety, and quality of life scores (McCathie, et al., 2002). Increasing dependency, loss of confidence, and reduced social interaction have been associated with a loss of perceived power, self-image, and self-esteem in patients suffering with COPD (Ek & Ternestedt, 2008).

Spiritual Effects.

For some patients, existential/spiritual concerns and fear of dying by suffocation are more distressful than physical symptoms or disability (Ek & Ternestedt, 2008; Grant, et al., 2004). Existential factors in chronic illness are embedded in concerns about independence, self-control, self-responsibility, and relationships, all of which are influenced by personal values related to choice and dignity (Delmar, et al., 2006). Patients experiencing a type of spiritual distress may openly question and search for meaning and purpose in an effort to make sense of the COPD illness experience (Delmar, et al., 2006; Ek & Ternestedt, 2008; Garrett, 2004; Wright, Watson, & Bell, 1996). The relentless disabling trajectory of COPD also means patients and intimate others must constantly grapple with current and anticipated losses and the effects of ongoing grief (Nicolson & Anderson, 2003; Rando, 2000).

Cumulative losses related to independence, social interaction, and certain types of meaningful work and recreation are common in COPD (Nicolson & Anderson, 2003; Seamark, et al., 2004). A previously taken-for-granted sense of freedom and spontaneity is often a casualty when every action requires detailed planning because of dyspnea and fatigue-imposed limitations (Booth, et al., 2003; Cicutto, et al., 2004; Guthrie, et al., 2001; Kanervisto, et al., 2007; Kralik, Koch, Price, & Howard, 2004; Leidy & Haase, 1999). A general sense of security and trust in life tends to be lost to the uncertainty, anxiety, and intense vulnerability arising from illness crises (Bailey, 2004b). Some patients experiencing a loss, or narrowing of hope-related possibilities, react by focusing on the present moment and avoiding all consideration of the future (Kanervisto, et al., 2007; Ring & Danielson, 1997). Other sources of loss relate to a dwindling sense of social connectedness with its resulting loneliness, isolation, and sense of abandonment (Barnett, 2005; Booth, Farquhar, Gysels, Bausewein, & Higginson, 2006; Booth, et al., 2003; Ek & Ternestedt, 2008; Guthrie, et al., 2001; Nicolson & Anderson, 2003; O'Neill, 2002; Ring & Danielson, 1997; Seamark, et al., 2004). Such losses can further impact already fragile self-efficacy, role-identity, and identity-related coherence (Kanervisto, et al., 2007; Kralik, et al., 2004; Nicolson & Anderson, 2003).

When patients experience loss of meaning, identity, coherence, and support for facing the unknown, they need opportunities and safe, supportive environments to talk about these issues with family and/or healthcare clinicians (Grant, et al., 2004). Given the difficulty many intimate others as well as healthcare clinicians seem to have with discussing death, dying, and/or spirituality issues with their patients, the potential for distress related to these unmet needs remains high in COPD (Blackler, et al., 2004; Curtis, Engelberg, Wenrich, & Au, 2005a; Curtis & Rocker, 2006; Goodridge, 2006; Hansen-Flaschen, 2004; Heyland, et al., 2006; Heyland, et al., 2010; O'Donnell, et al., 2004; Pierson, 2004). COPD patients and their intimate others experience growing isolation and abandonment, ongoing grief, anxiety, and depression. They display significant death-related fear and avoidance of future-oriented thinking. Initiating advance care planning dialogue sensitive to these concerns may be a way to begin to counteract some of the isolation, fear, and abandonment. It could provide a safe venue to

sensitively explore these issues with patients and their intimate others, and perhaps provide a way to boost a flagging sense of self-efficacy.

Unique features of COPD.

Although other chronic terminal conditions may share one or more of the following characteristics, none share all of them. Advanced COPD is in a category of its own in the sense of being a unique illness marked by fear, vulnerability, little formal support, and significant unaddressed issues in advanced stages.

Death salience.

Severe breathlessness exacerbations in advanced illness often constitute a brush with death. As such they tend to be associated with intense anxiety due to fear of suffocation and sense of powerlessness (Bailey, 2001, 2004b). "We all know we will die, but there is a greater vividness and proximity in that knowledge for someone who has been through mortal extreme experience" (Little & Sayers, 2004, p. 1329). This expression, "mortal extreme experience," refers to any episode perceived as life threatening. Such an experience heightens "death salience," defined as "the reflective awareness in a survivor that a mortal extreme experience could have led the subject down a fork in the road of serious illness to death and personal extinction." (Little & Sayers, 2004, p. 1332) Severe refractory breathlessness crises are a common occurrence in late stage COPD, heightening both physical and emotional distress, along with the sense of powerlessness and vulnerability for patients, intimate others, and healthcare clinicians. The unpredictability of such episodes makes this illness especially hard to live and cope with in later stages, and to prognosticate about or treat effectively (Goodridge, 2006; Goodridge, et al., 2008; Goodridge, et al., 2009; Gysels & Higginson, 2009; Hasson, et al., 2008; Heyland, et al., 2009; Spence, et al., 2009).

Oxygen-dependency.

Long-term oxygen therapy, a common treatment in advanced COPD, further constrains some patients' already limited mobility (Blackler, et al., 2004; Eaton, et al., 2002; Hasson, et al., 2008; Ingadottir & Jonsdottir, 2006; Katsura, Yamada, Wakabayashi, & Kida, 2007; Ring & Danielson, 1997). Once it is implemented patients

live at the end of a length of plastic tubing connected to a compressor, and many experience increasing psychological, if not physical, dependence on this technology for a sense of comfort and security. For some the oxygen tank becomes a symbolic, if not a literal 'life line.' Fears of a power outage or the possibility of an empty tank haunt these patients and consequently their intimate others (Arnold, et al., 2011). In addition, the financial implications of the portable tanks/compressors that could expand the boundaries of their mobility are more than many can accommodate. Plus many are embarrassed or distressed by the attention they attract when using their portable tanks in public (Arnold, et al., 2011).

Social death.

Dyspnea and fatigue prompt fear, erode mobility, and sap motivation so that patients increasingly withdraw from their social settings and become isolated (Abernethy & Wheeler, 2008; Agusti, 2007; Baghai-Ravary, et al., 2009; Gardiner, et al., 2009; Goodridge, 2006; Guthrie, et al., 2001; Gysels, et al., 2007; Hansen-Flaschen, 2004; Simpson, et al., 2010). This type of "social death" (McKechnie, MacLeod, & Keeling, 2007) is extremely common in COPD. Patients often feel less vulnerable and more comfortable at home, yet many find that friends and family curtail visiting or stop altogether as the illness worsens. Intimate others often feel compelled to stay home with patients as their mobility declines and illness-related dependency increases (Gysels & Higginson, 2009; Hasson, et al., 2009; Simpson & Rocker, 2008a; Simpson, et al., 2010). These dynamics result in a growing sense of isolation, loneliness, and abandonment for both patients and their intimate others.

Stigma.

A diagnosis of COPD carries significant stigma because of the link to smoking, especially for those who continue to smoke after the diagnosis is made (Chapple & Ziebland, 2004; Street, 2004). Clinicians spend considerable time "preaching" to patients about the importance of smoking cessation and the link between COPD and smoking (Jonsdottir & Jonsdottir, 2007). Patients feel blamed for their illness and consequent suffering; many sincerely regret their smoking habit and try to quit (Odencrants, Ehnfors, & Grobe, 2007). This attitude along with a growing sense of being a burden to loved ones

can foster feelings of guilt, shame, anger, resentment, and/or hopelessness in patients (Jonsdottir & Jonsdottir, 2007). Such feelings may be intensified by the sense of appearing to be a "fraud" to observers—the dyspnea that cripples them tends to be invisible when patients are not moving around (Nicholson & Anderson, 2003).

Social determinants of health.

COPD tends to be more prevalent where negative social determinants of health such as lower socioeconomic status, lower education levels, and/or poorer lifestyle-related behaviours (nutrition, smoking history, substance abuse, lack of exercise) are also prevalent (Mannino & Buist, 2007; Parnell, 2001; Salvi & Barnes, 2009). Other chronic conditions like diabetes and heart disease also tend to be more frequent in such circumstances and many patients with advanced COPD contend with significant co-morbidities (Chatila, et al., 2008; Mannino & Buist, 2007). In one study 50% of 1,145 patients with COPD had one or two additional conditions, 15.8% had three or four, and 6.8% had five or more (van Manen, et al., 2001). Heart disease, depression, anemia, malnutrition, diabetes, and osteoporosis occur commonly in association with COPD (Chatila, et al., 2008; Mannino & Buist, 2007).

Communication issues.

Communication difficulties are implicated in many of these factors. Communication deadlock results in a lack of adequate advance care planning and timely palliative support for those with advanced COPD (Blackler, et al., 2004; Curtis, et al., 2005a; Curtis & Rocker, 2006; Dahlin, 2006; Goodridge, 2006; Murray, Pinnock, & Sheikh, 2006; O'Donnell, et al., 2004). Less than adequate communication can result in a mismatch in goals of care between physicians and patients, with negative effects on compliance and satisfaction with care (Partridge, 2003; Pierson, 2004; Rocker, Dodek, & Heyland, 2008; Rocker, et al., 2009). Clinician-cited advance care planning concerns about hope, uncertainty, time constraints, and skill level all relate to communication difficulties (Crawford, 2010; Curtis, et al., 2005a; Davison & Simpson, 2006; Goodridge, 2006; Gott, et al., 2009; Reinke, et al., 2011; Seymour, Almack, & Kennedy, 2010). A feasible approach to advance care planning might ameliorate some of these communication difficulties for clinicians and address at least one of the gaps in continuity

of care for those living with advanced COPD (Curtis, et al., 2005a; Curtis & Rocker, 2006; Goodridge, 2006; Hansen-Flaschen, 2004; Murray, et al., 2006; Reinke, et al., 2011; Seamark, et al., 2007).

Advance Care Planning

The following descriptions provide some sense of the breadth, depth, and richness of the ideal that is advance care planning:

> *a process of recurring clinician-patient-family communication that includes:*
> *(1) individualized delivery of medical information; (2) utilization of a shared*
> *decision-making paradigm; (3) focus on multiple and evolving treatment*
> *decisions across the entire trajectory of a life-limiting illness; and (4)*
> *clarification of the patient's future treatment preferences (Weiner & Cole,*
> *2004, p. 818).*

> *an ongoing process, giving patients an opportunity to consider, discuss and*
> *plan end-of-life care, with the intention of alleviating potential worries and*
> *concerns, and enabling patients to prepare for a potential deterioration in*
> *health. (Barnes, et al., 2007, p. 23)*

> *various processes, including specifying surrogates; bringing together the*
> *patient, caregivers, and providers; anticipating treatment alternatives;*
> *soliciting values; and melding preferences and alternatives into a plan. Other*
> *important processes include documenting those plans; making treatment*
> *directives available when patients need them and across settings; revisiting*
> *plans at critical junctures; and understanding their effects on patients,*
> *caregivers, and the healthcare system. (Lorenz, Rosenfeld, & Wenger, 2007, p.*
> *S320)*

The common theme here is "process," one that includes elements of encouraging, supporting, and collaborating with patients as they reflect on their illness in terms of potential care preferences in advanced stages. An important component of this process relates to increased understanding of patient/family values, goals, identity, relationships, coping, end-of-life concerns, and decision-making preferences (Prendergast, 2001). The nature of advance care planning means it cannot and should not be a "once and for all"

discussion, but one that is frequently revisited to allow for changes in patients' perspective and preferences that may accompany illness progression (Barnes, et al., 2007; Jordens, Little, Kerridge, & McPhee, 2005, p. 565; Lorenz, et al., 2007; Weiner & Cole, 2004). "Response shift" is a well recognized phenomenon in which many are able to adapt to gradual health-related losses and view resulting quality of life with more equanimity than they once imagined they could (Moons, Budts, & De Geest, 2006; Pinnock, et al., 2011; Schwartz, et al., 2002). It is clear that such a shift could have implications for individuals' preferences related to end-of-life care. Thus, high quality advance care planning will include elements of identification, education, reflection, communication, review, and recording. Clearly advance care planning is not simply asking a patient to decide on particular life-sustaining interventions (Moskop, 2004). Ultimately advance care planning involves developing healthcare encounters to enhance goal setting related to care through to the end-of-life.

Ethics dimensions of advance care planning.

Professional ethics is one of the many frameworks shaping clinical practice. The goals of medicine and clinicians' codes of ethics reflect guidance derived from particular bioethics principles, particularly beneficence, respect for autonomy, non-maleficence, and justice (Beauchamp & Childress, 2001). Based on this bioethics perspective, advance care planning has been viewed as a way to extend the principle of "respect for autonomy" and its subsidiary "informed choice" forward into a time when a patient may not have cognitive capacity (Jordens, et al., 2005; Lynn & Goldstein, 2003; Rosenfeld, Wenger, & Kagawa-Singer, 2000; Singer, et al., 1998; Steinhauser, et al., 2001). Advance care planning as respect for a patient's autonomy has to be balanced with physicians' clinical judgment with regard to which treatment options are appropriate to offer (Winzelberg, Patrick, Rhodes, & Deyo, 2005b). But advance care planning is about much more than simply an effort to safeguard an individual's decision-making autonomy during possible periods of future cognitive incapacity (Barnard, 2002). For some it can be an opportunity to reflect on and begin to prepare for dying (Singer, et al., 1998; Steinhauser, et al., 2001). This preparation process may include efforts to relieve potential burdens on loved

ones, address particular relational needs, and/or discussion of these concerns with intimate others and/or healthcare professionals (Singer, et al., 1998).

The goal in the provision of ethically sound end-of-life care and/or the decision-making related to it, is meaningful, clinically feasible patient-centeredness (Barazzetti, Borreani, Miccinesi, & Toscani, 2010). To accomplish this, clinicians need to engage patients in a discussion of preferences related to end-of-life care and decision-making (Epstein, 2006; Gravel, et al., 2006; Kiesler & Auerbach, 2006; Mazur, et al., 2005). There are at least two foci to consider in that discussion: a) patients' preferred approach to decision-making, b) values/goals for end-of-life care (Frank, 2011; Gravel, et al., 2006; Heyland, et al., 2003; Kiesler & Auerbach, 2006; Mazur, et al., 2005; Woolf, et al., 2005).

In a shared decision-making approach patients (with or without named intimate others) participate with clinicians in deciding on appropriate goals of care (Gravel, et al., 2006). Some patients prefer that clinicians make decisions for them, and others that the decision-making responsibility be more their own (Kiesler & Auerbach, 2006; Woolf, et al., 2005). Patient-centredness does not equate with shared decision-making; it does equate with figuring out what sort of decision-making model a patient prefers in any type of care planning discussion (Parker, et al., 2007). As Mazur et al (2005) suggest, "how the patient defines participation in decision making would be expected to influence the types of information that the patient desires in a shared decision-making context" (p.98). Once clinicians understand a patient's preferences in this regard, the discussion can move on to considering personal values and preferences for goal setting. Controversy and/or dissatisfaction with care is more likely when these discussions are missing, inadequate, or ignored (Heyland, et al., 2003).

Controversy in end-of-life care situations often pertains to withholding or withdrawing life-sustaining treatment(s) such as cardiopulmonary resuscitation (CPR) procedures and the use of feeding tubes and intravenous hydration (Dubler, 2005; Farber, et al., 2006; Luce & White, 2007; Lynn, 2005; Wiegand, 2008). The "high tech" curative focus that tends to dominate institutional healthcare is often a source of tension in emotionally charged end-of-life decision-making scenarios that centre on such treatments (Bernat, 2001; Brock & Lynn, 1986; Brock & Veatch, 1997; Callahan, 2000; Casarett,

Kapo, & Caplan, 2005; Kaufman, 2005; Kinlaw, 2005; Rousseau, 2002). Issues about rights and obligations with regard to maintaining, refusing, or limiting the use of life-sustaining treatments are further complicated by inappropriate expectations among the public regarding what is clinically possible (Sibbald, Downar, & Hawyrluck, 2007). The current default of initiating life-sustaining interventions when a patient's preferences are unknown highlights a pressing need for appropriate goal setting and advance care planning (Sibbald, et al., 2007).

> *Despite informed consent being a requirement for all other invasive procedures when there is sufficient opportunity to obtain it (e.g., in nonemergent [sic] situations with a capable patient), cardiopulmonary resuscitation (CPR) and mechanical ventilation are assumed, until otherwise stipulated, to be procedures all patients want. (Nicolasora, et al., 2006, p. 162)*

Timely, meaningful advance care planning to guide decision-making and care planning, including but not limited to the use of life-sustaining treatments, may decrease such controversies (Fried, Bradley, Towle, & Allore, 2002; Hickman, Hammes, Moss, & Tolle, 2005; Prendergast, 2001; Winzelberg, et al., 2005b). The palliative care approach when implemented well is a model of such an approach to advance care planning.

Relational dimensions of advance care planning.

Palliative care is based on a relational construal of respect for autonomy which views the patient within her/his relational context as most knowledgeable concerning her/his own body, illness experience, values, and evolving needs (Carter, MacLeod, Brander, & McPherson, 2004; Holm, 2005). This approach focuses on planning and delivering care that is consistent with patient and intimate others' preferences as articulated through an ongoing collaborative, informed decision-making process (Chochinov, 2006; Chochinov, 2005; Chochinov, et al., 2004; Kristjanson, 2005). From a relational perspective, the "unit of care" within the palliative approach includes those individuals the patient chooses to include (Carroll & Quijada, 2004; Foley, 2004). The success of the approach rests on good quality communication, including advance care planning discussion, so that patient and intimate others' care needs and preferences are elicited and understood (Back, Arnold, & Quill, 2003; Curtis, 2000; Curtis, Engelberg,

Nielsen, Au, & Patrick, 2004; Lang & Quill, 2004; Lynn & Goldstein, 2003; Weissman, 2004; White & Curtis, 2005). These identified needs and preferences then tailor the approach to care and ongoing advance care planning to each patient/family context. Murray and Jennings (2005) allude to the importance of relational elements in advance care planning:

> *Law, ethics, and policy must come to grips with the fundamentally communal and public—not private—issues of mortality and meaning. We sometimes seem to act as though dying were solely the concern of the dying person. The fact is, we die, as we live, in a web of vital and complex relationships. (p.S54)*

Advance care planning is considered to be a way of respecting a patient's autonomy and right to informed choice, but these require adequate attention to the relational context within which individuals define themselves (Cooper-White, 2007; Mezirow, 2000; Murray & Jennings, 2005; Scanlan & Kerridge, 2009; Sherwin, et al., 1998). The relational and interdependent nature of human life requires clinicians to rethink the traditional understanding of autonomy (Bergum & Dossetor, 2005).

An understanding of autonomy from a relational perspective is needed to balance the usual bioethical, legal, and political interpretation which many view as too rationalistic, individualistic, and narrowly construed (Bergum & Dossetor, 2005; Nedelsky, 1989; Scanlan & Kerridge, 2009; Sherwin, et al., 1998). Sherwin (1998) and Nedelsky (1989) propose a more relational view of autonomy, one that is reflective of loyalties, histories with, and emotional ties to intimate others, communities, organizations, and culture. These sources of social connection act as mediators of self-understanding, identity, preferences, and the capacity to exercise autonomous decision-making. According to this view, part of what it is to be human arises from our embodiment within particular relational contexts that necessarily influence the choices we make (Bergum & Dossetor, 2005; Cooper-White, 2007; Mezirow, 2000). Thus relational factors are relevant considerations within healthcare decision-making and therefore advance care planning (Larson & Tobin, 2000; Murray & Jennings, 2005; Prendergast, 2001; Weissman, 2004; Winzelberg, Hanson, & Tulsky, 2005a).

A relational perspective is particularly relevant to advance care planning in advanced chronic illness. The integrity of health-related decisions requires that the patient at the heart of the situation is able to engage meaningfully in the dialogue. This can happen only when a patient is deemed to have decisional "capacity" (Beauchamp, 1997; Beauchamp & Childress, 2001). During illness crises, common in advanced COPD, this may not be the case. When severely ill patients are unable to participate in decision-making due to incapacitation from advanced disease, treatment side effects, or complications, clinicians must rely on alternate decision-guiding options (Azoulay & Sprung, 2004; Counsell & Guin, 2002; Curtis, et al., 2002a; Curtis, et al., 2005b; Hsieh, Shannon, & Curtis, 2006; Kirchhoff, Song, & Kehl, 2004; Lins Fumis, Nishimoto, & Deheinzelin, 2007; Lorenz, et al., 2007; Nelson & Danis, 2001). One estimate suggests that fewer than five percent of ICU patients have capacity for, or are able to communicate adequately about, health-related decisions (Hsieh, et al., 2006). In cases of acute COPD exacerbation, it is not uncommon for a patient to be admitted to ICU for mechanical or non-invasive ventilation and potentially be unable to participate meaningfully in care-related decision-making (Goodridge, et al., 2008; Lorenz, et al., 2007). Such incapacity necessitates alternative decision-making arrangements.

Factors such as quality of the relationship, trust, and communication between the patient, substitute decision-maker, and clinicians are central to sound advance care planning discussion (Ballard-Reisch, 1990; Kinlaw, 2005; Murray & Jennings, 2005). Patients and their substitute decision-maker(s) identify trust in the clinician as central to helping them think about and make decisions regarding end-of-life treatment preferences (Heyland, et al., 2006; Heyland, Groll, Rocker, Dodek, & et al., 2005). The quality, sensitivity, and honesty of the communication process involved in any healthcare encounter influences the nature and degree of trust the patient and family have in the clinician, the team, and the system. The power imbalance inherent in any therapeutic relationship heightens the potential vulnerability of patients and their intimate others and underscores the need for, and difficulty establishing, trust (Christ & Blacker, 2006; McGeer, 2004). Often participants in the therapeutic encounter have very different power and perspectives, which can unconsciously undermine trust.

Legal dimensions of advance care planning.

An advance directive to guide care decisions if the patient should lack decision-making capacity is one possible outcome of advance care planning discussion. Two types of advance directive documents are recognized in law: 1) an instructional advance directive (living will), 2) a proxy directive (naming a substitute decision-maker) (Beauchamp & Childress, 2001; Brock & Veatch, 1997; Downie, et al., 1995; Murray & Jennings, 2005). The content of an instructional advance directive document may describe the patient's preferences with respect to life-sustaining treatments or decision-making approach. Alternatively it may provide some direction to the healthcare team and substitute decision-maker(s) by describing the patient's values and goals related to quality of life and dying (Beauchamp & Childress, 2001; Hickman, et al., 2005). Instructional directives have some potential for preventing end-of-life controversy that may arise due to lack of consensus on goals of care during later stages of illness (Ditto, et al., 2001; Hawkins, Ditto, Danks, & Smucker, 2005; Jordens, et al., 2005; Lynn & Goldstein, 2003; Prendergast, 2001; Teno, Stevens, Spernak, & Lynn, 1998; White & Curtis, 2005; Winzelberg, et al., 2005b). Although quality advance care planning involves much more than developing a legal document, for some patients the clear boundaries involved in completing an advance directive makes the the advance care planning process more acceptable. When there is no instructional directive, clinicians look to the patient's substitute decision-maker named in a proxy directive.

When the patient has named a proxy, this person assumes responsibility for helping clinicians make treatment decisions for the patient only if s/he lacks capacity at the time a decision is needed. The authorization of a substitute decision-maker is a popular alternative to an instructional directive for many patients (Collopy, 1999; Hawkins, et al., 2005; Prendergast, 2001; Rosenfeld, et al., 2000; Steinhauser, et al., 2001). Some prefer a proxy directive to an instructional one because the substitute decision-maker is privy to the real situation and thus able to respond to rapidly changing, and perhaps unanticipated, conditions common to crisis situations in critical care (Murray & Jennings, 2005; Sudore & Fried, 2010). Also, if s/he has a relational history with the patient, the substitute decision-maker may be familiar with the patient's values and/or preferences relevant to end-of-life care (Collopy, 1999). This relational familiarity can

enable the avoidance of life-sustaining measures that are not desired by the patient, or alternatively facilitate the use of such measures on behalf of the patient who values them. Proxy decision-makers are expected to follow certain criteria.

A proxy directive is also known as a "durable power of attorney for healthcare" (Downie, et al., 1995). In the absence of a previously designated proxy or substitute decision-maker, one will be selected according to regionally legislated criteria, although this may be less than ideal (Murray & Jennings, 2005). The substitute decision-maker is expected to make decisions regarding the patient's treatment according to "substituted judgment" standards, that is according to what s/he believes the patient would want (Beauchamp & Childress, 2001; Brock & Veatch, 1997; Collopy, 1999; Murray & Jennings, 2005). However, substitute decision-makers (often intimate others) may not be aware of the patient's care preferences, values, and/or concerns despite an ongoing relationship with that person (Murray & Jennings, 2005). It is not rare to find that patients have not discussed their end-of-life care values and preferences with their substitute decision-makers or their healthcare clinicians. When healthcare clinicians do not broach these conversations, patients and substitute decision-makers may lack information and preparation they need for informed care planning. The emotional impact of being a substitute decision-maker may be somewhat relieved if the substitute decision-maker is aware of the patient's relevant preferences or values (Wagner, Riopelle, Steckart, Lorenz, & Rosenfeld, 2010). However, when the substitute decision-maker does not know the patient's preferences, s/he must rely on a "best interests" standard, which requires choosing the treatment s/he deems best for the patient in the given circumstances (Beauchamp & Childress, 2001; Brock & Veatch, 1997; Collopy, 1999). Trust between patient and substitute decision-maker is therefore a significant component in proxy decision-making (Collopy, 1999; Prendergast, 2001). Proxy decision-making is thus not without its difficulties, but there have been more problems with instructional directives.

Despite their supposed potential to improve end-of-life decision-making, instructional directives have had a disappointing track record primarily because of vagueness, inapplicability, and/or inaccessibility (Hickman, et al., 2005; Jordens, et al., 2005; Lynn & Goldstein, 2003; Prendergast, 2001; Rosenfeld, et al., 2000; Singer, et al., 1998; Teno, et al., 1998). Adding to the problem, many patients have not completed

either type of directive (Azoulay & Sprung, 2004; Barnes, et al., 2007; Counsell & Guin, 2002; Fagerlin & Schnieder, 2004; Jordens, et al., 2005; Kinlaw, 2005; Kirchhoff, et al., 2004; Nicolasora, et al., 2006; Prendergast, 2001).

> *The informal culture of specialty medicine, the reward system, the institutional pressures faced by families, the range of choices people in extremis are being asked to make—each of these factors and more make up a system that is remarkably resistant to change. (Murray & Jennings, 2005, p. S54)*

There is a move toward a more informal and patient-centered advance care planning process in the hope of addressing some of the difficulties plaguing the current approach (Barnard, 2002; Briggs, et al., 2004; Hammes, 2003; Hawkins, et al., 2005; Larson & Tobin, 2000; Wagner, et al., 2010; Weiner & Cole, 2004).

Effective advance care planning.

In the past, effectiveness of advance care planning has been considered in terms of completion rates of formal documents, primarily instructional advance directives, proxy directives naming patients' substitute decision-maker(s), or both (Beauchamp & Childress, 2001; Brock & Veatch, 1997; Downie, et al., 1995; Garrett, Tuokko, Stadjuhar, Lindsay, & Buehler, 2008; Murray & Jennings, 2005). As previously mentioned, the effectiveness of instructional directives, has increasingly been questioned on the grounds of problems with vagueness, inapplicability, and/or inaccessibility (Barnard, 2002; Barnes, et al., 2007; Hawkins, et al., 2005; Hickman, et al., 2005; Jordens, et al., 2005; Rizzo, et al., 2010; Seymour, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Weiner & Efferen, 2005; Weiner & Cole, 2004; Westley & Briggs, 2004). Researchers have suggested advance care planning effectiveness involves much more than increasing completion rates of advance directives (Briggs, 2004; Fried, et al., 2009; Hawkins, et al., 2005; Hickman, et al., 2005; Jordens, et al., 2005; Perkins, 2007; Romer & Hammes, 2004; Schickedanz, et al., 2009; Sudore, et al., 2008; Tulsky, 2005; Vogel, 2010; Westley & Briggs, 2004; White & Curtis, 2005; Zinkler, 2005). Instead, current advance care planning research emphasizes a more comprehensive, patient-centred approach (Barnes, et al., 2007; Black, 2007; Briggs, 2004; Briggs, et al., 2004; Davison & Torgunrud, 2007; Detering, et al., 2010; McCormack, et al., 2011; Parker, et

al., 2007; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004).

The idea is to enhance end-of-life care planning by engaging patients in a reflective process consistent with their current stage/readiness and preferred style of decision-making (Barnes, et al., 2007; Rizzo, et al., 2010; Seymour, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Weiner & Cole, 2004; Westley & Briggs, 2004). Studies of advance care planning based on "stage of change" theory support the premise that the process involves a number of stages, including consideration and discussion, prior to formal documentation (Fried, et al., 2009; Garrett, et al., 2008; Havens, 2000; Rizzo, et al., 2010; Schickedanz, et al., 2009; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). Thus creating opportunities for and supporting patients and their intimate others to think about and discuss care and decision-making preferences may facilitate the process. According to some researchers, such opportunities increase the likelihood that participants will go on to complete an instructional and/or proxy directive, continue to discuss the subject with family, or talk about it with their clinicians (Detering, et al., 2010; Garrett, et al., 2008; Havens, 2000; Sudore, et al., 2008). There is increasing evidence that encouraging a discussion between the patient and her substitute decision-maker(s)/family can be a valuable outcome on its own (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). Even if no further discussion or documentation occurs, the substitute decision-maker is likely to have a better sense of the patient's care and decision-making preferences/values and therefore feel more confident and less stressed when making a decision if and when the time comes (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Parker, et al., 2007; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004).

Barnard (2002) has suggested that the autonomy-preserving goal of traditional advance care planning approaches obscures other potentially fruitful perspectives by focusing efforts on "getting it right," ethically speaking. Such a view implies there is a "right" choice just waiting to be made. Surely this is a naïve notion given the profound uncertainty, complexity, and variability associated with end-of-life scenarios, particularly in the context of a highly unpredictable chronic illness like COPD. Re-envisioning

advance care planning within a framework of patient-centred care is an approach viewed by many as a way to increase meaningfulness and therefore effectiveness (Barnard, 2002; Gott, et al., 2009; Hickman, et al., 2005; McCormack, et al., 2011; Quill & Cassell, 1995; Spence, et al., 2009; Weiner & Efferen, 2005; Weiner & Cole, 2004).

Models of advance care planning.

An increasingly popular advance care planning model globally is *Respecting Choices*[(R)] developed in 1993 in La Crosse, Wisconsin under the auspices of the Gundersen Lutheran Medical Foundation (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Hammes, 2003). Extensively researched and revised, it has been adopted by clinicians in the US, Canada, Australia, and Spain. The goal that informs this approach is described in terms of preparing patients and their intimate others who are living with progressive symptoms of chronic disease to make decisions about their future/end-of-life care treatment. The focus is on creating a patient-centred process to address:

> *selecting a surrogate decision-maker, clarifying and understanding the patient's values and preferences with the surrogate decision-maker, deciding what decision-making authority the surrogate will have, and providing information regarding the benefits and burdens of certain medical treatments" (Briggs, et al., 2004, p. 47).*

The theoretical basis for the model includes Pierce and Hicks' (2001) interactive decision-making model, and Donovan and Ward's (2001) representational approach to patient education (Briggs, et al., 2004). Briggs et al (2004b) describe the interactive decision-making model in terms of three foci: *decision problems* (relevant information to be considered when presented with a number of options), *patient-related factors* (values, preference for participation, decision-making style, expectations, psychological and physical state, risk perceptions), and *context* (patient/clinician relationship). Their application of the representational approach to patient education includes attention to five dimensions of illness beliefs--identity, cause, timeline, consequences, and cure/control. They use this as a cognitive framework within which patients may interpret and process new illness and end-of-life related information. "Encouraging patients to describe their

illness beliefs along [these] five dimensions of illness representation can set the stage for highly effective patient-centered intervention" (Briggs, et al., p. 48).

The resulting interaction is referred to as the patient-centered advance care planning (PC-ACP) interview in *Respecting Choices*[R] (Briggs, et al., 2004). This interview is done to enable the patient (and surrogate decision-maker/intimate others) to review belief systems and embedded limitations/misconceptions. This enables the interviewer to "present new information, individualized to the patient so that the misconceptions can be replaced" (Briggs, et al., p. 48). Initially the approach was a one-session "interview" facilitated by a healthcare professional and the desired outcome was a documented plan of the patient's end-of-life care goals. The model now refers to the likelihood of multiple sessions to allow patients and their intimate others adequate time to reflect and consider the alternatives in light of their values and preferences before attempting to clarify/document a plan. The model is still somewhat proscriptive in its structure.

The other frequently mentioned model is based on "stage of change" theory (Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). The *Respecting Choices*[R] model has been revised to incorporate this theory as well, to guide facilitators' efforts to identify and respond to patients/their intimate others/substitute decision-makers' particular information needs (Westley & Briggs, 2004). Based on the work of Prochaska (1997), the theory describes six stages or phases individuals tend to pass through (not necessarily in order) and revert back to as part of decision-making, and action to move individuals along this continuum to achieve behavioural change. It is the Transtheoretical Model (TTM) version of this theory that is most commonly used to guide advance care planning. This version includes

> *a temporal component, represented by stages of change, which include* precontemplation *(no intention to change behavior in the near future),* contemplation *(thinking about changing behavior in the near future),* preparation *(commitment to changing behavior soon),* action *(a recent change in behavior), and* maintenance *(ongoing behavior change). The TTM also includes the concept of processes of change, strategies used to increase readiness for participation. (Fried, et al., 2009, p. 1548)*

The goal of advance care planning models based on this theory tends to be stated in terms of understanding "the process by which patients identify, communicate, and document their treatment wishes" (Sudore, et al., 2008, p. 1006). Research into advance care planning models based on stage of change theory has shown they encourage discussions appropriate to patients/intimate others' stage of readiness, which can enhance advance care planning outcomes (Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004).

Although other approaches were mentioned in the literature, the *Respecting Choices*[(R)] model and those based on "stage of change" were prevalent. They seemed most effective in terms of outcomes related to clarifying values and preferences (by increasing discussions with substitute decision-makers, family, friends, clinicians, and/or documentation) to guide end-of-life care decision-making.

Inadequacies in current models of advance care planning for advanced COPD.

Common elements across these two advance care planning models include: a skilled health professional (not necessarily a physician) as facilitator, a clinical setting, a communication approach focused on developing an advance care plan, attention to uncertainty and timing/readiness, inclusion of the substitute decision-maker, information/education, and team collaboration. Although these models could be used in chronic illness contexts, there are several conspicuous omissions from the perspective of those living with advanced COPD.

Hope is one factor repeatedly mentioned by clinicians when they explain their reluctance to address advance care planning in this context. Neither of these models deals directly with hope. The uncertainty factor is also important because its pervasiveness in advanced COPD heightens the discomfort for those clinicians who need predictability and precision. Practitioners' personal and clinical hopes, fears, and uncertainties influence their interactions with patients and their intimate others (Simpson, 2000, 2002, 2004). Many are unaware of the nature and workings of these inner psychic processes, and thus unaware of their impact on clinical communication. I believe understanding how patients and intimate others live with hope and uncertainty is a significant focus if advance care

planning discussion is to be meaningful, effective, and not damage hope. Practitioners developing self-awareness concerning these issues is also important.

Those living with advanced COPD are often experiencing significant breathlessness that limits their mobility and increases their anxiety. Many lack easy access to transportation and find travel to and from doctors' clinics difficult, tiring, time-consuming, and costly. Attention to these contextual details seems important in developing patient-centred advance care planning. Facilitating these discussions with patients during a hospital admission may be apt in terms of their readiness, but may undermine patient-centredness related to privacy, confidentiality, comfort, relational and time considerations. Finding ways to enhance comfort levels and access to advance care planning for patients and their intimate others seems more consistent with the spirit of patient/family-centred care. Finally, much of the recent advance care planning research suggests encouraging patients to chat with their intimate others (spouse/partner, family members, friends, informal carers) may be as valuable a goal as documenting an advance care plan. Therefore it seems we need to broaden the focus somewhat from documenting a plan to approaches that promote informal outcomes such as discussions with intimate others.

The proposed study was developed with these issues in mind. The design includes many of the elements described in the *Respecting Choices*[(R)] and "stage of change" models. However, I felt that the somewhat proscriptive nature of these models required adaptation for the advanced COPD context.

Advance care planning in advanced COPD.

The Canadian Thoracic Society outlined ongoing gaps related to the end-of-life for patients with advanced COPD (Goodridge, et al., 2009; O'Donnell, et al., 2004). Among the issues listed were: providing opportunities for patients to discuss their illness experience and related needs and initiating open and honest communication with patients and their intimate others concerning prognosis and end-of-life issues. Pierson (2004, p.108) suggested that achieving the goal of providing excellent "symptom relief and counseling in the shadow of death" will require attention to developing good, open communication that deals honestly with prognosis, acknowledges uncertainty, and

supports the patient through a process of advance care planning. Studies have shown that many patients living and dying with COPD have a desire to discuss end-of-life care with their healthcare clinicians (Black, 2007; Curtis, et al., 2004; Curtis, et al., 2002b; Gardiner, et al., 2009; Heyland, et al., 2006; Reinke, et al., 2011). Despite clinicians' fears to the contrary, most patients' hope(s) seems not to be negatively affected by such dialogue (Back, et al., 2003; Curtis, et al., 2004; Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005).

Clinicians seldom initiate these discussions in a timely manner. Advance care planning conversations often take place during a crisis and in an emotionally charged settings like the ER or ICU with little sensitivity for patients and/or their intimate others' comfort or expectations (Goodridge, 2006; Heyland, et al., 2009; O'Donnell, et al., 2004). It is not unusual for a single, clinically focused "code status" question to serve as advance care planning in the eyes of physicians (Downar & Hawryluck, 2010). Avoidance of even these minimal interactions to discover a patient's life-sustaining treatment preferences is also common (Downar & Hawryluck, 2010). In the absence of advance care planning discussions and informed decision-making, patients' goals of care may remain unspoken and often unclear. This raises the potential for conflict and suffering in the wake of unexpected hospital admissions and outcomes, and is associated with dissatisfaction with end-of-life care for patients and their intimate others (Heyland, et al., 2010).

It is not uncommon for patients with advanced COPD to experience one or more ICU admissions for treatment of exacerbations and thus it is not surprising that many patients with advanced COPD experience lengthy ICU stays and/or death in an ICU setting (Curtis, 2006; Goodridge, et al., 2008; MacIntyre & Huang, 2008). Additionally, there is evidence that COPD patients admitted to ICU may have certain unique needs among critically ill patients due to factors such as longer than average stays in the ICU, multiple previous admissions, increased risk for ICU syndrome (delirium observed in some ICU patients), and potentially prolonged periods of mechanical ventilation or difficulty being weaned from the ventilator (Goodridge, et al., 2008). More worrisome is how often the avoidance of a discussion about patients' goals of care results in a unilateral decision by a clinician to initiate or withhold life-sustaining interventions (Goodridge, 2006; Goodridge, et al., 2008; Lynn, et al., 2000; O'Donnell, et al., 2004). There is also

evidence to suggest potential clinician bias toward withholding life sustaining intervention in the context of late stage COPD (Wildman, et al., 2007). This 'treatment/non-treatment by default' scenario challenges our understanding of, and respect for, informed choice and other underlying principles of ethical professional practice (Kinlaw, 2005; Lynn & Goldstein, 2003; Nicolasora, et al., 2006). It is also in conflict with the current institutional goal of patient-centred care.

The current approach to critical illness has had a tendency to "overuse technologically aggressive, life-prolonging treatments and underuse communication skills" (Weissman, 2004, p. 1740). This situation will only be improved through the development of a commitment to high quality advance care planning dialogue that encourages patients to consider and talk about their care preferences (Weissman, 2004). Many clinicians otherwise committed to providing excellent care for their patients, allow the uncertainty that characterizes chronic terminal conditions like COPD to undermine this commitment when it comes to initiating advance care planning discussions in these contexts (Curtis, 2006; Exley, Field, Jones, & Stokes, 2005; Munday, Dale, & Murray, 2007; Shah, et al., 2006; Spence, et al., 2009; Yohannes, 2007). Ethical and professional practice dilemmas and distress can be a source of conflict and gaps in care related to end-of-life decision-making in advanced COPD (Goodridge, et al., 2008). Achieving quality advance care planning is one of the more powerful and enduring issues in delivering ethically robust professional care for patients and their intimate others dealing with chronic or potentially life-threatening illness (Kinlaw, 2005). Gaps in goals of care decision-making indicate less than adequate communication particularly in the domains related to COPD prognosis and advance care planning, a reality that challenges the integrity of the entire informed choice process and the ethics framework upon which it rests (Rosenfeld, et al., 2000). Without timely, collaborative ways of identifying goals of care, patients and their substitute decision-makers will continue to be vulnerable to less than adequate end-of-life decision-making in these contexts (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Gardiner, et al., 2009; Habraken, et al., 2008; Sibbald, et al., 2007).

Traditional palliative care services have been a source of sensitive illness-related information sharing and psychosocial support to help cancer patients adapt their hope(s)

and resulting end-of-life decision-making. The same cannot be said consistently for chronic incurable conditions like COPD (Lynn & Goldstein, 2003; Weissman, 2004; White, 2005; Winzelberg, et al., 2005b). Currently, we know that patients and their intimate others living with advanced COPD do not receive the same level of patient/family-focused advance care planning (Curtis, et al., 2004; Curtis, et al., 2005a; Gott, et al., 2009; Hardin, et al., 2008). Unlike a cancer diagnosis, a diagnosis of COPD does not automatically trigger images of death and/or dying for patients and their intimate others who hear it (Au, et al., 2006; Blackler, et al., 2004; Curtis, et al., 2005a; Curtis & Rocker, 2006; Edmonds, 2001; Elkington, et al., 2005; Gardiner, et al., 2009; Goodridge, 2006; Habraken, et al., 2008; Neerkin & Riley, 2006; Rocker, et al., 2007). The mostly unpredictable but chronically downward trajectory of COPD does not fit comfortably in either the cure-oriented acute care setting or the traditional "comfort care" setting often associated with palliative care (Rocker, et al., 2007; Rocker, et al., 2009; Simpson & Rocker, 2008b). This lack of fit symbolizes the uncertainty that plagues clinicians who struggle with what to tell patients about COPD prognosis, how to define an 'end-stage,' when and how to initiate advance care planning to discern goals for end-of-life care (Black, 2007; Blackler, et al., 2004; Curtis, et al., 2005a; Curtis & Rocker, 2006; Goodridge, 2006; Reinke, et al., 2011; Rocker & Hernandez, 2005; Rocker, et al., 2007; Varkey, 2003; White, 2005). The result is often reluctance to initiate the discussion.

Knauft et al (2005) examined patient and clinician barriers and facilitators related to end-of-life discussions in COPD (Knauft, et al., 2005). The two most common barriers expressed by patients in this study were a preference to concentrate on staying alive (75%) and anxiety caused by not knowing which clinician would be providing care at the time of the final crisis (64%). For clinicians, lack of time (64%) and fear of damaging hope (23%) were the two top barriers. The two facilitators most commonly endorsed by patients were having had family or friends who had died (88%) and trust in their clinician (87%); for clinicians, the facilitators were having a good relationship with the patient (85%) and having significant experience caring for those with lung disease (80%) (Knauft, et al., 2005). Besides revealing some commonalities with respect to barriers and facilitators, the study also revealed great diversity in these factors, such that the authors recommended interventions be based on characteristics and needs of individual

clinician/patient dyads (Knauft, et al., 2005). Given the existing diversity in contextual factors, communication goals, emotional dimensions, interpersonal knowledge and competencies among participants in any clinical encounter, it is not hard to understand the frequency of confusion, misunderstandings, dilemmas, and conflict, especially in highly emotional end-of-life crises. This is further complicated by uncertainty experienced by substitute decision-makers in COPD contexts. These individuals often have a significant role in advanced COPD because patients can be incapacitated due to hypoxia, dyspnea, and/or a need for mechanical ventilation (Lorenz, et al., 2007). These patients are seldom encouraged to choose a substitute decision-maker or to talk about their values and preferences related to end-of-life care with that person (Crawford, 2010; Gott, et al., 2009).

Besides the obvious uncertainty, clinicians cite a number of reasons for their reluctance to engage in advance care planning with advanced COPD patients and their intimate others/substitute decision-makers. These include fear of damaging patients' hope, concern about time constraints, and lack of confidence in their own communication skills (Blackler, et al., 2004; Crawford, 2010; Curtis, 2000, 2006; Curtis, et al., 2004; Curtis, et al., 2005a; Goodridge, 2006; Gott, et al., 2009; Hardin, et al., 2008; Rocker, et al., 2008; Rocker, et al., 2009; Spence, et al., 2009; Yohannes, 2007). Each of these concerns is rooted in a form of uncertainty—about the time requirements and communication skills needed for good quality advance care planning as well as the role and nature of hope (for patients, their intimate others, and presumably clinicians themselves) within such interactions. The uncertainty, unpredictability, and particularity that characterize end-of-life in advanced COPD present considerable challenge to a system founded on values of certainty, predictability, and generalizability (Thorne, Hislop, Kuo, & Armstrong, 2006; Thorne, Oglov, Armstrong, & Hislop, 2007). Perhaps consistent with an inherent quest for certainty, research into advance care planning has focused more on the time and communication skills requirement, and less on the nature and role of hope. Still, the goal of improving satisfaction with end-of-life care in advanced COPD requires attention to hope and other factors implicated in communication dynamics within the advance care planning research agenda. These issues—uncertainty about the COPD trajectory and the effect of advance care planning

on hope(s)—suggest a need to better understand the interplay of hope and uncertainty within the complexity of COPD and advance care planning.

Hope considerations in advance care planning.

Hope plays a significant, if imprecise role in illness, especially at times of major illness transitions (Davison & Simpson, 2006; Simpson, 2000, 2004). This makes it very pertinent in chronic terminal illness and end-of-life scenarios. Clinicians not only appear to accept the salience of hope in these situations, they often cite it as an obstacle to appropriate disclosure in 'bad news' situations and end-of-life discussions despite best practice and ethics standards to the contrary (Benzein & Berg, 2005; Davison & Simpson, 2006; Nicolasora, et al., 2006). This reluctance continues despite recent research reporting that honest, sensitive discussion of disease prognosis and related end-of-life implications is high on the list of needs identified by patients and their intimate others living with advanced COPD (Heyland, et al., 2006; Lorenz, et al., 2007). Research into patients' responses to the implications of end-stage illness has acknowledged the centrality of hope and related constructs such as hopelessness, despair, the will to live, and the desire for hastened death (Breitbart, 2005; Breitbart, et al., 2000; Chochinov, 2006; Chochinov, 2005; Felder, 2004; Perakyla, 1991; Sullivan, 2003; Yedidia & MacGregor, 2001). Studies of illness experiences have repeatedly demonstrated a variety of positive hope-related effects including enhanced coping, reduced psychosocial and spiritual distress, improved immunological measures, and quality of life (Chochinov, 2006; Farran, Herth, & Popovich, 1995; Richardson, 2000; Weingarten, 2004). Hope is thus an acknowledged factor in health, healing, and wellbeing (Clayton, et al., 2008; Kylma, Duggleby, Cooper, & Molander, 2009a; Miller, 2007; Milne, Moyle, & Cooke, 2009; Wiles, Cott, & Gibson, 2008). Research has also highlighted our tenacious capacity for finding, creating, adapting, and revising hope, right through to the end of life (Back, et al., 2003; Bovens, 1999; Chochinov, 2006; Glass & Cluxton, 2004; Morse & Doberneck, 1995; Ruddick, 1999; Simpson, 2002; Tulsky, 2005). Thus hope is both an influential factor and a relevant concern when considering advance care planning.

In her doctoral thesis entitled "The Intersections of Hope, Health, and Illness: Moral Responsibilities of Health Care Providers," Christy Simpson (2000) defined hope as:

> *an emotional attitude whereby the person who hopes for* p *(where* p *is the event or state of affairs hoped for): a) desires/wants* p; *b) believes* p *is in accordance with her values and/or goals; c) imagines* p *is a realizable possibility for her, even though it is uncertain whether* p *or* not-p *will occur; d) acts in such a way as to support her hope (i.e., where it is possible to affect whether* p *will occur, she will try to bring* p *about; minimally she will not act to foreclose the possibility that* p *will occur) – this may include making use of available opportunities and resources (personal, material) and/or relying on other individuals. (p. 81)*

This definition suggests several implications about hope in terms of advance care planning considerations in advanced COPD.

First, in the context of illness, hope is paradoxically a source of personal vulnerability and personal autonomy, identity, and coping (Simpson, 2000). It is rooted in a longing for a certain desirable outcome that aligns with the patient's values, beliefs, and goals in life. This suggests that hope is very much a part of what contributes to that person's unique identity, life project, personal narrative (McAdams, 1993). It follows from this that exploring someone's hope(s) can help to elucidate what matters most to her/him at any given time and situation (Wright, et al., 1996). Such a view is relevant to accomplishing the first goal of medicine, the relief of suffering, which tends to be uniquely experienced and thus requires the individual tailoring of care for an adequate response (Bergum & Dossetor, 2005; Frank, 2001, 2002). Ek and Ternestedt (2008) speak in terms of the "dignity of identity," a concept that is associated with self-identity, and therefore an individual's hope. Self-identity, and therefore hope, are often vulnerable in advanced COPD when many patients come to feel they are no longer able to contribute to life in any personally meaningful way.

Hope also relates to a person's tendency to imagine her/his preferred outcome in terms of a *potentially* acceptable and realizable future, even though this may be contrary to 'scientific probability' expressed as statistical odds (Simpson, 2000; Thorne, et al.,

2006). Naylor (1995) paraphrasing Sir William Osler once said, "Let us agree that good clinical medicine will always blend the art of uncertainty with the science of probability" (p.842). Uncertainty differentiates 'hope' from 'fact.' It is the foundation for linking scientifically derived statistical probability, especially probability for cure or survival, with the concept of hope (Glass & Cluxton, 2004; Simpson, 2000, 2004; Thorne, et al., 2006). Depending on the percentages, a healthcare clinician can view statistical probability as hope-destroying while that same probability can be hope-sustaining in the minds of patients and their intimate others (Thorne, et al., 2006). Patients and their intimate others tend to interpret the ambiguous, uncertain data so typical of COPD contexts according to what they value, prefer, and hope will happen (Wright, et al., 1996). Hope-related imagination is thus a source of strength, but it also gives rise to vulnerability because it enables us to envision negative as well as positive possibilities (Back, et al., 2003; Davison & Simpson, 2006; Simpson, 2004).

Part of being able to imagine, and thus hope, includes the notion of "imagining with," a relational process of envisioning potential future scenarios dependent to some extent on input from influential others (McGeer, 2004; Simpson, 2000). Thus hope has a relational, interactive element, which, while it embodies a source of positive energy for a desirable future, also introduces a negative potential. There is risk and vulnerability in articulating personal hopes to others who may not support them (Benzein & Berg, 2005; Simpson, 2000, 2004). How significant others (clinicians, intimate others, and/or friends) "imagine with" patients can motivate them to retain, modify, or lose hope (Coyle, 2003; Simpson, 2000, 2004). Thus relational effects can en-courage or dis-courage the individual doing the hoping. Within this consideration, though, it is good to bear in mind that human beings have an amazing ability to maintain hope despite occasions of unconscious or thoughtless hope-eroding comments or behaviour by others (Ezzy, 2000; Glass & Cluxton, 2004; Hagerty, et al., 2005; Yedidia & MacGregor, 2001).

The flexible nature of hope is a factor in whether, how, and when patients adapt their hope(s) in the face of negative developments in terms of illness (Hines, 2001; Morse & Doberneck, 1995; Nekolaichuk & Bruera, 1998; Rando, 2000). This aspect of hope also contributes to patients' sensitivity to particular nuances, real or imagined, within their clinicians' words and/or actions. For instance, a patient may read into a physician's

continued offer of active treatment or avoidance of discussing dying that there is no reason to abandon his/her hope for cure or longevity (Coyle, 2003; Simpson, 2000, 2004). Clearly, advance care planning needs to be designed in such a way as to respect these hope dynamics and their unique role in how each patient copes. The adaptive, coping dimension of hope includes a degree of agency on the part of the person doing the hoping, an <u>active</u> engagement in helping achieve, or at the very least, not impeding the hoped for outcome (McGeer, 2004; Simpson, 2000). It may be this agency aspect that clinicians are most concerned about in their hope-related reluctance to initiate discussions concerning prognosis and advance care planning in COPD (Davison & Simpson, 2006; Larson & Tobin, 2000; Steinhauser, et al., 2001; Weissman, 2004).

Given the context of uncertainty that is characteristic of advanced COPD on so many levels, hope is obviously a relevant factor for clinicians as well as patients and their intimate others. In situations of uncertainty, hope provides a resource for coping by enabling patients to imagine, seek support for, and invest energy in scenarios that help them to engage with life despite illness progression. In each clinical encounter, the hopes and uncertainties of patients and their clinicians are active, though often unarticulated and unconscious factors (Simpson, 2000). Part of the challenge of doing advance care planning with those living with advanced COPD is figuring out how best to work with these influential but implicit hope and uncertainty forces. It seems logical to suggest that advance care planning in these contexts should explore hope with patients and their intimate others as an indicator of their concerns, beliefs, and values. As a reflection of what matters to individual patients and as a source of concern for their clinicians, hope is a logical focus for advance care planning research into enhancing end-of-life decision-making and ultimately care in the context of advanced COPD. If hope is a logical focus in advance care planning, uncertainty as a necessary condition for hope, is an important corollary.

Balancing uncertainty and hope in advance care planning.

Babrow's (2001b) "Problematic Integration" (PI) theory seeks to explain how individuals resolve tensions related to uncertainty and hope. Because of this focus, it has been used in the study of advance care planning generally, and in chronic illness settings

specifically. The theory has two underlying premises vis-á-vis uncertainty: 1) human beings develop probabilistic orientations to their world (expectations, beliefs); 2) human beings develop evaluative orientations to their world (judgments about what seems good or bad) (Babrow, 2001a, 2001b; Gillotti, 2003; Hines, 2001; Hines, et al., 2001). These are not separate, incidental, co-occurring phenomena, but mutually informing dynamics impacted by time and circumstance (Babrow, 2001b). The theory holds that the integration of these two premises shapes an individual's ongoing life experience by influencing the priority--the hope--assigned to various expectations at any given time. The intricate, interrelated nature of human life means this integration process is related to probabilities and values, and thus is seldom straightforward. Expectations and related evaluations, probabilities and associated values, tend to act upon and destabilize each other, such that their integration is problematic at times (Babrow, 2001b). In analyzing this further, Babrow (2001b) suggests that the likelihood of such "problematic integration" increases with dynamics of: *divergence* (when probability and value go in opposite directions); *ambiguity* (when a situation has multiple meanings); *ambivalence* (when there is co-occurrence of mutually exclusive, equally valued options); and *impossibility* (when a valued outcome is not attainable). These scenarios tend to overlap and/or co-occur, especially in serious illness situations like advanced COPD.

Problematic integration theory has provided some insight to guide advance care planning in chronic illness. First it suggests that advance care planning should be something more than a listing of preferences related to particular end-of-life care interventions. Deciding on care preferences related to specific end-of-life care scenarios that are as yet unknown and highly unpredictable is a difficult if not impossible task. A listing of uncertainties related to end-stage chronic illnesses like COPD demonstrates the variability and complexity affecting decision-making in these situations (Hines, 2001):

- prognosis is poor yet timing/cause of death is highly unpredictable
- degree and nature of suffering secondary to on-going physical and psychosocial effects varies from patient-to-patient, family-to-family
- material, relational, and emotional costs are ongoing but unpredictable as are individual perceptions of burden related to increasing care needs
- information-related concerns vary throughout the course of the illness—not enough, too much, too complex, changing

- coping concerns are affected by and in turn affect uncertainty in relation to shifting quality of life, social support, fears, hopes, and preferences

These same uncertainties that make prediction difficult for clinicians are the ground of hope for patients and their intimate others. Thus when contemplating how to design and initiate advance care planning in advanced COPD, it is important to understand something about the nature of uncertainty and its relation to hope.

Five important misconceptions about uncertainty have been elucidated as contributing to inadequate communication strategies and care in advanced chronic illness contexts (Babrow, 2001b):

- uncertainty is a negative factor
- uncertainty has a single, homogeneous meaning
- more information should be the primary response to uncertainty
- reducing uncertainty should be the primary goal
- the course of uncertainty is predictable

These misconceptions are perpetuated by the "uncertainty reduction" model of decision-making so common in science and consequently biomedical approaches to care (Babrow, 2001b). Clearly there will be many different responses by patients, their intimate others, and clinicians to the uncertainty present in advanced COPD, which suggests a need for clinical decision-making that is flexible and responsive within the individual patient/clinician dyad (Godolphin, 2009; Kiesler & Auerbach, 2006; Knauft, et al., 2005). As mentioned in the earlier section on decision-making preferences, some patients will defer to clinicians for decision-making, others prefer that a process be clearly outlined and followed, some that clinicians make recommendations, and some who will just refuse to consider the topic of decision-making altogether (Godolphin, 2009; Henman, Butow, Brown, Boyle, & Tattersall, 2002; Hines, 2001; Kiesler & Auerbach, 2006; Rosenfeld, et al., 2000; Tulsky, 2005; Tulsky, Fischer, Rose, & Arnold, 1998). Gaining insight into a patient's particular preferences in this regard is important for preventing confusion, misunderstandings, and/or disagreements about what strategies the patient is using to deal with illness and end-of-life uncertainties. Clinicians who do not understand the strategies being used by their patients risk undermining important coping efforts, such as hope, that these strategies serve to support (Brashers, 2001).

Certain kinds of uncertainty in illness provide an opportunity for hope to develop and be maintained as a way to cope with illness progression. From a problematic integration theory perspective, when a patient expresses hope it infers that s/he holds a positive probability orientation toward a valued outcome, and also that this outcome is uncertain (Brashers, 2001; Simpson, 2000, 2002, 2004; Thorne, et al., 2006). The patient's hope is a positively valenced expression of both an emotional and behavioral (agentic) response to this particular situational uncertainty. In contrast, his/her expression of anxiety, fear, and/or frustration would suggest a negatively valenced response in the face of this uncertainty (Brashers, 2001). The two are not mutually exclusive and motivate individuals to employ particular uncertainty management strategies, some of which are communication based, to enable them to cope with uncertainty in the moment and beyond (Brashers, 2001).

As already mentioned, in traditional Western healthcare contexts decision-making is often based on the 'uncertainty reduction' model (Brashers, 2001). However, in cases where preserving hope is predicated on maintaining a certain type of uncertainty, use of this model may be counter-productive. The "hope for the best, prepare for the worst" approach exemplifies a sensitive, more collaborative communication approach that respects a patient's hope rather than ignoring or using it as an excuse to avoid the discussion (Back, et al., 2003). At the same time, this approach upholds respect for autonomy and informed decision-making (Back, et al., 2003; Brashers, 2001; Varkey, 2003). When a clinician uses the phrase "hope for the best" s/he lends credibility to the positive valence of uncertainty needed for the patient to sustain her/his hope despite what may be overwhelmingly negative implications of scientific probability (Brashers, 2001). But effective advance care planning does not stop with "hope for the best."

Communication continues with "prepare for the worst" which brings into view negatively valenced uncertainty dimensions of advanced illness states. These may be mitigated through the use of rhetorical strategies designed to identify and address the patient's particular concerns (Brashers, 2001). For example, if a patient has expressed concern about becoming a burden to loved ones, "preparing for the worst" can be framed as an opportunity to address this. Advance care planning can be a way for the patient to relieve potential burden by decreasing uncertainty for loved ones who may be asked to

make end-of-life care decisions for this patient. A clinician can also choose to highlight particular relational concerns by including the patient and her/his intimate others in discussions about preferred outcomes. This acknowledges that the patient and her/his intimate others are likely most knowledgeable when it comes to that patient's sense of dignity and care preferences (Brashers, 2001; Cherlin, et al., 2005; Larson & Tobin, 2000; Prendergast, 2001; Teno, Casey, Welch, & Edgman-Levitan, 2001; Weissman, 2004; Winzelberg, et al., 2005b). In this way advance care planning can be crafted to address uncertainty more effectively by working with that which is valued by the patient, for example hope, and addressing that which is of concern to the patient, to reduce her/his sense of burden and/or suffering (Brashers, 2001).

It appears that both process and content of advance care planning matter when considering how best to work with patients/intimate others' uncertainty and hope. Choices about what information to provide to patients, along with when, and how, are integral. These choices can influence the meanings patients associate with various uncertainties, their emotional responses and hopes, and ultimately their end-of-life decision-making (Babrow, 2001b; Gillotti, 2003). The process can often benefit from both a broadening of focus and an individualization of content and delivery (Barnard, 2002). Increased sensitivity to patient-specific decision-making needs related to illness uncertainty, values, probabilities, and relevant meanings is integral to the usefulness of the process (Cherlin, et al., 2005; Hawkins, et al., 2005; Larson & Tobin, 2000; Weissman, 2004). This highlights the importance and nature of the communication challenge for clinicians—to engage in flexible, evolving, patient-centred, but efficient discussions (Lang & Quill, 2004; Steinhauser, et al., 2001; Teno, et al., 1998; Tulsky, 2005).

Problematic integration theory has identified other issues pertaining to advance care planning in the context of chronic terminal illness. These include the tendency to:

- privilege clinicians' uncertainties over those of patients and/or their intimate others
- privilege the 'patient/clinician' context over that of 'patient/family'
- neglect process-related uncertainties
- proceed as if end-of-life uncertainties are reducible/manageable
- fail to accommodate changes arising from illness progression (Hines, 2001)

First, the privileging of clinician uncertainty is often manifested in a one-way flow of mainly biomedical information, something the clinician feels more sure of, from clinician to patient (Hines, 2001). This information may not be understood or desired by the patient, many of whom do not feel able to ask for what they do need/want. This is a source of significant potential for confusion, conflict, and mismatched goals. Second, privileging 'patient/clinician' context ignores the fact that in end-of-life healthcare crises, clinicians most often look to intimate others to act as substitute decision-makers for incapacitated patients unable to participate in this process. Uncertainty is a major factor in substitute decision-makers' difficulties in these situations, often because they have not talked with patients about their end-of-life care values/goals (Hines, 2001). Encouraging these discussions between patients and their intimate others is thus a logical focus for advance care planning efforts.

Third is ascertaining patients/intimate others' preferences concerning *process*-related uncertainties. Participants may prefer a structured rather than an open-ended approach to advance care planning, even in the context of a patient and intimate others discussion. It seems that establishing boundaries around the discussion, for example by using an advance directive template, can give some participants a sense of predictability that enhances their feelings of confidence and comfort (Hines, 2001). Others may prefer a less set agenda, but one that is sensitive to their ways of coping. Fourth, the assumption that end-of-life uncertainties are reducible or manageable denies the nature of death and dying as an undesirable, uncomfortable, and difficult event for most people to contemplate (Finucane, 1999). Traditional approaches have tended to focus on highly uncertain aspects such as asking patients to specify interventions they prefer to have/avoid in as yet unknown end-of-life situations (Hines, 2001).This focus ignored more stable issues that could help guide substitute decision-makers and clinicians, things like the individual's core values related to quality of life and/or preferences about the decision-making process itself (Hines, 2001; Sudore & Fried, 2010; Sudore, et al., 2008). Newer models like *Respecting Choices*[(R)] address these issues. Fifth, as the illness progresses, uncertainties are likely to shift and give rise to revised hopes, fears, and goals (Hines, 2001; Wittink, et al., 2008). This may result in different informational needs and

coping strategies on the part of patients and their intimate others, which in turn will require up-dating care goals by revisiting advance care planning.

Timing, or readiness, is a crucial element in how patient/intimate others' needs unfold, are recognized, and shared, and ultimately impacts the relevance and acceptability of clinician-initiated advance care planning (Hines, 2001). All of these issues provide a focus for research aimed at enhancing advance care planning through the testing of more patient/family-centred communication strategies designed to address hope/uncertainty related tensions.

Patient-centredness in advance care planning.

The construct of patient-centred care is central to relational care ethics and advance care planning broadly construed. "Patient-centredness," the guiding tenet of patient-centred care, refers to being respectful of and responsive to a patient's preferences, needs, and values, and attending to these throughout care planning and delivery (Epstein, Fiscella, Lesser, & Stange, 2010). In essence, patient-centred care embodies the view that "the patient needs to perceive that his or her individual needs or circumstances are at the heart of the clinical care he or she receives" (Hudson, Fortin, Haggerty, Lambert, & Poitras, 2011, p. 161). The provision of patient-centred care requires the establishment of a trusting therapeutic alliance with a sense of mutuality about it (Duggan, Geller, Cooper, & Beach, 2006; Epstein, et al., 2010; Fiscella, et al., 2004; Hudson, et al., 2011; McCormack, et al., 2011; Saha, Beach, & Cooper, 2008; Wagner, et al., 2005; Yedidia, 2007). This is dependent on clinicians' ability to share power/responsibility appropriately by listening, encouraging patient and intimate others' input, respecting their perspectives and values, addressing relevant dimensions of the patient's life beyond the physical, and seeking to create a shared understanding (Epstein, et al., 2010; Epstein & Peters, 2009; Hudson, et al., 2011; Saha, et al., 2008; Yedidia, 2007). Patient-centredness shares philosophical elements from a number of ethics frameworks.

Traditional bioethics principles of beneficence and non-maleficence stress the necessity of putting the interests of patients above all else and thus clearly support a patient-centred care approach (Beauchamp & Childress, 2001; Epstein, et al., 2010). The

principle of respect for patient autonomy that is foundational to "informed choice" further strengthens the argument (Beauchamp & Childress, 2001; Epstein, et al., 2010). The notion of relational autonomy, contributed by a more relational care ethics framework, views patient-centredness as inclusive of patients' preferred relational contexts of intimate others, community, and culture (Bergum & Dossetor, 2005; Gadow, 1999; Nedelsky, 1989; Sherwin, et al., 1998). Finally, patient-centred care has been associated with a 'justice' focus as well through improved targeting of resources (consistent with patient preferences rather than by default) leading to potential cost reduction and/or containment (Epstein, et al., 2010; Murphy, 2011; Wagner, et al., 2005). Other associations include reductions in racial, ethnic, and socioeconomic care-related disparities along with better health outcomes in the areas of patient self-efficacy, adherence to treatment plans, and access to appropriate levels of care (Epstein, 2006). Thus patient-centredness as a goal is clearly consistent with and advocated by professional practice and relational care ethics.

Model.

Hudson et al (2010) have synthesized the patient-centred care literature into a four-dimensional model, Figure 1, inclusive of: a) disease and illness experience, b) whole person, c) common ground, and d) patient-doctor relationship. The *patient-doctor relationship* refers to the need for developing a positive therapeutic alliance, a working relationship, between clinician(s) and patient/intimate others (Hudson, et al., 2011; Poochikian-Sarkissian, Sidani, Fergusan-Pare, & Doran, 2010; Zoffmann, Harder, & Kirkevold, 2008). The *disease and illness experience* highlights the need for deeper insight into the patient-as-person to guide clinical perspectives in line with what is meaningful to the patient and her/his intimate others. The *whole person* perspective acknowledges the need for the focus of care to expand beyond the pathophysiology and biochemistry of disease to include biopsychosocial and spiritual dimensions as well. Finally, *finding common ground* concerns fostering shared understanding on the part of clinicians, patients, and their intimate others through the appropriate sharing of power, information, and responsibility.

While these four dimensions appear as separate quadrants in Figure 1, Stewart (2001) suggests, "patient-centred clinical practice is a holistic concept in which components interact and unite in a unique way in each patient-doctor encounter" (p.445). Theoretically, adequate attention to each of the four dimensions by all clinicians (not just physicians) can facilitate that unique encounter, enhance patient-centredness, and thereby improve healthcare outcomes and overall satisfaction with care for all (Hobbs, 2009; Hudson, et al., 2011; Wagner, 1998; Wagner, et al., 2005).

Figure 1. Conceptual framework of patient-centered care (PCC).
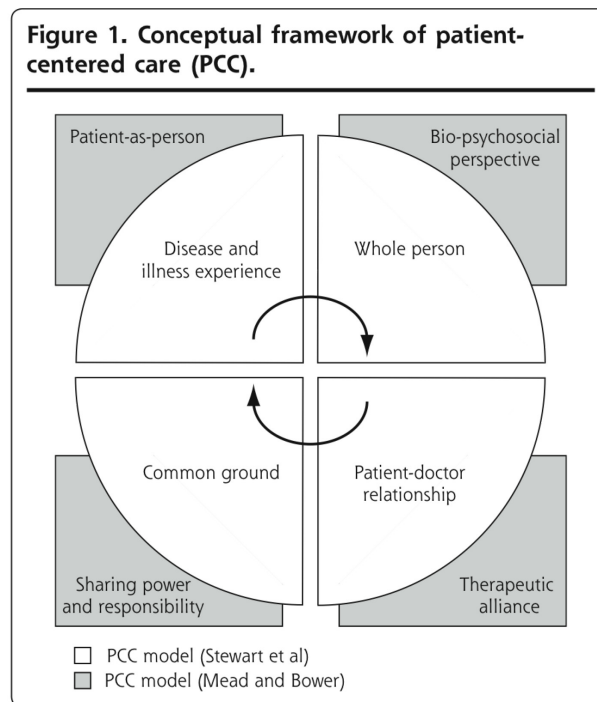
(Hudson, et al., 2011, p. 156; Mead & Bower, 2000; Stewart, Brown, Weston, & Freeman, 2003)

Principles of patient-centred care.

Two basic principles are communication and therapeutic relationship. The basic unit of health "care" delivery is the patient/clinician encounter, the quality of which depends greatly on the relationship or therapeutic alliance between the two (Ballard-Reisch, 1990; Finucane, 2002; Heyland, et al., 2006; Leach, 2005; Lee, Kristjanson, & Williams, 2009; Tulsky, 2005; Wenrich, et al., 2003). However the strength (or weakness) of this relationship is itself greatly dependent on the quality of communication between clinician(s) and patient (Cherlin, et al., 2005; Curtis, et al., 2005a; Knauft, et al.,

2005; Knops, Srinivasan, & Meyers, 2005b; Tulsky, 2005; Wagner, et al., 2010; Zoffmann, et al., 2008). Numerous authors have stressed both the interrelationship of communication and therapeutic relationship, and their importance for healthcare outcomes (Ballard-Reisch, 1990; Barnes, et al., 2007; Coyle, 2003; Heyland, et al., 2006; Leach, 2005; O'Gara & Fairhurst, 2004; Tulsky, 2005; Wenrich, et al., 2003). The degree of interrelationship between the two concepts suggests they should be considered together, but examining each one separately helps to understand underlying dynamics and relation to the four dimensions of patient-centred care. *Therapeutic relationship* and *communication* appear to be the primary modes of accomplishing patient-centred care with the goal being "shared information, shared deliberation, and shared mind." (Epstein, et al., 2010, p. 1490)

 Therapeutic relationship.

 The "patient-clinician relationship/therapeutic alliance" dimension has several associated principles relevant to advance care planning. From a relational care ethics perspective a dynamic of mutual *respect* is important. This refers to an interactive, reciprocal dynamic with an inherent notion of worthiness and a requirement for significant self-awareness and humility. It demands competency balanced by humility to counter the certainty that may develop with an increasing sense of professional expertise. "It is respect for uncertainty that holds power in its place." (Bergum & Dossetor, 2005, p. 96) *Trust* is essential and very much related to the inherent power asymmetry and patient vulnerability that arises from it (Christ & Blacker, 2006; Glass & Cluxton, 2004; Hebert, Hoffmaster, Glass, & Singer, 1997; Kinlaw, 2005; McDonald, 2004; McGeer, 2004; Pearson & Raeke, 2000; Tuckett, 2004). In any therapeutic relationship, there is an asymmetry of authority because of patients' vulnerability related to illness needs and clinicians' status related to biomedical expertise and position as care service gatekeepers (Bergum & Dossetor, 2005; Christ & Blacker, 2006; Dubler, 2005; Simpson, 2000, 2002). A positive therapeutic relationship depends on the level of trust developed between clinician(s) and the patient (Lee, et al., 2009; Pearson & Raeke, 2000) and trust cannot be taken for granted but is something that requires work (Christ & Blacker, 2006; McGeer, 2004). It is also important to acknowledge that trust and therapeutic relationship

are mutually informing (Glass & Cluxton, 2004; Hebert, et al., 1997; Kinlaw, 2005; McDonald, 2004; Tuckett, 2004).

A primary factor related to building trusting relationships with patients includes sensitivity to individual patient suffering and resulting needs, a focus encompassed in the patient-centred care dimension "patient-as-person/disease and illness perspectives" (Epstein, et al., 2010; Frank, 2001; Hudson, et al., 2011; Leach, 2005; O'Gara & Fairhurst, 2004; Tulsky, 2005). Patients have identified clinician qualities of compassion, concern, interest, hopefulness, and honesty, along with a capacity to be respectful and considerate of patients' dignity and self-worth as trust enhancing (Coyle, 2003; Curtis, et al., 2005a; Larson & Tobin, 2000; Wenrich, et al., 2003). A sensitive consideration of individual patient vulnerability and the need for trust mandates increased attention, self-awareness, and skill development on the part of clinicians as those professionally responsible for patient wellbeing (Curtis, et al., 2005a; Larson & Tobin, 2000; Weissman, 2004; Winzelberg, et al., 2005b). Communication is a primary focus for this skill development. Increased skill in and use of patient-centred communication has been associated with better concordance between patients and substitute decision-makers, greater satisfaction with end-of-life care and decision-making, as well as overall care (Black, 2007; Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; McCormack, et al., 2011; Parker, et al., 2007; Westley & Briggs, 2004). Such data suggests that skill in patient-centred communication is key in developing more effective approaches to advance care planning.

Communication.

A strong, trusting therapeutic relationship is encouraged through communication that encompasses the other three patient-centred care dimensions: patient-as-person/ illness and disease perspectives; common ground/sharing power and responsibility; and whole person/biopsychosocial (and spiritual) perspectives (Hudson, et al., 2011). When considering communication approaches that foster patient-centred care, it is important to begin from the premise that communication is a creative, cooperative, flexible process embedded in culture and context (Trenholm & Jensen, 2004). The collaborative essence of the dynamic implies that "what is important in interpersonal communication is what people do when they are together, not what each one does separately" (Trenholm &

Jensen, 2004, p. 9). Hence the implicit aim to work out a mutual understanding that is the "common ground" dimension of patient-centred care and the ultimate goal in any clinical encounter. This involves a commitment to *negotiating shared understanding*, a dynamic in which the process is as influential as the content (Beauchamp & Childress, 2001; Sharf, 1990; Trenholm & Jensen, 2004). From a relational care ethics perspective, there is a need for relational engagement, "the shared moment in which people have found a way to look at something together." (Bergum & Dossetor, 2005, p. 103) This type of conversation is rooted in serious attention to participants to develop a sense of fittingness (Bergum & Dossetor, 2005).

The nature of the communication process (how the healthcare provider frames and delivers the information, his or her tone, stance, timing, and demeanor, along with the time devoted to this discussion) influences understanding (Beauchamp & Childress, 2001). This process includes attention to language and literacy issues to facilitate *understanding*. It is enhanced by "presence" which refers to an *active listening* stance, a sense of "being with" that embodies aspects of *accompaniment* and *witnessing* (Franks, 2010; Sinclair, Pereira, & Raffin, 2006). "[T]he power of presence is about "companioning" the suffering. Entering into their painful world and walking along side them" (Franks, 2010, p. 331). To do this well, clinicians need to listen more than speak, be attentive to signs of distress (physical, emotional, relational, spiritual) in the patient and themselves, and engage empathetically (Bergum & Dossetor, 2005; Sharf & Vanderford, 2003). In response to revealed suffering, clinicians committed to the patient-centred care must ensure that patients have access to appropriate and timely psychosocial and spiritual support. Aligned with the patient-centred "whole person/biopsychosocial perspective," the spiritual/existential dimension is an important though often ignored aspect of care planning for patients and their intimate others (Canada, Murphy, Fitchett, Peterman, & Schover, 2008; Galek, Flannelly, Vane, & Galek, 2005; Heyland, et al., 2010; Sinclair, et al., 2006).

The previously discussed power differential inherent in the therapeutic relationship also affects the communication process related to "finding common ground." A dimension of the patient-centred care paradigm by Hudson et al (2011), "finding common ground" is also a focus advocated for by Hines (2001a,b) to improve relevance

and acceptability of advance care planning for patients and their intimate others. Clinicians need to be able to share power and responsibility appropriately to enhance trust and address vulnerability. Communication dynamics known to be associated with enhanced trust include attention to *truth-telling*, *privacy*, and *confidentiality* (Freedman, 1993; Glass & Cluxton, 2004; Leach, 2005; O'Gara & Fairhurst, 2004; Tuckett, 2004). Making an effort to safeguard confidentiality within whatever boundaries the patient desires is important for fostering trust through effective communication. Patients have indicated that *genuineness* on the part of their clinicians also encourages trust, and can be facilitated through clinicians' timely sharing of pertinent stories/experience (Bergum & Dossetor, 2005). A further aspect of both genuineness and truth-telling is a willingness to *acknowledge uncertainty* inherent in illness, prognosis, and resulting care decisions, something clinicians may find difficult to do in chronic illness settings (Apatira, et al., 2008; J. R. Curtis, et al., 2005; Davison & Simpson, 2006; Glass & Cluxton, 2004; Kaufman, 2005; Larson & Tobin, 2000; Nicolasora, et al., 2006; Weissman, 2004). *Exploring hope* as an indicator of vulnerability, goals, identity, and coping (McGeer, 2004; Simpson, 2000, 2002, 2004) and adapting discussion to these perspectives is also a dynamic to foster patient-centred care.

Healthcare communication is ultimately shaped by the goals of those who participate in it—patient, her/his intimate others, clinician(s)—making it important for clinicians to explore what goals are at stake and for whom in a given conversation (Carlson, Feldman-Stewart, Tishelman, & Brundage, 2005; Trenholm & Jensen, 2004). Working to match the content and process of communication with patient goals regarding information and decision-making can foster common ground and trust (Frank, 2011; Heyland, et al., 2003; Kiesler & Auerbach, 2006; Lee, et al., 2009; Mazur, et al., 2005). The patient-centred care dimension of patient-as-person/illness and disease highlights this focus. Developing this patient-centred insight depends on exploring the patient's needs, values, beliefs, expectations, and emotions, (Carlson, et al., 2005; Simpson, 2000). Exploring a patient's hope can provide a window into these personal dimensions to aid understanding (Simpson, 2000). Stories of illness-related experience, another potential source of this insight, should be encouraged and listened to attentively (Bergum & Dossetor, 2005; Knops, et al., 2005b; Larson & Tobin, 2000; O'Gara & Fairhurst, 2004;

Steinhauser, et al., 2001; Tulsky, 2005; Weissman, 2004; Wenrich, et al., 2003; Wright, et al., 1996). Narrative accounts of chronic illness experiences often include descriptions of conflicts and problems encountered by the narrator and/or other characters in the story. Such tensions imply gaps between the narrator's experience (her/his understanding), the way s/he would like it to be, and/or believes it should be (Sharf & Vanderford, 2003)--the right-and-wrong of it according to the story-teller. This sort of narrated evaluation reflects individual beliefs, value systems, and experiences (Wright, et al., 1996) that are so relevant to healthcare decision-making. Listening for these moral dimensions in stories can help clinicians identify relevant underlying values and assumptions influencing the goals of the participants. Active listening helps develop understanding of the dilemma as the patient and family see it, that is to find "common ground" (Bergum & Dossetor, 2005).

Advance care planning in chronic illness.

Important considerations come from advance care planning research in the context of uncertainty management and chronic illness as discussed in the previous sections of this chapter. The importance of focusing on *patients* and/or *their intimate others' uncertainties* rather than those of clinicians cannot be overstated (Hines, 2001; Hines, et al., 2001). This means that clinicians must be aware of the personal uncertainties most likely to sabotage advance care planning, including things like prognostic difficulties, time constraints, concern for the patient's hope, and lack of confidence regarding communication skills and/or dealing with painful emotions. This awareness may enable a movement toward being honest/open and more genuine with patients/intimate others about such uncertainties to strengthen trust. Further to this there is a the need for timely advance care planning discussions framed in terms of topics the patient/family want to discuss as well as their preferred type of decision-making (Heyland, et al., 2006; Heyland, et al., 2009; Heyland, et al., 2003). A discussion sensitive to individual patient/intimate others' goals, beliefs, values, needs, hope(s) and whatever uncertainties/vulnerability these represent is the ideal.

Second is a need to focus on the *patient/family context* rather than that of patient/clinician, a principle that embodies respect for the patient as "person" with an

ongoing life story and significant relationships (Hines, 2001; Hines, et al., 2001).
Applying this principle to advance care planning means including the patient's substitute
decision-maker (and/or any others the patient wants) provided s/he is comfortable with
this idea. This recommendation implies a concern for choosing a venue that maximizes
patient/family comfort, which may involve moving outside of clinics and hospitals to a
community setting like the patient's home. Third is the need to *be attentive to relevant*
process-related uncertainties that may be engendered by a free-floating, open-ended
discussion focused on unpredictable illness crisis (Hines, 2001; Hines, et al., 2001). For
patients/intimate others uncomfortable with the idea of advance care planning and this
sort of approach generally, establishing clearly delineated conversational boundaries may
help. Imposing limits through the use of print materials like hospital-generated advance
care planning information booklets and advance directive templates may provide a sense
of security for those intimidated by the thought of a completely open-ended discussion.
Additionally, ensuring these discussions take place within an environment of appropriate
psychosocial and/or spiritual support may also make them more acceptable (Hines, 2001;
Hines, et al., 2001).

Related to this is the need for clinicians to *acknowledge the uncomfortable nature*
of implications/uncertainties associated with advance care planning, that in fact some
aspects of end-of-life uncertainties are not amenable to reduction or easy management
(Hines, 2001). Fears related to worsening dyspnea, increasing dependence, isolation,
relationship changes, dying, and death are a major part of late stage COPD (Booth, et al.,
2006; Curtis, 2006; Goodridge, 2006; Rocker & Hernandez, 2005; Rocker, et al., 2009;
Seamark, et al., 2004; Simpson & Rocker, 2008a; Simpson & Rocker, 2008b; Simpson,
et al., 2010). Dyspnea is unpredictable and often refractory despite clinicians' best efforts
to the contrary (Curtis, et al., 2005a; Goodridge, et al., 2008; Heyland, et al., 2006;
Heyland, et al., 2005; Murray, et al., 2006; Pinnock, et al., 2011; Rocker & Hernandez,
2005; Rocker, et al., 2008; Rocker, et al., 2009). This uncertainty calls for clinician
genuineness and a stance characterized by being "present" to the patient and her/his
intimate others through active listening, empathy, and accessible, timely psychosocial/
spiritual support. Finally there is the need to *acknowledge and accommodate the*
likelihood of change in perspective, uncertainties, preferences, and openness to the topic

as illness progresses (Hines, 2001; Hines, et al., 2001). It is important to help patients/intimate others understand that the discussion and decisions can be revisited and revised. This implies that advance care planning is a recurrent process, not a one-time crisis-oriented event. Together with principles drawn from the patient-centred care model, these uncertainty-oriented principles provided the theoretical scaffolding for the advance care planning approach used in the study.

Chapter Summary

Currently COPD is a source of significant suffering worldwide, projected to be the third leading cause of death by 2020 (Buist, et al., 2007; Mannino & Buist, 2007). It is a chronic terminal condition with a protracted, highly unpredictable downward trajectory interspersed with frightening episodes of breathlessness and increasingly frequent exacerbations that can result in hospital/ICU admission and/or death (Bailey, 2004b; Cully, et al., 2006; Goodridge, 2006; Rocker, et al., 2007). Patients report high rates of anxiety, depression, and poor quality of life as they become increasingly dependent, socially isolated, and functionally compromised (Bailey, 2004b; Boyle, 2009; Brenes, 2003; Burgess, et al., 2005; Cully, et al., 2006; Hasson, et al., 2008; Hill, et al., 2008; Kaptein, et al., 2009; Maurer, et al., 2008; Ng, et al., 2007). The lives of intimate others are also negatively impacted by anxiety, social isolation, and patients' increasing dependence (Boyle, 2009; Simpson & Rocker, 2008a; Simpson, et al., 2010). Formal care tends to be episodic, targeted to acute exacerbations, and delivered in hospital settings despite clear needs for care that is ongoing, community-based, and inclusive of psychosocial and spiritual concerns (Goodridge, et al., 2009; Rocker, et al., 2008; Rocker, et al., 2009; Simpson & Rocker, 2008b). Patients with advanced COPD receive little opportunity to plan goals of care for end-stage illness despite research to show many are willing and want to do so (Heyland, et al., 2006; Heyland, et al., 2009; Reinke, et al., 2011). At the end of life, many COPD patients experience poorly controlled breathlessness and/or pain, a loss of capacity to participate in making care decisions, and interventions that are contrary to their care preferences (Goodridge, et al., 2008; Goodridge, et al., 2009). Intimate others may be asked to make decisions regarding life-sustaining interventions at such a time, but often without the benefit of any previous discussion of the patient's preferences or related values (Briggs, 2004; Briggs, et al.,

2004; Evans, et al., 2009; Hines, et al., 2001; Sudore & Fried, 2010; Sudore, et al., 2008). Despite the clear need for advance care planning for these patients, if it occurs at all, it often takes the form of a single discussion at the time of an illness crisis.

Advance care planning is a comprehensive process of ongoing discussions about patient and family preferences for care at the end-of-life. However, patients and their intimate others only infrequently are invited to participate in such discussions, despite the potentially negative impact of such deficiencies on end-of-life care decision-making and satisfaction with care (Crawford, 2010; Goodridge, et al., 2009; Reinke, et al., 2011; Spence, et al., 2009). A significant number of clinicians resist discussing prognosis and related goals of care with these patients and their intimate others due to pervasive uncertainties, one of which concerns the potential for eroding patients' hope (Crawford, 2010; Goodridge, et al., 2009; Reinke, et al., 2011; Spence, et al., 2009). If implications of terminal prognosis are not part of the goals of care discussion in advanced illness, patients and their substitute-decision-makers/intimate others lack information to enable an informed reconsideration of care-related values, hopes, and preferences. Too often crisis decision-making during emotionally charged illness exacerbations is the norm in advanced COPD.

Advance care planning research done using the theoretical lens of "problematic integration" (Babrow, 1992, 2001b; Babrow & Mattson, 2003; Brashers, 2001; Hines, 2001; Hines, et al., 2001) has produced a number of recommendations for those seeking to develop a more efficacious approach to advance care planning in chronic illness settings. Contributions from this, and ethics-related research, suggest a revised approach to advance care planning should start with engaging patients and their intimate others in conversation in a setting that is comfortable and not intimidating for them. Creating a hospitable environment whether this occurs within a clinical or community setting seems to be an important part of engaging in effective advance care planning.

Clinicians often assume uncertainty is a negative factor and reducible when in fact neither may be true. Some uncertainty may be considered positive in that it allows for hope; some uncertainty is not amenable to reduction, such as figuring out when death will occur in COPD. Instead of asking patients to list preferences for specific life-sustaining interventions based on possible scenarios that may or may not happen, exploring their

values, hopes, fears, and quality of life indicators may yield a more stable sort of information for guiding substitute decision-makers and clinicians making end-of-life care decisions. The approach should be one based on skilled patient-centred communication in which clinicians listen more than they talk, look for emotional, social, and spiritual as well as physical cues, and seek patients' and their intimate others' preferences for information sharing and decision-making. Such an approach would include an invitation for them to share their illness experiences and related hope(s), particularly as these concern care already received, ongoing therapeutic relationships, and expectations for future care. It should acknowledge the existence of multiple, sometimes conflicting uncertainties, seeking to identify those that are important to the patient. These discussions need to happen between patients, their intimate others, and/or substitute decision-makers as the people most likely to be called on to make decisions for the patient at the time of crisis (when COPD patients are less likely to have decision-making capacity). Part of the focus should be on aspects that are somewhat more certain such as how to choose a substitute decision-maker and how much authority the patient wants the substitute decision-maker to have in making the final decisions.

There has been a tendency to approach advance care planning as a completely open-ended process, but the nature of the topic combined with the high level of illness and end-of-life uncertainty provide rationale for adding some degree of structure to the process. Decision-aids or templates such as hospital generated patient information booklets related to advance care planning policies, process, and content may help alleviate uncertainty for some with respect to what needs to be discussed and how to go about it. Finally, it is necessary to make advance care planning a periodic and ongoing process responsive to changing patient priorities and uncertainties at different stages of illness. Designed in this way, the continuing evaluative nature of advance care planning makes it well suited to the uncertainties inherent in chronic terminal conditions like advanced COPD. Some communication theorists postulate that it is exactly these uncertainties that must be explored with patients during advance care planning if it is to truly reflect their concerns and preferences (Knops, et al., 2005b). Timeliness and relevance are important considerations in initiating patient-centred advance care planning.

Respecting Choices[(R)] and models based on "stage of change" theory offer some guidance for those interested in initiating advance care planning discussions with patients and their intimate others/substitute decision-makers (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Sudore, et al., 2008; Westley & Briggs, 2004). However, they use a clinical setting, have less focus on hope (patient's, intimate others', and/or clinician's), lack attention to contextual features like social determinants of health, and appear to rely on a relatively proscriptive structure aimed at moving patients toward documenting care preferences. Certain features of the advanced COPD context made these models less appropriate. Many of those living with advanced COPD find it very difficult to travel to and from clinic appointments, and many feel forgotten, ignored, and mistrustful of the healthcare system in any case. As well, clinicians have significant time constraints in such settings. Hope as a potentially key element of coping for these patients and intimate others as well as a source of concern for clinicians contemplating advance care planning makes it an important focus in these discussions. And finally, the prevalence and effects of negative social determinants of health in the lives of those living with COPD requires particular attention within any approach to advance care planning in this context.

Chapter Three: Methodology and Method

Interpretive Description

Interpretive description was developed to answer the "compelling, complex and contextually embedded questions" that are relevant to clinical practice settings (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 2). It is a qualitative approach employing both description and interpretation to improve understanding of a clinical phenomenon. It is appropriate to use interpretive description when a researcher wants to

> *locate the particular within the general, the state within the process, and the subjectivity of experience within the commonly understood and objectively realized conventions that contemporary health contexts represent as the temporal and symbolic locations for health and illness. (Thorne, et al., 2004, p. 3)*

The theoretical basis of interpretive description draws from grounded theory, naturalistic enquiry, ethnography, and phenomenology. The philosophical basis has an interpretive naturalistic orientation, where the emphasis is on the social construction of experience and knowledge. While from this perspective experience is viewed as being constructed and situated (Harding, 1991; Harroway, 1988; Jack, 2008; Jonsdottir, 2007), there are also identifiable commonalities across its various expressions. The value of interpretive description lies in its capacity to capture the practice-relevant particularities of these individual "lived experiences" as well as broader commonalities or themes across them (Ravenscroft, 2005; Thorne, 2008; Thorne, et al., 2004). Thus understanding "lived experience" as it relates to a particular phenomenon of interest--in this case more effective advance care planning in the context of advanced COPD--is a primary focus of interpretive description.

> *"Lived experience researchers study reality as it is seen and lived by the participants. They try to uncover the meaning that events and occurrences have for the participants and how they give meaning to their situation" (de Casterle, et al., 2011, p. 234).*

Physicians tend to interpret disease in terms of biomedicine, its patho-physiological and biochemical manifestations, whereas patients experience it as "illness,"

that is, the "lived experience of dwelling, embodying a lifeworld filled with relationships, concerns and salient distinctions and meanings" (Sunvisson, Habermann, Weiss, & Benner, 2009, p. 242) affected by that disease. Thus research that focuses on understanding lived experience of illness can help clinicians respond in ways that are more relevant to patients' actual concerns (Greenfield & Jensen, 2010). Interpretive description as a way to enhance our understanding of this lived experience employs several interconnected processes: describing, interpreting, and relating.

Thorne (2008) speaks of "describing" as a way of "telling what one observed" (p.47). It is not about theory testing, model building, or relationship proving. Rather researchers report what they saw/heard while they were collecting data on the phenomenon of interest. It is a report about the "what," not the "why" or "how" of that phenomenon. Despite a tendency to downplay the usefulness of such approaches, description has significant potential for expanding healthcare knowledge when thoughtfully chosen and appropriately carried out.

> *For the health field, description is and will remain an extremely important element in bringing phenomena to the awareness of our colleagues, in creating an empirical basis from which new questions can be generated, and for taking note of the manifestations of the complex and messy world of human health and illness. (Thorne, 2008, p. 48)*

But description is just the first step in studies using interpretive description. Moving to interpretation enables the researcher to grapple with the "so what" question that these descriptions inevitably prompt. "The clinical mind tends not to be satisfied with "pure" description, but rather seeks to discover associations, relationships, and patterns within the phenomenon that has been described" (Thorne, 2008, p. 50).

"Interpreting" is about making sense of what the researcher observes and records in the descriptive phase. Interpretation attempts to address questions about possible meanings of the described observations from a clinical perspective. Put simply, describing is about observing and documenting, while interpreting is about 'sense-making.' Interpreting involves inductive reasoning, a type of logic that moves outward from specific occurrences to various possibilities for understanding those occurrences in a more abstract and general sense. Such sense-making efforts begin on some level the

moment the researcher steps into the first data collection session. In interview or focus group sessions, all the participants, including the researcher, work to make sense of what is happening as the talk evolves (Eide & Kahn, 2008; Jack, 2008; Jonsdottir, 2007; Ravenscroft, 2005). More formal interpretive engagement occurs as the researcher works with whatever data (text, audio, video and/or photo) is generated from this talk, often via transcription of audio-recordings, hand-written notes, and/or the researcher's field notes.

Interpretation involves a dialectic that moves between and among the available texts as a whole unit in light of their context, the researcher's history/experience, pre-understandings, and other contextual influences such as the relevant literature (Alvesson & Skoldberg, 2005; Koch, 1996; Lindseth & Norberg, 2004; Wiklund, Lindholm, & Lindström, 2002). Termed the "hermeneutic circle" this dialectic is envisioned as a spiral movement. The researcher moves back and forth between viewing and developing insight into the study encounter in its entirety and its constituent parts, the relationship between these, and its influential context and theoretical frames of reference (Alvesson & Skoldberg, 2005; Wiklund, et al., 2002). The dialectic also moves between the researcher's understanding of the encounter as co-created with participants during the interaction and any pre-understandings or assumptions that have influenced the evolution of this understanding. As the interpretation progresses the researcher begins to develop a new, revised, or richer understanding of the phenomenon. This is facilitated by the researcher staying open to the dialectic process, attentive to various pre-understandings, theoretical pre-suppositions, contextual factors (personal, professional, clinical, and the participants'), and the unfolding material as presented and interpreted (Thorne, 2008). Interpretation involves a consideration of possible meanings of patterns suggested by the commonalities and particularities identified during the data analysis. As well, Thorne (2008) suggests that combining description and interpretation commits researchers to an approach of working

> *within the world of studying instances and integrating what [they] learn about them with [their] reflective clinical reasoning process, searching for underlying meanings that might further illuminate what is happening and develop a deeper appreciation toward what would ultimately be the optimal clinical response. (p.50)*

Thus, interpretation done well leads into the final process, "relating," in which potential implications and proposed meanings are considered in light of current clinical practice. The ultimate goal of interpretive description to improve clinical practice is brought back into focus through this process of relating and reconfiguring. From a more concrete perspective, analysis in interpretive description is accomplished through processes of coding, developing themes, identifying patterns, and postulating meanings that make sense of them given the particular illness context under study. Constant comparison and iterative techniques are employed in this process as codes are refined and emerging patterns explored. Potential meanings that connect findings back to theoretical and clinical frameworks are viewed from the larger perspective of what is already known about the phenomenon. An iterative inductive process, it begins with a close-up view and through a series of transforming moves that gradually distances but retain connection to that original view, may enable a new practice-relevant perspective to emerge.

Interpretive description: appropriateness for this study.

Interpretative description is well suited to the study goal and phenomenon of interest. Thorne (2008) describes interpretive description as

> *a qualitative research approach that requires an integrity of purpose deriving from two sources: (1) an actual practice goal, and (2) an understanding of what we do and don't know on the basis of the available empirical evidence (from all sources). (p.35)*

Consistent with Thorne's description, the overarching goal in initiating this research concerns the enhancement of a *clinical practice* related to doing advance care planning with patients and intimate others living with advanced COPD. The study approach is based on theory and recommendations from previous research, which satisfies the second condition in the quote. Interpretive description relies on participants' lived experience as the primary source for enhanced understanding of the phenomenon of interest. The study considered individuals living with advanced COPD as most knowledgeable about this experience and thus the best resource for enriching clinical insight into the "what" and "how" of *meaningful, effective* advance care planning in this context. Thus study data is

text generated from researcher-facilitated advance care planning dialogue with patients/intimate others and their feedback concerning their experience of this dialogue.

As a research methodology interpretive description seeks to enhance clinical practice by accommodating significant particularities as well as commonalities within participants' lived experience of the phenomenon of interest. It "allows for shared realities, but also acknowledges the constructed and contextual nature of the health-illness experience." (Ravenscroft, 2005, p. 504) The phenomenon of interest in this study had a highly personal focus (end-of-life care goals/values) as well as a broader professional one (enhancing end-of-life care decision-making in advanced COPD). This combination of personal and professional interests necessitated a research methodology able to identify what mattered to individual participants as well as factors with significant clinical implications common to all or most participants. Finally, interpretive description also allows for "contextual" influences to be preserved and respected. The method acknowledges the role of the researcher as a research tool. The researcher is considered a co-creator of the study dialogue with participants. Pre-understandings, theory, and previous experience are considered important influences for interpretation and overall analysis. Session surroundings and participants' histories, beliefs, relationships, cultural and community ties are all considered important in interpreting and making sense of the findings. For all of these reasons interpretive description was considered an appropriate methodological choice for this study.

Applying interpretive description.

Interpretive description begins with the researcher becoming familiar with current literature relevant to the phenomenon of interest. This provides an initial analytic framework to guide study design, recruitment, and preliminary analysis decisions (Thorne, 2008; Thorne, et al., 2004). Study participants are usually recruited according to a purposive strategy shaped by the theoretical basis of the study's phenomenon of interest. In the case of this study, the phenomenon of interest was meaningful and effective advance care planning in the context of advanced COPD. Consequently, participants were: a) individuals identified as being in later stages of COPD by their physicians according to Canadian Thoracic Society (CTS) criteria, and, b) the intimate

other identified by each patient who agreed to be in the study. Researchers using interpretive description methodology often collect data via participant interviews, focus groups, observation, and/or written materials. Interview data are then transcribed to written text to simplify the analysis. Field notes generated by the researcher during and following interactions with participants are also considered in the analysis.

Data analysis in interpretive description.

As the analysis proceeds, researchers use inductive reasoning, influenced by the theoretical background of the study as well as their own clinical experience to identify and begin coding segments of data. Coding involves marking segments of text—single words, phrases, a paragraph, or longer sections—that catch the attention of the researcher. Some authors refer to these as "meaning units"—segments that stand out to the researcher for some reason (Henricson, Segesten, Berglund, & Maatta, 2009; Lindseth & Norberg, 2004; Upton & Reed, 2006). *A priori* codes are based on the researcher's experience or selected from categories drawn from previous theory, while others, *in vivo* codes, are generated from actual wording found within the materials being analyzed (Bazeley, 2007, p. 76). Thus as Thorne (2004) suggests, "the earliest stage has to do with recognizing the nature and shape of the theoretical scaffolding that has been used to construct the study, and gradually taking distance from it as alternative conceptual emphases and intrigues arise" (p. 10).

Codes are labels attached to these "remarkable" segments of text as a way of highlighting and also easily finding them again. Coding records the first step of the inductive reasoning process as data are transformed through the attachment of these labels. While some of the codes arise from the background pertaining to the study, the researcher must be open to recognizing instances where the data present something entirely new that demands a purely inductive response. To track this process and maintain a sense of how their thinking is evolving, researchers make notes or "memos" that include the working or provisional definition, any related thoughts and/or comments linked to the referent segment of text. This process continues until all the text has been read, significant sections/words coded, and repeated passes through the data do not generate further revisions of codes or memos. To consider similarities, overlap, adequacy

of definitions, and possible revisions as more data are added, researchers use an iterative process to compare codes to themselves and one another within and across texts. As a consequence, codes continue to evolve through initial selection, definition, revision, redefinition, merging, and/or splitting. A record of this evolution is kept via memos and/or notes linked to the codes so that the researcher is able to track the developing thought processes behind this evolution as analysis continues. It is important to maintain a broad focus through the initial coding run, and then begin to recode and redefine more precisely as patterns begin to emerge, seeking the exceptions, anomalies, occurrences that do not fit readily into the patterns identified.

Once all the data have been considered and coding passes have been completed, the researcher begins to systematically explore for commonalities and particularities reflected in the codes within and across sessions. Groupings of codes are formed on the basis of perceived commonalities to yield provisional "themes." Pre-understandings arising from prior experience, literature review, and contextual factors must be monitored by the researcher because of their influence on the development of these codes and themes. Emerging themes may arise in a single session or may cross multiple participants/sessions. As potential themes are identified they foster further thinking and revision of existing codes and other themes, which fuels an ongoing, iterative, interpretive dynamic. The task of the analyst becomes one of engaging "in a dialectic between theory and the data, avoiding theoretical imposition on the one hand, and atheoretical description on the other" (Thorne, et al., 2004, p. 11). Thus the analysis seeks new understandings, but without losing sight of the relevant clinical context.

Analysis continues with the consideration of potential relationships between/among various themes in an effort to identify and make sense of any recurring patterns. Positing possible meanings implied by these patterns concerns itself with the context of the sessions first and then moves out into the clinical context that gave rise to the study question. As part of this sense-making process, the researcher pays particular attention to occurrences that do not seem to fit, exceptional or contrary circumstances for which alternative understandings seem to be required. Once there is an understanding that accommodates the apparent tensions as well as the identified patterns, the researcher

must configure it in terms of current clinical knowledge. Reporting the findings in terms of potentially relevant clinical implications is the important last step.

Researcher as research tool.

In interpretive description the researcher is viewed as an integral part of the research process. This perspective encompasses everything from identifying the issue to be investigated, choosing how to phrase the question, designing the study, collecting and analyzing data, collating and discussing findings, drawing conclusions, to writing related reports (Thorne, 2008).

> *Because, as a researcher, your mind and your personhood are integrally*
> *involved in what you will accomplish, it is only with some honest reflection on*
> *these elements that you can ensure that the research products you generate are*
> *true to your purpose and become meaningful empirical contributions. (Thorne,*
> *2008, p. 64)*

This call to "honest reflection" on the part of the researcher demands s/he consider theoretical allegiances related to the study, location within a professional discipline, and personal relationship to ideas/philosophical stances/values held (Thorne, 2008). Each researcher is encouraged to "locate" her/himself with reference to these factors.

Reflecting on my 'location' vis-à-vis this study, several perspectives are relevant. I am keenly interested in relational, experiential, communication-related care issues and am drawn to relational care theory that promotes and champions patient/family-centered care approaches. This has implications for how I understand therapeutic relationship and communication in healthcare, with particular relevance to advance care planning approaches. I have had personal experience with the effects of advanced chronic co-morbidities having watched my father struggle and ultimately die with complications of congestive heart failure, COPD/asthma, and cirrhosis. My mother is currently living with gradually declining quality of life secondary to peripheral vascular disease, COPD, and frailty. My professional experience as a hospital-based spiritual care practitioner with patients and their intimate others living with COPD sensitized me to the suffering engendered by advanced COPD and frequently associated co-morbidities. This suffering

was complicated by the readily apparent, seemingly unnecessary gaps in end-of-life planning and care for those most affected.

Since September 2010 I have been part of a Capital Health based collaborative team (INSPIRED) that provides in-home self-management education, support, and advance care planning post-hospital discharge to patients and their intimate others living with advanced COPD. In this capacity I have facilitated a number of advance care planning discussions with patients and families and have provided ongoing emotional and spiritual support as they struggle to come to terms with their inevitable, but unpredictable downward course. I have witnessed first-hand the illness-related suffering, the sadness, guilt, shame, anger, depression, fear, anxiety, and/or concern about burdening their loved ones. I have also marveled at their gritty determination and resilience in the face of significant social, emotional, physical, and cognitive losses. Their deep appreciation for these sessions despite the uncomfortable focus is an important reminder to me of the vulnerability and loneliness associated with this illness because of social isolation, inadequate resources, and fragmentation of care. My heart goes out to these people and I am more motivated than ever to find ways to enhance care in line with their needs as they see them.

As for professional discipline, I locate myself most recently within the profession of hospital-based spiritual care, but my background includes some experience with formal medical training and allied health education. My education in spiritual care included a one-year residency in Clinical Pastoral Education (CPE), which focused on developing self-awareness, reflective practice, and provision of psychosocial/spiritual support. The other requirement for certification was 2000 hours of direct service including emergency 'on call,' which I fulfilled on General Medicine units and the ER of the hospital where I am currently employed. My earliest module of CPE took place at the Nova Scotia Psychiatric Hospital where I worked with a community-based out-patient and a hospital in-patient service. For a number of years I coordinated the Clinical Ethics Consultation support service for the hospital system in which I work. In this position, I participated in numerous consults related to end-of-life care dilemmas arising from inadequate advance care planning. The suffering experienced in these situations often seemed preventable with better, more proactive communication. The lack of this sort of

communication seems indefensible. For the past five years I have helped coordinate a number of qualitative studies exploring intimate others' vulnerability in the context of advanced COPD. This has further heightened my awareness of incredible gaps in care for these patients and their intimate others. Thus my pre-understandings and experience favour efforts to enhance relational, collaborative, experiential, and dialogical approaches to care for these patients and their families.

Finally from the perspective of my professional training, I try to help patients and their intimate others manage and make sense of their experience of living with disease effects. Thus I work in the area of illness experience. From this vantage point, it seems the current crisis-driven acute care approach to COPD potentiates certain gaps in care for those living with illness. I see their lack of access to palliative and supportive care as inequitable, and I continue to seek options to redress needless suffering. I embrace a feminist perspective that acknowledges clinicians, by virtue of our professional expertise and status, occupy a position of power and influence with respect to patients and their intimate others. This puts the onus on us when it comes to initiating dialogue, ensuring understanding, and facilitating decision-making that will be truly collaborative. My approach to dialogue is thus influenced by my training and experience in hospital chaplaincy, my background in health education, medicine, and qualitative health research, my feminist and relational care ethics perspectives, and my experience. All of this will influence to some degree how I engage patients and their intimate others in advance care planning discussions as well as my perspective for interpreting the data collected from these encounters.

Study Procedure

The study was designed to address the research question: *What is required for meaningful and effective advance care planning in the context of advanced COPD?* This complex question gave rise to a three-fold purpose: a) to engage patients and their chosen intimate others jointly in advance care planning discussion with a skilled facilitator and solicit their feedback, b) to understand content and process of the resulting engagement, and c) to develop a model based on these findings to guide advance care planning efforts and related research in this clinical context. This purpose led to four actionable objectives: a) to explore participants' experience of advanced COPD especially in terms

of hope, fear, and uncertainty, b) to gain insight into the dialectic of living and dying with COPD, c) to provide an opportunity for participants to consider, discuss, and/or document their advance care planning values/preferences, and d) to solicit participant feedback on this process. The design was also guided by the need for a process sensitive enough to identify and respond to individual patients and their intimate others' needs, but with sufficient consistency to provide a framework broadly applicable across all participants. I sought a process with potential for addressing the gaps in clinical practice in this area by addressing clinicians' concerns regarding communication skills, timing, hope, and time and venue constraints.

The study objectives were pursued through a procedure that included:

- designing an approach to the advance care planning discussion based on principles of patient-centred, relational care, and recommendations arising from advance care planning research using Problematic Integration communication theory (Babrow, 2001b)

- developing a conversation guide that covered diagnosis, changes in quality of life, hope, fear, death, dying, and end-of-life care and decision-making preferences (Appendix B)

- meeting with each patient and intimate other at their home or elsewhere when they chose to begin the discussion

- an initial focus on putting them at ease and reviewing informed consent principles

- fostering rapport, trust, and a good therapeutic relationship through sensitive relational communication based on active listening, empathy, genuineness, and unconditional positive regard

- creating an advance care planning framework responsive to individual needs and readiness

- providing individually relevant information, including the March 2007 CDHA Patient and Family Education brochure, "Let's Talk about Advance Directives," (Appendix B)

- helping clarify and/or document preferences/values related to end-of-life care and/or decision-making

- soliciting feedback on the discussions - timing, duration, content, approach, facilitator, suggestions for change, any other comments

- offering additional help or referral(s) related to advance care planning and/or current care, when this is desired and permission granted

- closing the discussion and the therapeutic relationship sensitively

- assessing the need for additional sessions

- collaborating with participants' healthcare team as requested/needed

- making field notes following each session
- audio-recording and transcribing study sessions

The intention was to collect data over two or three sessions, with the understanding that each family's situation/needs would determine the number of advance care planning sessions. These sessions included elements of both conducting and evaluating the advance care planning process. The approach drew on Babrow's (2001b) "problematic integration" theory, the healthcare ethics literature (Beauchamp & Childress, 2001; Bergum & Dossetor, 2005; Kinlaw, 2005; Sherwin, et al., 1998) as well as the clinical expertise of the researcher. Several principles drawn from these areas informed the initial approach within an overarching theme of patient-centeredness. The enactment of patient-centeredness in advance care planning depends on:

- attending to the "whole person" with concern for person/family values, meaning, and both "disease" and "illness" dimensions. Advance care planning encompasses "family" or the person's "intimate others" however defined by the person (Hudson, et al., 2011).

- therapeutic relationship, characterized by presence, active listening, and empathy that encourage the necessary rapport, trust, and relational engagement. Other "common factors" such as genuineness, self-disclosure and authenticity are also important aspects of the therapeutic relationship (Briggs, 2004; Epstein, et al., 2010; Hudson, et al., 2011; McCormack, et al., 2011; Saha, et al., 2008; Street, Makoul, Arora, & Epstein, 2009).

- a cooperative, flexible process that is adaptable to the person's needs and respectful of culture and context (Klessig, 1992; Saha, et al., 2008; Searight & Gafford, 2005; Turner, 2005)

- sensitivity and clinical skill to engage with hope and to address the uncertainties and distress that can arise in advance care planning discussions (Casarett & Quill, 2007; Clayton, Butow, Arnold, & Tattersall, 2005; Clayton, et al., 2008; Curtis, et al., 2008; Davison & Simpson, 2006; Eliott & Olver, 2007; Fan, 2005; Feudtner, 2005; Flaskas, 2007; Kylma, Duggleby, Cooper, & Molander, 2009b; Mack, et al., 2007)

- attention to, and respect for, dignity and self-worth, including needs for privacy and/or confidentiality. The clinician actively works to reduce the power differential that is inherent in the person/health professional relationship (Beach, Duggan, Cassell, & Geller, 2007; Bergum & Dossetor, 2005; Chochinov, 2006; Chochinov, et al., 2004; Woods, 2005).

Each of these requirements helped guide the development of the study procedure.

Sampling.

Study participants were recruited according to a purposive sampling approach (Thorne, 2008).

> *The strategy of purposive sampling is to try to identify, in advance of the study, the main groupings or conditions that you will want to have ensured you include in your study so that the eventual findings you produce have the potential of ringing true or seeming reasonable to your intended audience (Thorne, 2008, pp. 90-91).*

Silverman (2005) points out that it is appropriate for qualitative researchers to use purposive sampling to maximize the potential for recruiting participants who have sufficient experience of the phenomenon of interest for a given study. Thus qualitative researchers logically seek participants from groups and in settings where individuals with the necessary experience are most likely to be found. In purposive samples, participants are, by definition, chosen according to some common criteria relevant to the phenomenon of interest. Because the phenomenon of interest in this case was the "what" and "how" of effective advance care planning in the context of advanced COPD, I considered patients and an intimate other living with late stage COPD as the target population for recruitment. Previous research has recommended patients' family members be included in advance care planning. The final sample was eight patients and seven intimate others. The study group included eight patients with a primary diagnosis of COPD in an advanced stage according to Canadian Thoracic Society (CTS) severity criteria (see inclusion criteria section below). Each patient then named an intimate other (the person most involved in their daily care at home), but in the case of the fourth patient this person was away for several months and thus not able to participate.

Inclusion/exclusion criteria.

Inclusion criteria were defined as:

1. Severe COPD, with a Medical Research Council (MRC) score of 3-5. (O'Donnell, et al., 2004). These criteria include shortness of breath causing the patient to stop walking after 100 meters or a few minutes on the level, along with at least one the following:

    - body mass index (BMI) less than 21 (BMI < 21)

- post-bronchodilator forced expiratory volume at one second (FEV_1) less than 30% of the predicted value ($FEV_1 < 30\%$ predicted)
- one or more hospital admissions for acute exacerbation of COPD in the previous year

At this level of COPD severity, patients had an estimated life expectancy of greater than 6 months, but an overall expected risk of mortality less than or equal to 50% within 12-24 months of study entry.

2. Residing in the Capital Health District, Halifax, Nova Scotia, or within the Horizon Health Network - Zone 2, Saint John, New Brunswick.

3. Patients admitted to hospital with an acute exacerbation of COPD, or those recovering from an admission to an intensive care unit with or without mechanical ventilation, were also eligible, if after a follow up clinic assessment (within 4-8 weeks of hospital discharge) they agreed to participate.

4. An ability to speak and understand English.

5. Patients and/or intimate others free of cognitive or other difficulties that precluded in depth conversation.

Information concerning the patient's COPD severity score was noted in the transcripts related to the each family to provide relevant additional context.

Recruitment.

Respirologist physicians and registered respiratory therapists identified patients who met the CTS-specified inclusion criteria outlined in the previous section. They described the study to prospective participants and asked if they were willing to be contacted regarding the study. They also explained that if a patient chose to participate s/he would be asked to name one "intimate other" (spouse, other family member, friend, or individual most involved with daily supportive care) to take part as well. In Halifax, specialist physicians mentioned the study to four qualifying patients during their visits to the outpatient Respirology clinics at the QEII Health Sciences Centre. I followed up with these prospective study participants. Three agreed to proceed with the informed consent process and named an intimate other to participate as well; one patient was feeling quite unwell and opted not to take part. In New Brunswick, a respiratory therapist with the Extramural Program, Horizon Health Network - Zone 2, Saint John, explained the study to five prospective patients. All expressed an interest in participating and she followed up with them to identify an intimate other in each case and have them all complete the informed consent process.

Informed consent.

Because patients were recruited in two sites, two Research Ethics Boards (REBs) approved the study and consent form (Appendix A)--the Capital Health REB in Halifax, NS, and the Atlantic Health Sciences Centre REB in NB. In Nova Scotia, I called each of the four patients and intimate others who had indicated a desire to participate and given permission to be contacted. I arranged to meet with each of the three patients and intimate others who chose to complete the informed consent process. I then met with each patient and intimate other in the patient's home to discuss the study further, giving them an opportunity to ask questions and/or request more information about the study. For the one Nova Scotia patient who said he could not read or write I went over the consent orally with him, answered his questions, and followed up to check for understanding before asking him to initial it. I also reviewed the form orally with the second Nova Scotia patient when he explained his difficulty with reading comprehension. His intimate other had been called away for a family emergency in another province and thus was not present for the informed consent process and ultimately did not participate in the study. The participants chose to have me begin the initial phase of the study intervention immediately following the consent process rather than schedule another date.

The recruiting respiratory therapist completed the consent process with each of the ten participants from the Extramural Program, Horizon Health Network - Zone 2, Saint John, New Brunswick. She contacted each patient and intimate other by phone and arranged to meet with them to discuss the study, their questions and concerns, and have them sign the consent forms if they chose to participate. At this time, she also set up an appointment for me to meet with them to begin the initial phase of the study intervention. Having the local respiratory therapist complete the informed consent process was a logistical decision made to optimize the use of time and finances—if after going over the consent forms a patient and/or intimate other chose not to participate, I was saved the expense and time of a trip to New Brunswick. In the case of New Brunswick participants, I phoned them to schedule the date, time, and venue of the first study session to be convenient for them. In every case, the venue was the patient's home.

Participants.

Throughout the following chapters study participants are identified using their assigned study code. For example, the first patient is referred to as "P1," the intimate other for that patient is "C1," and that family is "F1."

Table 1. Characteristics of Participants

Study ID	Pt Sex	Pt Age	Marital Status	IO	Home Context	SES	Educ	Comor	MRC	Dur (yrs)	O$_2$	ICU
F1	M	71	M	S	R	L	JH	Y	5	>5	Y	Y
F2	F	76	D	D	U	<L	HS	Y	5	>5	Y	N
F3	M	66	W	D	U	<L	E	N	5	>10	N	N
F4	M	69	M	S	S	L	JH	N	4	9	N	N
F5	M	70+	M	S	R	L	E	Y	5	17	Y	Y
F6	F	66	M	S	R	L	JH	Y	4+	>4	Y	N
F7	F	66	M	S	R	<L	E	Y	5	7	Y	Y
F8	F	53	M	S	R	<L	HS	Y	5	15	Y	Y

<u>Key</u>: **Study ID** – F# = family identification code; **Sex** - M = male, F = female; **Marital status**: M = married, D = divorced, W = widow/er; **IO** = intimate other relationship to patient: S = spouse, D = daughter; **Home context**: U = urban, S = suburban, R = rural; **SES** – socioeconomic level: L = low (< $25,000), <L = very low (< $15,000); **Educ** – education level: E = elementary school, JH = junior high school, HS = high school; **Comor** – comorbidity: illness(es) other than COPD: Y = yes, N = no; **MRC** – Medical Research Council criteria for COPD severity (1 – 5, 5 being worst); **Dur** – Duration of COPD; **O$_2$** - oxygen: Y = yes, N = no; **ICU** – previous admission to intensive care: Y = yes, N = no

As Table 1 indicates, participants included four female and four male patients; two lived in a city, one in a suburban area, the rest were rural dwellers. They ranged in age from 53 to 76 and their COPD severity was staged as advanced (MRC 4-5), although a few were clearly at a more advanced stage than the others. Most were on long-term oxygen therapy, lived with complicating co-morbid conditions, and half had had at least one ICU admission. In two cases their co-morbid condition was cancer, which worried them more than the COPD. The intimate others were adult daughters in two cases (C2, C3) and

spouses in all others, three female (C1, C4, C5) and three male (C6, C7, C8). All the participants were Caucasian; none of the patients were currently employed. Most had worked at one time but were now retired due to age or illness. One intimate other (C2) was still working. They all had less than post secondary education and most did not finish high school. One (P3) was functionally illiterate (could not read or write) and one (P4) had difficulty with reading. While all were living at a low socioeconomic level with incomes less than $25,000 per year, four families lived on less than $15,000 per year. The five New Brunswick families were receiving ongoing healthcare support through the Extramural Program, Horizon Health Network - Zone 2, Saint John, community outreach team. The three Nova Scotia families had no comparable health service.

Data collection.

The study "sessions" were conceived of and facilitated as advance care planning discussions (*intervention*), not as traditional research interviews (*data collection*). The intervention consisted of me facilitating advance care planning discussions with each patient and her/his named intimate other. The research consisted of analyzing the data resulting from these study sessions. Details about the intervention and how the data was collected are described in the following sections under the headings: venue, timing, and process.

Venue.

All but one of the advance care planning discussions took place in participants' homes. I offered to meet with participants in their homes if they preferred to make things easier and more comfortable for them, and all welcomed this option. The one exception was the second session with the first family, which took place in a small conference room at their local hospital because the patient had chosen to delay his discharge from hospital by one day. Two of the three Nova Scotia patients were urban/suburban; the third lived in a rural area about 45 minutes outside the city. One New Brunswick patient lived in an urban area, one in a small town, and the other three in a rural area not far from that town.

Timing.

The study sessions were scheduled for a time convenient for the participants as much as possible. I arranged the first two New Brunswick sessions for one week in the spring of 2009; the follow-up sessions were delayed by several weeks due to P1's hospital admission for pneumonia and COPD exacerbation. The other three New Brunswick sessions took place in the late fall about six months later, with three days between the first and second sessions. Study sessions with F3 and F4 in Nova Scotia took place between mid and late October 2009 with a week to ten days between the first and second sessions. I visited with F8 in early December 2009 and there was a three-day interval between our two conversations. On average the sessions lasted about an hour, although I spent as much as two hours in the first session with two families and as little as 25 minutes in the second session with one family.

Logistics.

The study process included two sessions with each group of participants, and thus 16 sessions in all. I made field notes immediately following each study session. These notes included a description of physical surroundings, and my observations, feelings, thoughts, questions, and plans for the subsequent session. Prior to meeting the patient/ intimate other the second time I reviewed the field notes to help plan my approach to this next discussion. I noted highlights and anything requiring further clarification or review for inclusion in the second session.

The 'intervention' consisted of four loosely structured phases--an introduction and then three more "formal" (recorded) phases--spread across the study sessions. These latter three phases were digitally audio-recorded and later transferred to CDs to be transcribed. This electronic data was stored in password-protected computer files; CDs were stored in a locked cabinet along with copies of participants' signed consent forms. The data recorded during the 16 study discussion sessions resulted in 13 transcripts and 16 sets of field notes. Three of the 16 audio-recordings were poor quality due to technical issues; they were not included in the analysis.

Intervention.

The "intervention" involved initiating an advance care planning-related discussion adapted to the needs and circumstances of each patient and her/his intimate other(s). This discussion was designed to cover a number of topics and proceed through four loosely structured phases over one, two, three, or more sessions. Attention to participants' comfort (physical, emotional, social, spiritual) was also a focus throughout the sessions so that I could provide appropriate support when I discerned it was needed. This was psychosocial and spiritual support in the form of empathy, validation of feelings and views, affirmation, and soliciting and actively listening for hopes, suffering, distress and uncertainties, all within my scope of professional practice as a certified specialist in Spiritual Care. To do this well I needed to identify which topics/uncertainties patients/intimate others found relevant. I felt that by probing for and understanding their priorities, I would be able to adapt the conversational pace and advance care planning to suit their needs. Although I initially had allowed for three or four sessions with each family, it quickly became apparent to me that two was adequate and much more feasible for all of us. Because I could not anticipate how many sessions might be required in each case, I did not plan their structure beyond the semi-structured conversation guide. However, I realized four process-related "phases"--introduction, content, feedback, and closure--developed across the two sessions with each family. These flowed quite naturally into one another without any clear transitions between them.

Introduction phase.

At the start of the first session we spent time getting to know one another. I explained the study background along with my connection to and interest in it. Participants asked questions and shared thoughts as we explored mutual interests. The conversation in this early phase ranged over topics such as family pets (where applicable), pictures or other mementoes in evidence, family, aspects of the surroundings, or my trip to the participants' home. Usually one or more of these ideas would result in the patient or intimate other responding in more depth or with questions or a story of her/his own, which led to their increasing engagement in the discussion. The hope was that this sort of "ice-breaker" would be enough to enable a sense of rapport to begin to develop. I spent time on and was intentional about this focus to relieve any anxiety and to

increase their comfort. Thus the initial phase was the sort of informal, socially-oriented "back-and-forth" interaction that tends to occur when strangers find themselves thrown together for a purpose. That purpose from my perspective was to begin to establish the rapport and trust needed for a positive and comfortable therapeutic relationship. I asked participants about why they had chosen to take part in the study as a way to begin to hear about their values, what sort of things mattered to and motivated them. Most of them spoke in terms of altruism, viewing the study as a chance to "give back" by potentially helping others living with COPD.

Content phase.

When our conversation seemed to be flowing easily and participants appeared to be comfortable with the study process and with me, I eased us into the more formal aspects of the intervention. This began with me turning on the digital recorder. I then asked them what it was like to be living with COPD, how it had changed their lives, and what they found hardest now, questions from the conversation guide (Appendix B) adapted for the study. The topics were based on my own experience from previous studies with patients and intimate others living with advanced COPD and on those described in studies based on the *Respecting Choices*[(R)] model (Briggs, 2004; Briggs, et al., 2004). My intention was to use the conversation guide to begin the discussion and as a way to ensure that as it continued we would cover the topics other researchers considered most relevant for advance care planning. My goal was to encourage a free-flowing patient/family-centred conversation focused on what participants wanted to discuss; I did not want to impose a particular agenda by rigidly following a conversation guide. However, I also wanted to ensure as complete a consideration of potential COPD-related end-of-life implications as possible over the course of the unfolding discussion. Although the order of the topics varied depending on what sort of segues emerged, all conversation guide topics were eventually covered over the course of two study sessions with participants.

Advance care planning as currently practiced often consists of a minimal "code status" discussion in the midst of a stressful emergency situation, which can significantly limit informed choice, the ethics principle foundational to the entire project. Initiating these discussions in advance of illness crises is one aspect of addressing the problem, but

equally important is offering relevant information to allow patients and families to more adequately consider the nature of the decisions they may be facing as well as their values and preferences related to these issues and to the decision-making process itself. Thus I felt it was important to provide relevant information about COPD and the sort of end-of-life scenarios common in this illness as appropriate to the participants' situations. As well, in response to participants' questions/desires I offered information about life-sustaining interventions, goals of care, ethics, and legalities related to decision-making and advance care planning. Together with psychosocial and spiritual support, providing this information was well within my professional scope of practice, training, and experience. While these aspects added complexity to my roles as discussion facilitator and researcher, I felt they were key to my stated goal of helping "individual clinicians and teams working in this context [COPD] conduct more timely and meaningful advance care planning interactions with patients and families." (p.3)

I left a copy of the March 2007 version of the Capital District Health Authority Patient and Family Education brochure, "Let's Talk about Advance Directives," (Appendix C) with participants when they seemed ready. If during the first session we discussed dying/death and their preferences for end-of-life care, I left the brochure with them at the end of the session. If it became evident they were not ready for an in-depth discussion of this sort during the first session I waited until the end of the second session to leave the brochure. By the end of the second session each participant had received a copy of this resource. If I left it with them at the end of the first session, I referred back to it during the second to check for understanding and whether further discussion was needed/desired, to answer any questions, and assist with filling in the template if they wanted help with this.

Participants' responses to the initial questions from the conversation guide along with my follow-up responses led to a dynamic, uniquely unfolding dialogue. I made use of naturally occurring segues--participants' spontaneous references to worsening symptoms, frustration, anxiety, associated losses, experiences with dying/death--to gradually move this dialogue toward a consideration of hope(s), worries, fears, and eventually dying, and their end-of-life care values, goals, and preferences. I framed these topics in line with each patient/intimate others' particular needs as discerned from clues

contained in their stories, questions, exchanges, emotions, and surroundings. As they spoke, I was attentive to what each one was saying and how they were saying it, their interactions with each other, pauses, silences, and demonstrated emotion. I tried to gently bring into the conversation those who tended to say less or be dominated by the other speaker, but in a way that was respectful of their preferred mode of interacting.

At the start of the second session I spent a few minutes re-familiarizing participants with the process and giving a brief review of what we had talked about during our first meeting. I asked them for feedback, thoughts, and/or comments about that or anything significant that may have occurred between sessions. Issues to be clarified or reviewed were raised and discussed further. The focus in this session was to ensure participants had adequate opportunity to revisit or consider values and/or views related to worsening COPD, dying, end-of-life care options and their preferred decision-making process. By the end of the second session, all participants appeared to be satisfied that we had sufficiently addressed the advance care planning topic and thus I felt a third session was unnecessary. I made this decision based on participants' apparent needs/desires and the quality of our discussions with respect to clarifying their values/preferences related to advance care planning-related decision-making, interventions, and/or documentation. In keeping with the patient-centred focus of the study, it was important for me to encourage them to share their concerns and/or advance care plans with their primary care or specialist clinician(s). I considered follow-up within participants' own circle of care as the most appropriate option for accommodating advance care planning changes that could develop as the illness progressed. I could not ensure their treating clinicians would be up-to-date on participants' end-of-life care values, goals, and/or preferences, but I felt it was important to mention this to the patients and their intimate others.

Feedback phase.

Toward the end of the final (second) session with each patient and intimate other I solicited their feedback concerning the discussion and our time together. I asked them what the experience had been like for them and prompted them concerning their feelings about our discussion as well as their views on: the number, duration, and format of the sessions, the venue, me as facilitator (my style; a non-physician clinician versus their own physician), and any suggestions for improving the sessions.

Closure phase.

Given the emotional and intense nature of the some of the topics we discussed and the therapeutic relationship that developed, I felt it was important to facilitate appropriate closure at the end of each session. Finding a way to gradually de-escalate the emotional intensity of the talk without leaving participants feeling abandoned was my aim in this phase. Spontaneous pauses occurring later in a session provided natural breaks that enabled a shift to lighter topics and eventually back to the sort of informal "small" talk with which we had begun. This functioned to bring the process full circle in each session. I wanted participants to feel supported throughout the sessions and not to feel that after a set time the session was over regardless of where we were in the discussion or how they were feeling. This meant that although I anticipated sessions lasting about an hour, some were longer and others shorter depending on the stage of the discussion and participants' emotional vulnerability.

Closure in the second session was somewhat different than in the first. The second session was different because it included the participant feedback phase. I indicated to participants that we had reached the final part of our time together, and that this would entail me asking for their feedback on the discussions and sessions overall. Phrasing this in terms of "the last part of the study" helped participants understand the sessions were coming to a close. The second session was also different because participants knew I would not be returning to resume the discussion as I had following the first session. There was more emotion, more sharing, and a lingering at the end of the second session that did not occur in the first. I concluded the second session by thanking patients/intimate others for their participation and offering to send a summary of the study findings if they were interested. All indicated a desire to receive the summary and six of the eight families invited me to stop in for a visit anytime I was in their area. I detected on their part as well as on mine a reluctance to say 'good-bye' knowing we were unlikely to cross paths again and feeling the loss of what had become in most cases a very warm relationship.

Summary of study procedure.

The study procedure involved both an advance care planning 'intervention' and an evaluation provided through solicited participant feedback. All participants completed an informed consent process. A specialist physician or respiratory therapist from the patients' circle of care mentioned the study to prospective participants explaining that it would involve several sessions to discuss their illness experience and preferences concerning end-of-life care. They were asked to name an intimate other regularly involved in their informal care to participate in these discussions as a way to have a more inclusive dialogue. The offer was made to have the facilitator conduct the discussions in patients' homes as a way to add to their comfort, decrease formality, and thus help offset the power differential. As facilitator, I focused on encouraging the participants to talk about the effects of COPD in their lives, what they were hoping for, their worries and fears, and concerns for the future including those related to death and dying. I provided emotional and spiritual support and offered information related to their illness, potential end-of-life scenarios, life-sustaining treatment options, goals of care, ethics and legal issues related to advance care planning and decision-making in response to participants needs/desires. Establishing a trusting, supportive relationship to encourage reflection on experiences, fears, and hopes was considered key to fostering an effective, meaningful advance care planning discussion. Thus the study had a dual thrust--clinical practice and research--that involved significant potential for role conflict as the sessions progressed. This dynamic is discussed further in the sections on Rigor, Reflexivity, and Ethics toward the end of this chapter.

Analysis

Although data analysis is presented as a number of discrete steps, this is an artificial separation for the purposes of clarity. Generally speaking, the steps describe mutually informing, iterative aspects of two underlying phases: description and interpretation. Description was a process of sorting and documenting pertinent contextual details, segments of dialogue, observations, notes, and thoughts to provide a sense of the "what" of the study encounters. Interpretation, a process for making sense of that description, involved inductive reasoning that moved between study sessions within and across families and sessions to generate meaning pertinent to clinical practice. These

processes included coding data, identifying themes and patterns of commonalities, exploring significant particularities, creating potential units of meaning, and relating these potential meanings back to the clinical context of doing advance care planning in advanced COPD.

The first step in the formal analysis was transcription of the audio files. I transcribed the first four audio-recordings. A professional transcriptionist transcribed the other nine. I then reviewed each transcript while listening to the original audio-recording to correct transcription errors. My doctoral thesis supervisor also reviewed a sample of study transcripts to check for fidelity to the research design and assess whether changes to the process were indicated. I then reviewed my field notes from each session in conjunction with the transcripts and audio-recordings. This process was repeated several times for each study session. Each transcript was entered into the Atlas.ti$^{©}$ software program in the order the study sessions occurred, but keeping each family set together. Each data set, represented as an electronic "document" by the software, underwent the first step of coding. This involved reading the transcript and notes with a view to "content," which included topics discussed, participants' questions, concerns, explicit motivations, and any other issues that seemed significant either because of their frequency of appearance, associated emotion, or uniqueness.

In this first phase of analysis, codes were attached as broad categories that reflected topics from the conversation guide such as illness-related experiences and concerns, end-of-life concerns, hopes, uncertainties, and fears. The electronic "memo" function of the Atlas.ti$^{®}$ software was used to keep a list of codes with the date and a detailed working definition of each one along with any related thoughts, questions, or concerns. This code list was expanded as needed in response to each transcript that was added as part of the coding pass. Some codes were split, others merged, and others merely revised as more and more data was brought into the analysis. Electronic memos were revised to reflect these changes and to record the inductive reasoning process indicated by the revisions. Once all the sessions had undergone an initial coding pass, a second pass was initiated to refine broad codes into more descriptive, discriminatory codes. Examples of more refined codes include "shortness of breath," "mobility," "appetite," and "burden" for "illness concerns," and "ventilation" and "suffering" for

"end-of-life concerns." This evolution was also tracked by up-dating the relevant electronic memos and the resulting code list. My first attempt at analyzing the transcripts stopped here and produced findings that were limited to the "description" step of interpretive description. My committee's feedback on these results prompted me to return to the analysis and take it much further using a particular focus based on my purpose of providing some insight into how advance care planning might be improved in clinical practice.

Thus the next analytic step was done from the perspective of "process" rather than "content." Segments that illustrated principles underlying the design of the study advance care planning approach (principles from patient-centred care, relational care ethics, advance care planning and problematic integration theory) were coded as such. For example, codes such as "active listening," "empathy," and "witnessing" were attached to segments that reflected these strategies on my part. Some new codes, such as "education" and "literacy issues" were developed during this step as well to track process dynamics that seemed important to how the session unfolded but were not already captured in the code list. As with the more content related codes, process codes were refined during additional passes through the data and these revisions were tracked using the software memo function.

Following completion of the more descriptive coding phase, analysis continued with a review of the codes to identify possible patterns and connections between and among them. Grouping them into "thematic networks" (Attride-Stirling, 2001) based on identified common threads was the next step. Discerning commonalities among certain codes suggested a grouping to generate a theme. Such themes were then grouped based on patterns of recurrence in the data and implications generated by these associations explored for meaning. The underlying process of developing thematic networks was described by Attride-Stirling (2001) who organized the approach using *basic, organizing,* and *global* themes. According to Attride-Sterling (2001) a "basic theme" exemplifies a simple characteristic found in the data. It requires the broader context supplied by its related "organizing theme" to provide a sense of connection to and meaning within the data beyond itself. A group of related basic themes give rise to an organizing theme based on a meaning thread that ties them together. Thus an organizing theme provides a clue to

the meaning and assumptions underlying the grouping of basic themes associated with it. Representing a more abstract level of analysis than basic themes it implies more about the texts as a whole. A "global theme," based on groupings of "organizing themes," represents a yet more abstract and integrative level of interpretation. Global themes interpret and gather together primary ideas that make up recurring patterns in a given text. "Each Global Theme is the core of a thematic network" (Attride-Stirling, 2001, p. 389). As part of this process fragments of coded data that stand out by virtue of not fitting within identified themes or networks also must be considered. A configuration of the data that yields a reasonable potential meaning for study findings is one that makes sense of particularities as well as identified commonalities. In this study, the final step of the analysis after the thematic network was developed was to discuss the implications of this potential meaning for clinical practice related to effective advance care planning dialogue with those living with advanced COPD.

Inductive reasoning, the basis of these steps, was tracked using electronic notes and memos. Initial choices of codes, revisions and additions to codes, particular groupings of codes to form themes, networks, and patterns formed the substance of these notes and memos. Examples of these are included in the next chapter reporting the study findings. Reasoning about what thematic groupings might mean concerning the "what" and/or "how" of effective advance care planning in the COPD context was critical to enriching insight into what might improve clinical practice in this area. My "location," pertinent theoretical background, and new angles suggested by the themes, patterns, and relevant particularities identified in the data all influenced this reasoning process. The following chapters describe the "what" and "how" of the findings arising from this reasoning process along with relevant contextual detail.

Supervision

Because this study was designed as part of a doctoral program, my supervisor and doctoral committee were involved throughout the research process from initial design and analysis approach to the final write-up. My supervisor read a sample of the study session transcripts to monitor how these encounters were unfolding, fidelity to research design, and the nature of the intervention and evaluation. She reviewed early drafts of findings to

provide feedback on my approach to the analysis and the entire committee contributed to this effort as the research progressed. Their input was shaped by their diverse clinical, educational, and research expertise, all of which broadened my perspective, sharpened the analytic focus, and resulted in a more in-depth, practical, and relevant analysis of the study sessions. It also resulted in the realization that the third element of my initial purpose, "c) to develop a model based on these findings to guide advance care planning efforts and related research in this clinical context" was actually beyond the scope of the study given the small sample. While it is important to acknowledge this departure from the original purpose, this is not unusual in qualitative research which evolves in response to data collection. This change in the study does not undermine or detract from the value of the research findings I report in the following chapters.

Rigor

Different qualitative approaches require different understandings of rigor. However, rigor tends to be considered in terms of credibility, applicability, and trustworthiness of the reported results and the appropriateness of the method used to collect and analyze the data to answer the research question (Koch, 1995, 1996). For this study, I addressed issues of rigor in keeping with my chosen method as informed by interpretive description (Unger, 2005).

In the case of qualitative research findings intended to have currency within the clinical context, Miller and Crabtree (2003) suggest rigor should be judged by three criteria contained in the question: Is it methodologically, rhetorically, and clinically convincing? In terms of methodology I have tried to make explicit how an interpretive description framework is well suited to answering the research question related to this particular phenomenon of interest (Koch, 1996; W. L. Miller & Crabtree, 2003; Wright, 2003). I have aimed for transparency in the study process and analysis, including how the study was carried out, my location and values (pre-understandings), and other factors such as theoretical commitments that may have influenced how I answered the research question. My study procedures including memos, journaling, methodological decisions and revisions, plans for analysis, and interpretive frameworks have been clearly described.

To enable better understanding of the interpretive framework, the study context has been described in detail and includes clearly described conditions of data generation. Working from an interpretive framework, it has also been important for me to explain adequately the theory and process of interpretation and the factors that affected this—my pre-understandings, participants' stories, cultural, social, and historical influences, and interpretive dynamics. Miller and Crabtree (2003) suggest the following checklist of five questions to guide this methodological assessment:

- Is the method appropriate for the question?
- Is the sampling adequate and information rich?
- Is the research process iterative?
- Is the interpretive process thorough and explained?
- Is reflexivity addressed?

In terms of rhetorical credibility, readers should be able to assess the believability of the researcher's interpretation of the lived experience of the participants. Here the "logic of argumentation" is the focus rather than the more empirical "logic of validation" (Alvesson & Skoldberg, 2005, p. 104). Finally, a clinically convincing story is one that makes clinical sense to readers. It should address a question that is of interest to clinicians, include the wider audience as stakeholders for whom the results should also matter, and describe clearly any research presuppositions related to physical/behavioral, social/emotional, cultural/historical, or spiritual aspects of clinical participants' bodies, lives, and/or power (Miller & Crabtree, 2003). Wiklund et al (2002) put this in terms of the value of the study and its findings for motivating change of practice—the need to address the 'so what' question.

Attention to reflexivity is also important when considering rigor in qualitative research, particularly those applying interpretive paradigms.

> *Reflexivity or reflexive analysis is the process by which the researcher evaluates the self as the data collection instrument and analyzes the influence of personal and professional values, beliefs, and experiences that impinge on the research. (Jack, 2008, p. 60)*

As previously mentioned, qualitative inquiries using interpretive description consider that the researcher inserts her/himself into the study and therefore assumes participant status

within the research process. With this comes a certain authority claim that must be continually examined within the framework of the study as consent, data, and interpretations are negotiated (Alvesson & Skoldberg, 2005). There is a need to constantly guard against 'either/or' dichotomous or polarized thinking in favour of preserving a more open stance willing to balance harmony with difference, pattern with particularity (Alvesson & Skoldberg, 2005). The researcher's awareness and acknowledgment of her/his contributions, interpretive lenses, and preferences within this process have major implications for how the study findings will be received, judged, and reinterpreted by readers of the study report.

An example of the importance of reflexivity arose early in my research as I contemplated how I should introduce myself to study participants (Jack, 2008). Given that I am an ordained priest in the Anglican tradition, a former chaplain, a doctoral candidate and researcher, and have worked in health education, I realized that how I introduced myself to study participants could impact the dynamic of the ensuing research sessions (Jack, 2008). Participants' understanding of and previous history with each of these "roles" could influence their reaction to me and the study in general, thus affecting the rapport, trust, and relationship we might develop over the course of the sessions and the nature of data collected. In the end I opted to introduce myself as a PhD student at Dalhousie University because this seemed most relevant to my purpose for being in their homes. Some asked for more details as the sessions and research relationship progressed, and in these cases I shared more of my professional history and the basis of my research interest with them.

Interpretive approaches like interpretive description rely heavily on the development of strong relational rapport and trust between researcher and participants (Eide & Kahn, 2008; Jack, 2008). It is this relationship that permits the collection of sufficiently rich data to support in-depth analysis and the emergence of new insights into the phenomenon of interest (CIHR, NSERC, & SSHERC, 2010; Jack, 2008). This increases the onus on the researcher to be aware of the nature of the relationship that s/he encourages during the research process, and to maintain this awareness throughout the analysis and reporting of findings. Qualitative researchers who are clinicians must also acknowledge the potential for role conflict arising from competing demands between

their research role and their professional obligation to "care," especially in the case of study participants who may be ill, vulnerable, and/or marginalized (Eide & Kahn, 2008; Jack, 2008).

It is well recognized that dilemmas can also arise from the inherently therapeutic dimension of qualitative interviews, and that this can add a layer of complexity to the data and its interpretation.

> *Interviews represent a fundamentally social process and performance that involves interpersonal contact and dialog that may lead to a different type and level of meaning for the participant that he or she would not discover with personal reflection only. The making of meaning is an inherently therapeutic activity as well as a qualitative research activity; this caring concept therefore bridges the line that some authors attempt to draw between researcher and participant. (Eide & Kahn, 2008, p. 202)*

As participants begin to feel sufficiently comfortable with a researcher they know to be a clinician, they may seek his/her assistance with clinical issues. Even if these requests fall within the researcher's area of clinical expertise, the traditional view of the need for an "objective" research stance might prevent the researcher from intervening (Jack, 2008). Therefore there is a need for researchers to reflect on the potential for this sort of situation in order to decide whether/how they will respond in such cases.

> *It is clear from the literature that how to deal with the therapeutic dimensions that can emerge from the qualitative research relationship is an area of some contention and diversity of opinion. (Eide & Kahn, 2008)*

Several authors have highlighted this issue as a source of significant and ongoing ethics-related debate concerning qualitative research in general and clinically oriented researchers in particular (Eide & Kahn, 2008; Jack, 2008). Seeking insight into the lived experience of human beings requires the establishment of a relationship of sufficient trust between seeker and teller to facilitate a level of in-depth sharing (Eide & Kahn, 2008; Jack, 2008; Jonsdottir, 2007). Being present to, witnessing, responding sensitively are activities common to particular qualitative research approaches as they are to particular caring professions (Eide & Kahn, 2008). One author capitalized on this overlap by

employing a "research-as-if-practice" approach in her study to explore participants' experience of a partnership nursing approach to self-management in the context of COPD (Jonsdottir, 2007). Her study illustrates an ethical, patient/family centred approach that effectively straddled the research and clinician roles and produced significant outcomes for clinical practice. My study design is similar in that the intervention aspect also straddles the research and professional caring roles, with an ultimate goal that is also similar--to positively affect clinical practice. That my plan was to err on the side of care provision when participants sought my help was appropriate given both the patient/family-centred relational care ethics principals that were the foundation of the study, the intervention, and my professional background in spiritual care, health education, and clinically-related practice.

Ethics

Ethical awareness is a significant component of the relational integrity of qualitative research with respect to the interests of study participants and the authenticity of study findings, and reflexivity/role conflict. Working to safeguard the interests of participants is a central ethic of good research. In cases where participants are particularly vulnerable, such as may be the case for participants living with a chronic terminal illness such as COPD, researchers must seek a delicate balance in furthering the interests of future patients seeking clinical care while caring well for current study participants. Any consideration of research ethics in a context of 'vulnerable' populations must concern itself with the power differential that exists by virtue of the authority vested in the role of the researcher. Because the 'expertise' aspect of the researcher's role brings with it a particular status and authority, the researcher must take particular care that study participants do not feel unduly pressured, manipulated, or coerced to take part or to answer questions they are uncomfortable with, or in a way they think will please the researcher. As well, researchers must guard against imposing their own cultural biases and standards via the study design, types of questions posed, the way they are phrased, or how results are framed (Miczo, 2003). Miczo makes the point that while issues of power and status should not be overlooked, research interviewing may actually provide a venue for so called 'vulnerable' participants to enhance their sense of purpose and status.

Many chronic illness patients are suffering, and suffering profoundly, but giving them a voice and agency means that we cannot ignore their ability to manipulate language through the selective telling of stories. Such tellings are, in fact, a crucial part of the struggle to contest medical meanings, to educate others of the effects of rejection and social isolation, or even spit in the face of their own feelings of vulnerability. (Miczo, 2003, p. 487)

This was an important consideration for me as a researcher working within the context of advanced COPD, which tends to impose increasing social isolation and a sense of stigma on patients and their intimate others.

Working with participants experiencing advanced terminal illness and asking them to discuss topics such as hope, uncertainty, and end-of-life care planning can result in emotional intensity and/or increased distress. Participants' needs were foremost in guiding how the conversations and interviews unfolded. Beginning with the informed consent process, I tried to help participants understand the purpose of the study, what would be involved for them if they chose to take part (time commitment, the risks and benefits, effects on their care), their freedom to choose to take part or not, refuse to answer one or more of the study questions, withdraw at any time without prejudicing their care, and that they could contact me or their physician with questions or concerns at any time prior to or during the study. Providing and stressing assurance that their care would not be jeopardized in any way no matter what views or decisions they disclosed during the research was particularly important in this study. Because I asked participants to share their experience of the healthcare system and its employees, and because such sharing might have revealed real gaps or inefficiencies in the system, they needed to be able to trust that nothing they told me would in any way affect their future care at the hands of that same system. Although the subject matter was not necessarily comfortable for participants to consider, research interviews of this nature are known to have potentially therapeutic effects by virtue of the inherently healing nature of active listening—having the opportunity to have one's story heard and appreciated (Cooper-White, 2007; Emanuel, Fairclough, Wolfe, & Emanuel, 2004; Lo, Quill, & Tulsky, 1999; Street, et al., 2009; Weingarten, 2000, 2010; Wright, 2003).

The "caring" focus of the study approach to advance care planning required some blurring of professional boundaries from the perspective of research versus intervention. The study was designed to have both intervention and evaluation dimensions. The emotionally demanding nature of advance care planning, particularly in the setting of advanced COPD where patients and their intimate others often feel isolated, abandoned, and vulnerable, mandated that I provide appropriate psychosocial and spiritual support to the study participants as needed. My training and certification as a spiritual care practitioner helped me monitor and balance these two aspects throughout the study sessions. The qualitative approach chosen for the study was also consistent with this "participant-centred" dynamic.

As researcher, I had to keep an ethical focus clearly in the forefront throughout the study, particularly as bioethics and relational care ethics were central components of the theoretical background for this study. These ethical models require participants' experiences and needs to be the primary focus in the process. As previously mentioned, I understood this to privilege my clinical role over my research role if there was conflict between the two. Using an interpretive methodology, I was committed to seeking an understanding of participants' experience with advanced COPD in terms of hope, uncertainty, and advance care planning. In our time together I engaged them in conversation to explore the dialectic of living and dying with this illness, and because I wanted to bring a relational care ethics lens to this process, I sought to negotiate this conversation on their terms. Part of this negotiation was influenced by dynamics inherent in joint interviewing which mandate ongoing attention to respect for participants' relational concerns and relational autonomy. I made clear from the outset the joint conversation elements of the study design so that participants had a chance to consider this and make a decision based on their willingness to engage in conversations of this sort. I also was cognizant of and attentive to individual participants' comfort level within the unfolding joint discussion context. Patients' concerns to protect intimate others from any adverse effects of discussing what were often emotionally intense issues and the intimate others' similar desires were important dynamics that I tried to respect during these encounters.

With respect to safeguarding the authenticity of study findings, Alvesson and Skoldberg (2005) believe qualitative researchers must be particularly attentive to this aspect of ethical integrity.

> *Ethical awareness is all the more important in a research climate, where the clear-cut distinction between data (empirical material) has been impugned, data are seen as theory-laden, reality as socially constructed, and the boundary between fiction and non-fiction is being dissolved into narration and rhetoric. (p.263)*

Data collection and analysis procedures had to be consistent with the epistemological and methodological foundations of the study. The data, or text of the advance care planning conversations in this instance, and how this is gathered, textualized, analyzed, extrapolated, and reported all have ethical implications related to the authenticity and professionalism of the research. In this case my data collection via a series of conversations was consistent with an exploration of lived experience according to interpretive description methodology. My analysis of the interview material is described as completely and transparently as possible. I kept a record of my ongoing reflections on both the process as it unfolded, was revised, and documented, and my observations, feelings, thoughts, pre-understandings, and theoretical links as these relate to the study content. Ethical research implies a commitment to competence and transparency, both of which have been addressed in the previous section on "Rigor."

Wright & Flemons (2002) summarize the issues that can sharpen a researcher's ethical focus. They suggest that every researcher working in the area of interpretive studies on end-of-life issues should:

- Put respondents' needs first, and therefore make the necessary effort to discover what these needs are
- Recognize the impossible tension between self and other as the study progresses
- Treat interviews like conversations (invitational, non-coercive interactions)
- Consider data analysis as a process of composing stories about respondents' stories, not reproducing respondents' original versions or meanings, i.e., creating meta-stories that reflect the uniqueness of individual participants' voices while weaving them contrapuntally (Wright & Flemons, 2002, p. 268).

To carry out this sort of approach in an ethical manner then required a commitment of time, an attitude of flexibility and comfort with uncertainty, as well as a willingness to think and write clearly, transparently, and responsibly. It also required a commitment to the process in its entirety, which included working with the data, my colleagues, and the participants, and enabling appropriate follow-up for them as needed (Wright & Flemons, 2002).

Summary

This was a qualitative study using "interpretive description" methodology. Fifteen participants (eight patients and seven intimate others) living with advanced COPD were recruited for the study, five in New Brunswick and three in Nova Scotia. Participants completed an informed consent process in their homes following which I facilitated two in-home discussions with them concerning their illness-related changes in quality of life, uncertainties, fears, hopes, and preferences related to end-of-life care and decision-making. In the final phase of the second session I asked for feedback about their experience of these discussions. Transcriptions of the digital audio recordings of these conversations along with my written field notes provided the basis for the subsequent data analysis.

Chapter Four: Findings

This chapter presents study findings beginning with a composite description of the physical surroundings in which the study sessions took place. This is followed by an overview of the analysis based on the description and interpretation I did aided by the Atlas.ti® qualitative software program. The resulting thematic network provides a summary of the way I identified and linked study themes together given the focus provided by participant feedback, patient-centred care principles, and the study question. The final step is relating these findings back to the clinical problem that gave rise to the study forms the basis of Chapter 5: Discussion. Portions of these findings have been published in: i) Simpson, C. Opportunity to Care? Preliminary insights from a qualitative study on advance care planning in advanced COPD. *Progress in Palliative Care* 2011; 19 (5):243, www.maney.co.uk/journals/ppc, www.ingentaconnect.com/content/maney/ppc, and ii) DOI 445897 Simpson, C. Advance Care Planning in COPD: Care versus "code status." *Chronic Respiratory Disease* 2012, in press.

Physical Surroundings

Participants' homes, besides being a place of comfort for them, provided clues about factors potentially affecting their lives as well as their engagement in and reaction to the study discussions. Awareness of contextual details of this sort and my emotional reactions to them were thus important considerations during the data analysis. Being in participants' homes was emotionally evocative for me during the study sessions and afterwards as I reflected on the interactions, made and reviewed my notes, listened to, read, and analyzed session transcripts. During each session I was bombarded with sights, sounds, and smells, all of which I registered and reacted to whether consciously or not. The majority of study participants were living and coping with very challenging circumstances beyond those imposed by their illness--challenges such as poverty, often described rather dispassionately as "negative determinants of health." Such terms put a rather clinical and sterile spin on something that feels anything but when it confronts your senses in person. For the most part participants' homes and lives differed markedly from my own experience, a situation that caused me to acknowledge and reflect on my feelings of tension and discomfort. I began to realize more fully the extent and influence of my

assumptions, pre-understandings, perspectives, and expectations, especially those related to the inherent privilege, power, and authority of my professional roles. The impact of this initially less-than-conscious material was akin to suddenly becoming aware of a dark shadow across proceedings. I was surprised by the intensity of it, but determined to explore it as potentially important factor in how our discussions evolved and my interpretation of them. I continued to reflect on the feelings and memories associated with these observations and my reactions to them as I analyzed data from transcripts and field notes.

This context accounted for some of the emotional nature and depth of my experience of the sessions, which has figured in the analysis and therefore is important for me to include as an aspect of the study findings. The following description is a composite generated from my memory and as well as details recorded in my field notes. It provides a generalized view of the surroundings in which the study sessions took place to minimize the risk that a reader might be able to identify any particular participant by recognizing a description of his/her home. While this choice means readers will not "see" the uniqueness of each family's surroundings, I hope it will be sufficiently evocative to help readers understand the role of context as a potential factor in developing sensitive advance care planning discussions.

Composite context

The visit took place in an older model mobile home surrounded by uncut grass at the edge of a country road far removed from other signs of habitation. The front entry way was a tunnel of loose sheets of clear plastic flapping frantically in a vain effort to diminish the incursion of wind and rain. After passing through a porch with a wood stove going full tilt I entered the kitchen and was confronted by missing cupboard doors, a few loose floor tiles, and a plastic ice cream bucket that was doubling as ashtray and spittoon. A variety of sights and smells, some comfortable and some less so, scrambled for my attention. The participants began by apologizing--for repairs or maintenance not done, for the general state of things including the housekeeping. The patient's health was severely compromised by COPD and often co-morbid conditions, but so too was the health of his intimate other, who was living with cancer, arthritis, diabetes, and a heart condition.

Despite evidence that things were not as they might once have been or as a participant might wish they were, home was a place of warmth, personalized by family photos and memorabilia of all sorts. Hospitality, pride, and perseverance were alive and well. I was touched by their willingness to open their homes to me, a total stranger coming to initiate potentially uncomfortable conversations. The combined challenges of poverty and illness on their surroundings and daily lives, the contrast with my own home and history, and their graciousness in the face of all this gave rise to twinges of dissonance and discomfort as the sessions unfolded. Conscious of these feelings, it still took me a while to acknowledge them, and the huge differences in our life experiences. I began to realize how much our homes and surroundings and reactions to them convey about us, and our life story. It struck me also how much of that story and the information it provides remains hidden in healthcare interactions limited to clinic or hospital venues.

Study sessions.

As implemented, the study ended up being two sessions with each family. Establishing rapport and a trusting relationship with the patient and intimate other was the main focus in the first session; the topics covered were of secondary importance. The first few minutes of this session were spent in purely social talk aimed at getting to know the family, discovering and exploring their interests and activities in an effort to minimize feelings of stress and foster greater comfort with the process and me. Burard (2003) refers to this type of interaction as "phatic communication," which "denote[s] speech as a means of sharing feelings or establishing sociability rather than for the communication of information and ideas" (Burnard, 2003, p. 678). Engaging participants in this sort of "small talk" was an effort to begin the process of establishing rapport and a relational connection between us. The length of this phase was a subjective decision based on my sense of how comfortable participants appeared to be feeling with me and the process. A conversation transition occurred when I switched on the digital recorder and introduced the first item from the conversation guide. I monitored participants' response to this first formal question as an indication of whether they were indeed ready for this transition. The "phatic" stage of each session was not recorded in the interests of beginning the interaction with as much informality and comfort as possible. The sort of topics discussed and total time spent varied from family to family, but in every case this phase was shorter

in the second session--it took less time to reach as good a comfort level as that in the first session. I monitored participants' sense of ease in the early phase of the first session and introduced transitions in topics based on my assessment of their readiness to move on. Readiness was an important factor in participants' comfort level, which varied with the topics being discussed and the pacing of transitions. For example, P1 and P8 were clearly more interested in discussing past and current illness concerns, and seemed reluctant to move into talking about planning for end-of-life care. The following quotation is taken from my field notes recorded immediately following the first session with F8.

> *P8 answered my explanation [about the study purpose to have patients and families consider advance care planning] with a quick "we don't talk about it!" I wasn't sure whether this statement meant she wanted to but didn't get asked or chose proactively not to go there – it turned out to be the latter, but that did not become clear until later in the session . . . As we worked through their experience with her declining health, her worsening COPD, a history of multiple and increasing admissions, she talked about believing she coped best by not thinking about what is coming or when 'that' might happen. She much prefers a "one day at a time" approach and said she would ask for any information she might want or need – thinking ahead about what might happen (or 'will happen'--and I think she is all too aware that it is more a probability than a possibility)[1] depresses her she said.*

From comments such as this, I discerned she was not ready for the more emotionally difficult topics of planning related to death/dying and left these for the second session. The two-session format thus allowed me more latitude with respect to decisions on how far/deep/quickly to push the discussion during the first session. Knowing there would be a second session meant I could take more time to build the necessary relationship with participants' and gauge their readiness/willingness to transition to what be more emotionally intense advance care planning considerations.

I viewed the first two items from the conversation guide--when the COPD diagnosis was made and COPD effects on their quality of life--as a way to initiate our

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P8 died less than 24 months after completing the study sessions

advance care planning discussion and thus were consistent features of the start of session one with each family. The following example of the beginning of the intervention is taken from session one with F7.

> *R: I'll be coming to see you two times, the first time will probably be a bit longer than the second one because this is the one where I'd like to get a little bit of your story, what the COPD has been like for you and how life has changed and that sort of thing, so if you can kind of think back and start at the beginning for me. If you remember when that was.*
>
> *P7: Ah, it's kind of hard to remember because I was always so busy that I was always short of breath, so . . .*

From this point the conversation followed a route unique to the context and responses of those taking part in it. In most cases (F2, F3, F4, F5, F6, F7) all the topics in the guide were touched on over the course of the first session as participants' responses and stories seemed to naturally lead into these topics.

The first session was an opportunity for participants to talk about experiences that provided me with important clues about their outlook and ways of coping, things that mattered to them, and how they expressed/dealt with deep feelings. These were important clues for discerning their readiness/ability to discuss the more difficult implications of advance care planning as well as how best to frame these topics to be relevant for them. P4 told the following story early in the first session in response to my comment about how frustrating it must be to have lost his job and many meaningful activities due to increasing breathlessness. His general demeanor during the sessions tended to be subdued and flat, but as he told this story his face became animated, his voice louder, and the usual pauses, stops and starts, were gone.

> *P4: Yeah, I'm not now, I forget what year it was, 2006 maybe, we decided, my wife and I decided we're going to take the grandson and ended up taking his girlfriend too, to Six Flags and so the driving is no problem, driving's good for me you know. And we drove up and we got the tickets along with our accommodations. It made it a lot cheaper. We got up to Six Flags and I couldn't do it. The heat was too much for me, the heat just killed me and I tried to, those water things, I tried to get up so I could get splashed or something. I got so far up the stairway and that was it. We had to stand back and watch and wait for the kids to, you know, to have their time, but we wasted two tickets . . . They could have gone another day and enjoyed themselves.*

This incident seemed to be a pivotal moment for him, perhaps the first time he glimpsed something of the longer-term implications of his illness. It was an incident that he used to respond to my comment about frustration and it illustrated for me as well a sense of his feelings of powerlessness and loss.

The second session with each family began with a reference back to an issue or topic from the first session. This seemed to quickly reinstitute the depth of discussion attained in the previous session. The following example comes from the start of session two with F7.

> R: I was really interested after we talked last time and I got thinking about what you said and right at the end remember we were talking about how it's really nice to have your story told, to leave your story and I wondered if in the telling of your story, what message would you want people to remember most?
>
> P7: Have faith and hope and if you need help ask for it, don't let your pride or your fear of crying and all that, don't let that turn you inside out, just try to live a little bit.
>
> R: Yes, no matter what happens?
>
> P7: No matter what happens.

Another dynamic in the second session was hearing more details of participants' experience with end of life situations. The following excerpt taken from the second session with F3 comes immediately after my explanation of CPR and the comment that it seldom works the way it is depicted on television.

> P3: it doesn't work like that . . . I know it . . . same like when I tried to save my wife's life.
>
> R: Yes . . . but you did a great job, because you kept her alive [P3: yep—kept her alive 'til the paramedics got here] Yeah, so you know it can work and that's important.
>
> P3: and how it doesn't . . . I tried and I tried.
>
> R: it's hard to lose somebody.

This memory and related sadness connected to a profoundly traumatic experience with CPR provided important clues to this man's loneliness, negative view of CPR, and preference for comfort care (and death) if his health status deteriorated.

Interestingly following the feedback conversation about their experience of the study discussions near the end of the second session, many participants returned to or continued with the advance care planning-related topics raised earlier in the session. For

some it was as if their comfort level to talk about advance care planning increased once the formal part of the session was over. The context of the following example taken from near the end of session two with P4 was the final question from me about whether there was other information (besides what had been discussed in the two sessions) that would have been helpful for him. P4 responded by saying he already knew quite a lot about COPD because of his brother's diagnosis and death. He then went on to share the story of his mother's COPD and his thoughts about the final stages of her illness, despite his earlier reluctance to consider or talk about dying or advance care planning.

> P4: Yeah, well, she got sicker and sicker because she wouldn't throw that cigarette away . . . but there comes a point in time when your health is such that . . . what's the point, you know . . . One guy I felt for, going to the . . . rehab thing there [pulmonary rehabilitation program]. . . a lad there who couldn't exercise without the oxygen at all but he didn't carry oxygen with him . . . but I said "That woman smoking . . . the other day when we left here, she just got outdoors and lit up a cigarette!" Yeah, he says, "well I smoke 16 a day" and I said "What! . . . man, and you have to take oxygen". . . and ah, yeah . . . he died not too long after that.

This particular story prompted him to talk about how "down" he had been feeling, an admission I was slow to pick up on despite several attempts by P4 to have me do so. This was a concern that was clearly weighing on him, and one he had not mentioned to his clinical team or else they had not recognized it as significant.

It seemed that many of the experiences participants shared near the end of the second session were prompted by responses they gave during their feedback about the study sessions. The immediate context of the following excerpt near the end of the second session is P7 saying she appreciated my approach of asking for her thoughts and not forcing her to face/admit that she is dying. She then shared several emotional stories about death and dying beginning with the following.

> P7: When I had heart failure back in 2003 in [city], I was laying in an emergency room up there and I was all by myself and I was scared and the nurse says to me she says, ah . . . do you want us to pull the plug . . . no how did you say that now . . . it's, do you want us to pull the plug . . .
>
> R: Yeah, pull the plug, basically . . . no resuscitation, or . . .
>
> P7: I said, I don't want nobody to murder me!! [R: no, no] . . . what a thing to be saying to somebody when they're laying there petrified because they can't breathe . . . wheezing and gasping for air, the sweat running off me, I'm all alone, there's nobody for me to talk to . . .

Hearing about these difficult experiences provided insight into her earlier reluctance to talk about or consider advance care planning implications. It also emphasized the importance of discerning and respecting participants' needs regarding the process of advance care planning conversations.

Summary of study sessions.

The first session involved an emphasis on building relationship; the second on advance care planning considerations. However the specifics of each session were also shaped by the participants' different contexts and needs; the conversations were co-created. While there were common threads for each session across families, there were also particularities that added to the personal relevance of the interaction for each family/participant.

Thematic network

The description phase of the analysis involved the coding passes that began with the transcript and field notes from the first session with the first family. The codes developed in this process were then refined, revised, and redefined through subsequent passes and as more transcripts and field notes were entered into the analysis. Once no new codes were identified and existing codes were settled, the formal interpretation phase began. To organize and make sense of the coded material, I used a thematic network approach beginning at the least abstract level where codes were grouped to form "basic themes." The next, more abstract level was to develop "organizing themes" based on identifying commonalities tying together groups of basic themes, and then moving up a level to postulate one or more global themes to capture emerging patterns in the data. The coding passes revealed two broad categories within which to group the data--one related to content and the other to process. The findings described in the remainder of this chapter reflect my interpretation of the data related in large part to the process that evolved during the study sessions. I begin with the most abstract level--the "global theme" and work backwards to provide one view of the dynamics that enabled participants' appreciation of the study sessions.

Global theme: advance care planning as collaborative care.

"Advance care planning as collaborative care" was identified as a global theme that represented an important patient-centred interpretation of the wide-ranging, complex interaction reflected in the transcripts. The thematic network connected to this global theme included three organizing themes: a) partnering, b) negotiating ambiguity, and c) being a resource. Each of these described an underlying commonality within a cluster of associated basic themes. Although the thematic network is described as three discrete components, this is an artificial separation for the purposes of analytic description only (Attride-Stirling, 2001). The order in which I present the themes reflects to some degree my sense of their order in the unfolding study sessions. Thus I describe the nature of "partnering" first because I consider it to be the fundamental element of the process, the catalyst that enabled the development of "negotiating ambiguity" and "being a resource."

Organizing theme 1: partnering.

At the start of the first session participants and I were strangers to each other. An early phase of "small talk" in which we disclosed a bit about ourselves broke the relational "ice" somewhat. When I asked them why they had chosen to participate most spoke of a desire to help others if they could, and perhaps in the process help themselves. Thus we had something of a common goal right from the start. Despite the digital recorder and the formality of initial "questions" from the conversation guide (expressed and employed as appropriate for each family), participants seemed to become increasingly comfortable. I encouraged their input by listening closely, prompting for more detail or clarity as needed, urging everyone to add to the discussion, and contributing bits from my own experience when this connected with theirs. Their reminiscences of how life had changed for them provided clues for me to follow-up on and when I did so it fostered more reminiscence. As the talk flowed ever wider and deeper, our comfort with and sense of each other increased, perhaps due to time but I think also because of the emotion in the experiences they shared with me--sadness, humour, anger, guilt, shame, hope, and fear. I responded to their stories, supported them emotionally, answered their questions as well as I could, explored their fears and hopes with respect for their values and beliefs.

At the end of the each session I sensed a reluctance to stop, both in them and in me. Because of our time and talking together we were no longer strangers feeling our way forward. Rather we had developed a sense of coming together, a commitment to working together to achieve a common goal. There was a sense of balance to it even though it did not feel like an equal partnership--I was always aware they saw me as being "in charge" of the venture in a certain way. Yet their trust in me was humbling--most did not have a clear view of what our common purpose was and yet they were willing to throw in their lot with mine whatever that "lot" turned out to be. They trusted that it would be okay, that I would not put them at risk. This was how "partnering" felt to me in the sessions. I had an idea of how partnering felt to them when it came time to say good-bye at the end of the second session. They all thanked me for spending time with them, some were profoundly grateful issuing an invitation for me to come back for "tea" anytime I might be in their area. From this reaction I interpreted that contrary to the discussion leaving them less hopeful or more fearful, through it they felt cared for. Basic themes associated with "partnering" were: a) creating relational space, b) building therapeutic relationship, and c) discerning participant perspectives.

Creating relational space.

The early phase of each session developed in response to questions about when participants had learned about the COPD diagnosis and how their lives had changed because of this illness. I thought these issues would be most familiar and comfortable to ease participants into talking. In any event, all participants were willing to discuss them. Often the question about when and how their COPD was diagnosed brought out how insidiously and completely the illness had taken over their lives. This began a process of reflection that seemed quite new and foreign to some.

> R: I'd like to know a little bit about how long you've had the COPD, and what that's been like for you.
> P4: How long, I don't remember.
> R: It's been a while then?
> P4: It's been a while yeah, it's been, gosh I can't really, I don't have a number in my head as to when really, it's got to be seven or eight years maybe more, I just don't have a clue you know.
> R: Probably seems like forever.

> *P4: Yeah, really. It's been up and down, I've had some scary moments, couple of trips to the emergency that turned out really good of course, I'm here. But . . .*

This led naturally into asking how COPD had changed their lives, what things they could no longer do, what they missed most.

> *R: So what's, how has it changed your life having this disease? What's different since you've had it?*
>
> *P4: What's different? I can't do nothing. It's really, really ah, it's really a killer. You know to make a bed is a chore, you know. I'd sooner be working,*
>
> *R: So you had to quit work because of the diagnosis?*
>
> *P4: Yeah, because I can't, I just can't, I'm no good to anybody, I'm, I carry something from here to the back bedroom and I'm winded you know so that's no good.*

Not being able to "work" was a common and major concern for all the patients in the study. It seemed to bother the men more than the women particularly in terms of negative effect on sense of self, but all mentioned it as an important loss in their lives.

> The following illustration is from the beginning of the first session with F6.
>
> *R: I'd like to start just by getting an idea from you of how long you've had the COPD and how life changed for you after, once you knew you had it, that kind of thing. Just so I have some background.*
>
> *P6: I've had this for five years. Five, six years. Yeah, 2005 wasn't it, 2005 I think. And my life changed quite a bit because I can't do the things that I used to do. I can't work you know.*

Their COPD-related losses revealed so much about their values, their self-identity, and their emotions. Everything they shared with me gave me clues about what was most important to them, what worried them most, and consequently what they were hoping for even if they could not voice these hopes. Indeed some seemed not be aware of them.

Contributions to the conversation varied throughout the sessions. Sometimes the intimate others were the most talkative (F1, F5, F8), sometimes the patients (F3, F4, F7), and sometimes it was more evenly split (F2, F6). Most of the intimate others were also coping with significant health concerns.

> *P6: Yeah because he can be sick, he can be fine right today but he can be sick two hours from now or me, I mean as far as that goes. I might go that way too.*
>
> *C6: Now if . . . just like today I was telling the doctor, he said how are you feeling today, I said every sore spot I ever got all summer is hurting today, you know. And well come find out there is a broken bone in there.*
>
> *R: What did you do?*

> *C6: Oh I, we were fixing this place here, I cut a little tree down out there and of course, the first one that tripped over the stump was me. And the way my legs are they're all tightening up and stuff, I have an aneurysm on my aorta, so and my legs are starting to, between that and the diabetes, starting to tighten up. Well I tripped over that stump and I had some boards in my hand, and I could not get my arm out in front of me to hold myself and I ended up face first in an old pile of lumber I had in there and of course that hand went underneath it. But see how all puffed it is. And it's sore. But it hasn't been sore until we got that H1N1 shot and now everything that I hurt all summer long is hurting.*

Most were isolated due to the patient's dependency and many received only sporadic visits from family and/or friends. These factors may have contributed to their willingness to talk. It was important to give each participant a chance to talk, add opinions and stories. In each case the patient and intimate other appeared to have a well worked out relationship, some more hierarchical than others. So encouraging input from both helped me understand those dynamics and clues for exploring their expectations of each other particularly as these related to end-of-life decision-making. The following example comes from the second session with F7.

> *R: So in terms of the conversation we had last time and when we talked about you making sure that your preferences were known when you get really sick at the end, was that a helpful conversation or did you find it hurtful, was it something . . .?*
>
> *P7: No, it was something I know, I know and everything . . . but I just don't talk about it too much.*
>
> *R: But [C7] obviously knows what you want and . . .*
>
> *P7: Oh yeah, he knows. There's some times I go over it with him so that he'll remember what to do.*

Although the sequence for arriving at the topic of death and dying was different with each family, beginning the conversation with questions about the COPD diagnosis and imposed changes on quality of life sparked conversation with lots of hints about hope, fears, and uncertainty.

Creating relational space involved being "present" to participants through a process of "active listening." From the earliest moments of the first session until the final moments of the second, participants' memories were filled with emotion. Soliciting their memories, identifying their concerns and emotions, and responding empathetically typified active listening. In the analysis these interactional elements were identified as "relational strategies" which included empathy, interpretation, mirroring, validation,

reassurance, probe/prompt, and witnessing. I engaged in interpretation and empathy in an effort to ensure I understood participants' meaning and responded in a helpful way. I defined "interpretation" in a study memo as a "conversational response to express understanding of what the speaker has said; demonstrates facilitator is on the same wavelength as speaker; opportunity for empathy and compassion as well." Such a response involved reading into the participant's words, a process of extrapolating that deepened and clarified my insight into what s/he was saying. I defined empathy in a similar memo as the "ability to feel into the lived reality of the other--vicarious introspection; facilitator using this to establish rapport and discern meaning participants attach to particular contributions to the conversation." In the following example from early in the first session with F7, I had been listening to P7's description of the background related to her COPD. She had mentioned not remembering a time when she did not feel short of breath and she spoke of caring for her father who died with COPD. I heard and interpreted this comment in terms of the feelings it may have induced. She agreed immediately with this interpretation, suggesting that she and I are on the same wavelength at that moment.

> P7: *My daddy died of it. I had to take care of him until he passed on.*
> R: *So you kind of know what this is going to be like then.*
> P7: *Oh yeah that's, if you think about it, it get's kind of*
> R: *Scary?*
> P7: *Yeah.*

"Facilitator issues" was another code connected with the subthemes of active listening and communication strategies. In a related memo I described it as:

> *state of mind, memories, emotions, previous experiences, values, context--all of these factors and more could and did affect how focused I was on participants' needs and sharing; affected the process and contributed to its context and dynamic; person of facilitator impacts the discussion, comfort level, trust.*

In the analysis, the code "facilitator issues" was a useful indicator of my failure with respect to active listening. These moments often introduced a disruptive dynamic in what was otherwise proceeding as focused active listening and supportive presence. Memos connected to "facilitator issues" often referred to episodes of "empathic rupture" and/or "non-sequitur" that indicated such moments. At these times I was not sufficiently focused

on what participants were saying/feeling and missed cues for responding appropriately. The intense sense of floundering I felt at these moments rendered the communication connection and rapport developing in the session more explicit by its sudden absence. Thus these momentary disruptions highlighted the interrelationship of facilitator issues, communication/active listening, and relational elements. The following example of an empathic rupture/facilitator issue is taken from the first session with F7. P7 has been talking about her declining quality of life, her consistently difficult family history, and ongoing challenges with illness, finances, and healthcare. She has had a strong, trusting relationship with the respiratory therapist who recruited her for the study and was clearly disappointed early in the session that she was not going to stay for the discussion. The subject of the therapist's new puppy generated a long story from P7 about the death of a much beloved dog and the following after my comment, "Yeah, it's not been good."

> P7: *No I think that I'm a jinx.*
> R: *I think it's coincidence but it's not very nice coincidence. No it isn't, not at all. [trying to reassure her that she is not a jinx, that the experience she described was more likely to be coincidence, albeit not a pleasant or welcome one]*
> P7: *Well I've been doing all the talking instead of*

Here I failed to respond appropriately (empathetically, interpretively, or by using probe/prompt to find out more about her meaning) to P7's obvious concern that something about "herself" was causing things to go badly (jinxing) in her life. With my failure of active listening P7 immediately moved to withdraw from the conversation by saying, "Well I've been doing all the talking instead of . . ." In this case the rupture was mended when I reassured her that my aim was to have participants talk about their concerns. But the disruption in the conversational flow highlighted the significance and effort associated with attentive, active listening and accurate empathy for the overall integrity of the approach to creating relational space as a supportive environment for advance care planning.

Building therapeutic relationship.

The attentive implementation of active listening techniques was further associated with the codes "establishing rapport" and "trust" between the participants and me. Trust was associated with active listening and with a researcher-related quality referred to as

"genuineness." I developed a memo that described genuineness as something "linked to building trust and rapport; achieved through being "human" with participants via accessible language and sharing pertinent stories." "Sharing pertinent stories" was another communication strategy used to build rapport and trust. My memo described this code as "revealing personal details related to the situation being discussed as a way to level the playing field somewhat." It was a way for me to be more vulnerable with them and hopefully facilitate their ease with being vulnerable with me. It was a concept related to trust, genuineness, and rapport. The following is an example of "sharing pertinent stories," at times another way of expressing empathy.

> P7: *Yeah, and then I didn't even realize that this was getting worse until after I couldn't breathe and I was in the clinical trials and it said that . . . I was taking double doses, twice as often, that it could affect every part of my [body] so it could cause heart failure and of course I got heart failure. When I was in the hospital in St. John that's when I couldn't breathe and I was scared and my own, my very best friend, "Export." [cigarette brand]*
>
> R: *You sound like my mom, she says her cigarettes are her best friend, yeah she says, "they were my comfort and I have to give them up."*

These subthemes had to do with establishing and maintaining trust as a prerequisite for participants to feel comfortable enough to discuss topics that might be emotionally difficult for them. "Trust" has to do with faith, hope, belief, conviction, confidence, expectation, reliance, and dependence. In the analysis code book, the related memo described trust in terms of,

> *participants had to trust me as facilitator for there to be any in depth sharing of feelings, values, beliefs, hopes, fears, etc.; advance care planning is a frightening topic, often uncomfortable for people, therefore trust is an essential element in the discussion*

These descriptions suggest that trust is associated with a sense of risk, and therefore uncertainty and vulnerability. Participants demonstrated their willingness to take this risk, apparently trusting that I would support them as we navigated this risky unfamiliar territory. In contrast, the following quotation from the first session with F7 is an example of her mistrust of local hospital staff.

> P7: *And I told them the last time I was in there, if you're going to give me anything I said make darn sure I'm going to wake up.*

[few comments later] *I'm not going to be murdered!*

P7 [later]*: When they give me the pills I look at them and make sure I got, this one, this one, that one, this one.*

R: *What they're all for*

P7: *Yeah what they're all for, I know them all and if there's something that's different there I question what's this one for. There was a friend of mine who had a full handful of pills to take and they said how many of them is vitamins, I said none of them.*

For the most part, trust was difficult to demonstrate explicitly in transcripts, but was implied in participants' willingness to eventually engage in discussing topics they originally preferred to avoid. Once again, empathic ruptures and non-sequiturs made implicit trust dynamics more visible by their absence during moments of brief disruption.

The following excerpt exemplifies how "sharing pertinent stories" appeared to deepen trust. In this example taken from the first session with F5, they had been discussing their son's desire to "have everything done" to prolong life in contrast to P5's standing DNR order. I had commented that an advance directive could be a gift to intimate others who may have to make end-of-life care decisions for a loved one. This observation prompted C5 to give more details about her son's spouse who had served in this capacity for him during his ICU stay. My empathic response and subsequent sharing of a personal perspective (sharing pertinent stories) seemed to spark significant input from P5 who tended to speak sparingly compared to C5 in our sessions. This exchange seemed to add positively to his sense of trust and the developing relationship with me as indicated by his willingness to share some deeper thoughts. His sharing contributed substantively to my insight into his understanding of faith and something of the role it had for him and his view of hope currently.

C5: *So many times, I mean I had faith, yes I did, but I knew what [son] was suffering.*

R: *Well, that's why I'm a firm believer that God gives us a brain to be able to discern you know [pause] are we suffering?*

P5: *That's just exactly, just exactly.*

R: *We have to use our brains.*

P5: *God has given you the will to do your own work I want to say and God has given you the will to get out and go to work if you can. Not for God to do it all. You go to a pastor and you ask him to pray for you for something, that's alright, let him pray. And then he should drop it. Let him leave it in God's hands.*

R: You have to realize what you can do and what you can't.

Discerning participants' perspectives.

Based on principles drawn from the patient-centred care (PCC) model, the study design called for communication and relational dynamics responsive to participant perspectives. These perspectives were indicated by analytic codes assigned within the code family "participant factors" and included codes related to participants' views, contexts, and history. My memo assigned to the code family "participant factors" described it as "a collection of codes that add to my insight into what matters to participants--their motivation, experiences, history, values, etc." Breaking this down by subcategories, participant "views" included codes for motivation (for doing the study), values, beliefs, goals and priorities, need for control, hope, and readiness. "Context" encompassed codes for quality of life, current needs, COPD-related issues, literacy, social determinants of health, family context, vulnerability/trust, uncertainty, suffering, and the informed consent process (that mentioned advance care planning as a goal of the study). Participant "history" related to codes for COPD losses, family history, challenges, illness experiences, expertise of experience, coping, and history with healthcare. Each of these codes indicated a source of information to increase my understanding of how/why participants were thinking and feeling about particular topics.

Most of the insight into these participants' perspectives was drawn from the experiences they shared during the sessions. These encompassed a wide variety of concerns including "COPD-related" issues such as shortness of breath, sleeplessness, problems with appetite and weight; "illness-related losses" like loss of mobility, independence, social contacts, meaningful activity, a sense of control and predictability; "illness experiences" such as trips to the emergency department, admission to ICU, pulmonary rehabilitation programs, dealing with insensitive clinicians; "history" related to having watched intimate others suffer and die with COPD or witnessing difficult cases in the ICU; and "coping" efforts reflected in codes such as "one day at a time" and "caring others." A major portion of the sessions was taken up with encouraging this input through communication strategies and building therapeutic relationship to increase insight into participant perspectives. The time spent to explore in this way was clearly

appreciated by participants as reflected in their formal feedback on the sessions. Many were grateful for the chance to share their concerns and stories with an interested clinician. The following quotation exemplifies the sort of storytelling offered by participants talking about COPD effects on their lives. During the second session, P1 and I had been discussing his loss of meaningful hobbies due to increasing breathlessness. Although he answered all questions posed to him, he tended to be quite quiet and let C1 do most of the talking. In response to my interpretation of his feelings about his situation at this point he told the following story and exhibited more emotion and excitement than at any other moment in the sessions.

> R: *No* [pause] *kind of hard to* [pause] *sit around and have this happen, isn't it* [P1: mmm] [pause] *just gradually take it away from you.*
> P1: *I heard a singer* [pause] *they were interviewing on TV one day* [pause] *ah, I know the guy* [R: yeah] [long pause] *anyway, they asked him if he* [pause] *something about if he had gotten all he wanted from life* [R: yes] *and he said, "I was going to do a lot of things and then I got old."* [he chuckles]
> C1: *I got old.*
> R: *Yeah. Age happens when you're planning for other things* [pause] *right?* [laughter]
> P1: *yuh, he said, "then I got old"* [pause] *and that hit the nail right on the head.* [said with excitement and emphasis]

His emotion as he related this story indicated to me that this remark by a television interviewee held great significance for him. This story, more than anything else he said, provided insight into the meaning P1 had drawn from his current situation and hope. There was more passion in his voice when he shared this story and he repeated what he considered to be the punch line "then I got old." Through most of both sessions he showed little emotion, spoke in a low monotone, and seemed content to let his wife do most of the talking. This exchange offered quite a contrast, which was an indication of its significance. Other comments--clear concern about not being able to work or contribute around the house, ongoing loss of weight and muscle strength, inability to continue meaningful hobbies or social outings with his buddies, and increasing episodes of pneumonia and hospitalization--indicated a struggle with his very traditional self-image and gender identity as the strong (healthy) male head of his household. He seemed to be viewing illness as weakness and thus seeing himself as lacking control and strength. The televised comments by an individual he related to and admired offered a welcome alternative interpretation. His obvious pleasure with this alternative interpreted through

the lens of prior comments about the effects of COPD-related losses led me to think his primary fear was appearing "weak" and not "manly." The television role model enabled him to see his weakened condition in terms of "aging" rather than illness or weakness, which made it seem more acceptable and hopeful by enhancing his understanding, acceptance, and sense of control.

This in turn enabled me to make advance care planning more relevant for him by using a meaning framework based on this understanding. The following quote comes from the second session with F1.

> R: *Well I was kind of hoping this time* [pause] *last time we talked about what it's been like for you to live with this illness* [pause] *it hasn't been very pleasant* [pause] *sounds like it's taken a lot* [pause] *a lot of things away from you.*
>
> P1: *A lot* [pause] *it does* [pause] *can't do what you want to do.* [he laughs]
>
> R: *And you sound to me like a guy who pretty much liked to make your own decisions and get up and do what you wanted to do and look after the house and those kinds of things?*
>
> P1: *Work* [pause] *that was it* [pause] *work [R: yeah, yeah] I had my wind.*
>
> [few minutes later]
>
> R: *So now* [pause] *I'm going to push ahead a little bit* [pause] *and find out what you think about* [pause] *what you think about when the time comes that you're not going to get out of here.* [hospital]
>
> P1: *Nothing to think about* [pause] *that* [pause]
>
> R: *No?*
>
> P1: *I mean what's to think about?*
>
> R: *Well the team, the team that will look after you when you come in would probably want to know what you would want done if they couldn't make sure that you got better.*
>
> P1: *One thing I know I want—I don't want to be on one of those ventilating machines*! [forceful tone]

At the end of the second session participants were asked about their experience of the sessions. The majority of this feedback was positive with many (C1, P2/C2, P3/C3, P4, C5, C6, P7, P8/C8) expressing their appreciation in terms of having a chance to talk with someone from the healthcare system who seemed interested in hearing about them. For P3, isolated by anxiety in the small bedroom of his cramped, untidy apartment, the sessions offered a chance for him to talk about his current concerns, especially his debilitating loneliness and fear. He was a participant with major literacy difficulties.

P3: Good, it's been good [pause] *I'm glad we talked about it, good to get it off my chest and that.* [coughing, choking]

[a bit later]

No, no [pause] *Didn't bother me in the least [pause] nice to get it off my chest, a lot of things* [pause] *I got no education, I can't read or write.*

P8 identified with me as facilitator in expressing her appreciation, while C8 referred to the sessions positively and socially as a "visit." Their gratitude seemed connected to a relational focus, the connection with an "interested clinician" aspect of the sessions.

R: Yeah. This will be the last thing. Just to find out from you what it's been like for you two to have me come and push you to talk about some of these things, has that been difficult?

C8: No.

P8: No you're not difficult.

C8: Not a bit no. It's a nice visit actually. Nothing difficult about it.

Summary of "partnering."

The organizing theme "partnering" was an interweaving of three basic themes--creating relational space, building therapeutic relationship, and discerning participants' perspectives. Hoping to engage participants in a consideration of advance care planning with all its potential for emotional intensity, I focused on building a relational foundation based on trust and rapport. This was encouraged through the implementation of relational strategies, of which active listening was central. Much in the way a contractor begins to build a house by first setting out the forms and pouring a concrete foundation, I set out the forms by using the conversation guide to stimulate the discussion. Active listening can be likened to pouring the foundation around those molds. These foundational steps were augmented through genuineness and sharing pertinent stories that encouraged participants to respond with storytelling about their illness experiences, illness-related losses, history, challenges, and coping efforts. I in turn used this input to further guide active listening and deepen both the developing relational dynamics and participant input. These strategies worked together to create the necessary foundational support for the development of subsequent, potentially more emotional stages of the dialogue.

Organizing theme 2: negotiating ambiguity.

Ambiguity has been defined as "situations involving multiple meanings, hazy odds" (Babrow, 2001b, p. 555). As participants talked about their experiences of COPD--effects, treatment, understanding, prognosis (or lack of it), coping, fears/concerns, and hopes--they were often describing ambiguity. They were living with significant uncertainty due to exacerbations, dwindling mobility, and increasing social isolation imposed by late-stage COPD. At times this afforded room to continue to hope--nothing was for certain so anything was possible. At times it robbed them of any sense of control or choice. Thus ambiguity could be both a positive and a negative factor depending on the circumstances.

Negotiating ambiguity with participants involved acknowledging the presence, significance, and unassailability of the ambiguity in their lives. Trying to ignore it or convince them things were not this way would have been disrespectful, and likely have undermined my credibility, authenticity, and trustworthiness. Instead I tried to understand the significant negatives and positives of the ambiguity they were experiencing. Eliciting the negatives meant being prepared to hear and address associated suffering. Identifying their positive ambiguity often revealed sources of hope and coping relevant for creating the individualized advance care planning framework. Encouraging participants to expand on their visions of hope and parallel fears helped establish what issues were most important to them. Many of these issues emerged in some form in response to my first question about diagnosis and illness changes. By probing for further details about hope, fear, and uncertainty I worked to clarify participants' view of the ambiguity they had to deal with daily and increasingly as COPD progressed. Each discussion unfolded differently depending on what experiences and issues participants chose to share. Thus the study sessions imposed a further dimension of ambiguity for participants, because most were not clear about the purpose or what to expect during the process. Thus negotiating ambiguity/uncertainty was part of the process for all of us. As an organizing theme it encompassed a cluster of four basic themes: a) exploring hopes and fears, b) acknowledging uncertainty, c) engaging hope, and d) addressing suffering.

Exploring hopes and fears.

The study conversation guide was designed to provide a logical gateway into participants' hopes and fears related to COPD if the subject did not come up spontaneously in the discussion. The thinking was that participants' description of their illness related losses and concerns might contain references to unpredictability and their difficulties dealing with this. The inherent, well-documented unpredictability of COPD can be a source of hopes and/or fears for those living with it. Thus including these topics in the conversation guide was a way to make explicit what might remain implicit without these prompts. My memo related to "fear" describes it as a "general sense of apprehension connected to imagining the future or disease progression, ability to handle what might be coming; related to uncertainty of the situation." The memo related to "hope" puts it in terms of an

> *emotional attitude related to what a person sees as a realizable possibility for him/her, ability to imagine it, connects to personal values and goals, and a sense of agency (active not passive dynamic); important factor in motivation, desire to keep living, and quality of life; also has vulnerability as a characteristic by virtue of the potential for hope to be disappointed.*

This description of hope implies vulnerability, which makes any consideration of hope a natural segue into considering fears, particularly fears connected to unfulfilled hope(s). Including these topics in the conversation guide and the study conversation was intended to provide a natural transition into a consideration of fears and hopes related to end of life. The following are examples of this from the sessions, the first where it was raised by me, and the other where the participant raised the topic himself. The first quotation comes from session two with F7 and despite P7 hinting several times about her fear of dying, I had not explored the subject with her explicitly until this point which occurred in the context of her faith-derived hope.

> R: *Your hope sounds like it's pretty strong.*
> P7: *Oh yeah, I'll be here until God decides to take me away. He doesn't give us any more than we can handle and my shoulders is getting weaker but* [pause] [she laughs]
> R: *It's feeling like a load.* [pause] *You don't really have any fear then of what's to come?*

P7: Actually I'm terrified [pause] *of death.*

R: Of the actual dying part of it? [pause] *Yeah?*

P7: That's why you know I just think of other things instead of that part cause I know I'm going to be petrified if I know [pause] *we were just talking about that earlier, my second and a half cousin, he's* [pause] *they're twins, they're [J] and [S], and [J] he's dying of cancer and he knows he's dying and his twin brother just had surgery, had 14 inches taken off his bowel* [pause] *but [J]'s wife* [name]*, she's a Pentecostal so she's really into the church but still that must be so hard* [pause] *knowing* [pause] *for him to look at his wife and knowing that he's going to leave her and the pain that she's going to know, she's going to lose him, that would be* [pause] *awful.*

Her concern became clearly visible here, both emotionally and verbally. The idea of being faced with the fact that she is dying filled her with fear and she worked hard to protect herself from such an eventuality. This was an important insight for me to gain with respect to developing an acceptable approach to the advance care planning topics for P7, one of the most advance care planning-resistant of all the study participants.

The second example comes from the second session with F1. A discussion about P1's desire to avoid mechanical ventilation in favour of comfort care measures if he should suffer another respiratory failure provided clues to some of his end-of-life fears and hopes. After P1 responded ambivalently to my explanation of the advantages of a short trial on the ventilator in the event of a future episode of respiratory failure C1 suddenly asked if he was afraid to die. Her question prompted the following exchange.

C1: I asked him a question, "Is he afraid to die?" Some people are.

R: Yeah, a lot of people are actually, yeah.

P1: What?

C1: Are you afraid to die [pause] *when your time comes?*

P1: I don't know if I'm afraid or not [pause] *[R: no?]* [pause] *I think* [pause] *nobody wants to die* [pause] *unless they're in awful pain or something.*

P1's response here suggested that he might well have some fear of dying and was obviously hoping to continue with life even with its current illness-eroded quality. It also suggested his difficulty talking about such emotionally intense subjects.

Acknowledging uncertainty.

The second basic theme was strongly related to being honest and genuine with participants about the uncertain nature of their illness and situation more generally.

Acknowledging the unpredictable but generally negative trajectory of advanced COPD was considered a way of strengthening participant trust in me as the sessions progressed. Acknowledging uncertainty was also a strategy to get an idea of their thoughts/concerns about the future, if any, as well as approaches to coping. Many participants preferred to focus on the present moment and coped by taking things "one day at a time." I listened for and responded empathetically to participants' cues about their awareness of and coping with uncertainty. The uncertainty inherent in the COPD trajectory was increased for many by ongoing uncertainties connected to their current care. Examples of this sort of issue included lack of awareness of how to access needed resources such as additional home care, difficulty getting to and from clinics for care, trips to the ER to be seen by clinicians unfamiliar with their case, inadequate attention to intimate others' health issues and support, clinicians' unwillingness to discuss patients' and intimate others' concerns. Encouraging this sort of discussion provided insight into current concerns that I could help to address by providing information, advocacy, and/or appropriate referrals. Such interaction demonstrated interest, understanding, and care that resulted in deeper trust and relationship. Participants' obvious desire to discuss their current concerns and ways to address these, and the frequency with which we returned to this topic demonstrated the appropriateness of making this a major focus in any advance care planning discussion.

Talking about the existence and effects of uncertainty was also a way to forge common ground, an emotional connection, before transitioning to related topics such as fear of suffering and/or dying. The following example comes from the second session with F8. In the first session, this family was very clear about not wanting to think about the future or any end-of-life care considerations despite P8's very advanced COPD and fragile health status. I began the second session by asking P8 how she dealt with COPD-related uncertainty. When P8 asked for clarification about the meaning of the question, I answered with a description of COPD-related uncertainty.

> R: *I wanted to ask you how you cope with uncertainty, cause this is one of the big things in COPD, this notion of uncertainty?*
> P8: *What do you mean, like "how"* [pause] *what do you mean?*
> R: *Well, we don't really know anything for sure in this disease, so how would you say you deal with that? That even the doctors can't really tell you* [pause] *much.*

> *P8: Unless they have it they can't tell you much. They just assume* [pause] *that that's how it works.* [pause] *I just take it as it comes; you can't do anything else.*
>
> *C8: You don't think much about what's going to happen, you think about what's actually happening now, right?*
>
> *R: What's happening today?*
>
> *P8: That's mostly it. The truth is* [pause] *you'd just freak right out and throw things to the side.*

P8 described her preference for concentrating on today as a way of avoiding thoughts of the future. Her answer also gave a good indication of how much faith/trust she had in her physicians' prognostic abilities regarding COPD. Both of these were important clues to negative uncertainty and her way of dealing with it, and helped me frame the advance care planning discussion later in the session. Putting it in terms of what was most relevant to her meant phrasing advance care planning as spending a few minutes now preparing for the worst uncertainty (possible death) while continuing to have hope for the best uncertainty (continued life). In the ensuing discussion we slowly covered a lot of ground including making sense of the uncertainties of "life after death," the options for comfort care and life-sustaining interventions, her values concerning meaningful life, and her preferences for end-of-life care and decision-making. Ultimately she seemed matter-of-fact about it as the following excerpt shows.

> *P8: Okay so we've made up our mind, we want this and we want that, now as you say right, what do we do with that information? Should we be giving it to somebody?*

This comment indicated to me that through our discussion she was able to confront some of the uncertainty she dreaded most, adjust her understanding of how to cope with it, and emerge with her hope intact and perhaps an enhanced perception of control.

Engaging hope.

This involved me working to understand participants' hope(s) well enough to use them to shape an acceptable and meaningful advance care planning approach. It also meant connecting with those hopes sufficiently to activate participants' interest and involvement in subsequent advance care planning considerations. In order to do this I had to listen carefully for their hints about values, goals and priorities, beliefs, imagined possibilities, expressions of vulnerability and/or concern, challenges, coping and end-of-

life care preferences. Engaging hope meant I responded to such allusions and comments with empathy to encourage further/deeper sharing on the part of the participant. At times it meant probing/prompting for clarification or offering an interpretation as a way to check for understanding. Being clear about participants' hopes was important as they necessarily shaped subsequent advance care planning discussion. The following lengthy quotation from F2 exemplifies this aspect of the advance care planning process. In the first session, P2 said she hoped she would not die in her apartment, which surprised her daughter who assumed home was her mother's preferred place of death. The reasoning given by P2 related to her fear that dying at home would make her possessions undesirable to her family. Her logic reflected her pivotal value that she not burden or distress her family in any way, a value aligned with her self-image as the family's primary "caregiver." In the second session she gave more clues to her reasoning when I worked to clarify and engage her hope to not die at home.

> P2: *I don't want to go to the hospital [R: No?] No* [pause] *I went too many times, just get home and back in again.*
>
> R: *Yeah?* [pause] *but you also don't want to be here if you're not doing well ?*
>
> P2: *Sure.*
>
> C2: *That's what you told us.*
>
> R: *That is what you told us last time.*
>
> P2: *Yeah, yeah* [pause] *I'd rather just drift away in my sleep*
>
> R: *But not here you said* [pause] *you said I don't want to die here*
>
> P2: *Well, you know, I can't help it if I do that. [drift away in her sleep]*
>
> R: *Okay, so tell me more about that* [pause] *because that's a little different than what you said last time.*
>
> P2: *Sometimes, sometimes* [pause] *I wouldn't want to die here, because sometimes I'd be afraid that everybody would be afraid to touch me [R: Yes I know]*
>
> C2: *Well, no, we wouldn't be afraid, Mom, because it's you and anything that you have, right, we wouldn't be afraid to touch it. [R: They'd still want your things* [pause] *they would]*
>
> P2: *But if I fell asleep and* [pause] *[R: didn't wake up?] didn't wake up, well, what could I do?*
>
> R: *Exactly* [pause] *other than, if you really don't want to be here when you die* [pause] *[P2: yeah] then you need to understand that if you're not doing well you need to go to the hospital.*

P2: Well what I was thinking of, was these people who'll then have to [care for her in her dying] [pause] [R: I know] [pause] so then I'd rather go in there, have them [staff] jab me with needles instead of them [family]

R: Yeah, I know. So what you're saying is you want the care at the hospital [pause] at the end?

P2: Yeah, why suffer?

Clearly she connected increased potential suffering with her family having to provide her end-of-life care. Such a scenario seemed to raise the specter of physical as well as emotional suffering for her. Ongoing discussion included stories that added further detail about her preferences related to her understanding of suffering and hope, which helped her family understand more fully her wishes concerning end-of-life care.

Addressing suffering.

Participants' views concerning suffering, hope(s), and sense of vulnerability were interconnected. My note describes "suffering" in terms of "a reality and general concern in COPD; lots of sources of suffering from uncertainty to pain, dyspnea, fear [dying, death], relational changes, exacerbation, hospital admission, vulnerability, etc." I identified four main types of issues by grouping codes linked with the basic theme of suffering including those related to: 1) dying--fear of suffocation, unrelieved pain, being kept alive indefinitely on a machine (ventilator), not being able to make oneself understood, losing control, losing cognitive capacity; 2) illness-related effects--depression, loss of independence, dwindling quality of life, isolation, becoming a burden, loss of appetite and weight, long-term oxygen therapy, complex medication regimens; 3) healthcare concerns--treatment of illness crises, hospital and/or ICU care, ethical views/ trustworthiness of clinical staff, use of medications especially morphine; 4) after-death concerns--guilt, punishment, purgatory. Participants spoke at length about these many sources of suffering as well as the effects on their lives and on their uncertainty, hopes, fears, coping, and advance care planning preferences.

Again, I gained most insight into these issues through participants' storytelling and their descriptions of COPD-related losses, history, illness experiences, and coping. The process of acknowledging uncertainty, exploring participants' fears, and engaging their hope(s) tended to open up natural conversational segues into advance care planning, but at times also brought suffering to the fore. Participants who coped by studiously

avoiding thinking about their mortality, definitely experienced suffering due to the end-of-life implications made explicit by the mere mention of advance care planning. When participants expressed suffering either emotionally or verbally, I responded by providing psychosocial/spiritual support as appropriate. This involved witnessing, empathy, validation, reassurance, reframing, sense-making, and/or sharing pertinent stories, depending on the given situation. The following quotation from the second session with F8 illustrates this dynamic. This excerpt was preceded by a discussion of concerns about the afterlife in which C8 said he hoped he would meet up with loved ones after he died. This theory helped him make sense of dying. He then described the following experience from the couple's history that clearly was a source of suffering for him, although he did not seem comfortable expressing such feelings.

> C8: *Yeah, like we had a stillborn right, I'm anxious to see him, you know, yeah.*
> R: *Absolutely, that's always hard, to lose a baby is always hard.*
> C8: *We left* [village] *and everything was fine; we got into* [town] *and there was no sign of a heartbeat, that's a big change. [small laugh]*
> R: *Oh that's a huge change* [pause] *I look at my son* [pause] *how do you deal with those? Because I've gone in to do namings and blessings of stillborns at the IWK and it's hard, it's so hard* [pause] *because you already bond with that baby, you already have dreams for that child and it's tough.*
> C8: *It's as though he was here for a long time, yeah.*
> R: *I know it is tough. But you're right, so there's something to look forward to if you have that belief, right?*

I responded to his revelation and obvious suffering/discomfort (I read the small, but inappropriately placed laugh as a clue to this discomfort) with three expressions of empathy and by sharing a pertinent personal connection to the issue to validate his feelings. Finally, there was a moment of "sense-making" that brought the short exchange back to the meaning framework that had prompted it--the possibility that death might bring the chance of once again seeing loved ones who have died. The discussion then moved naturally on to a consideration of goals of care during end-of-life scenarios.

Addressing suffering was also about breaking the silence that many patients had imposed concerning the subject of dying and their preferences for care in such situations. Several participants (C5/P5, C1/P1, C3/P3) were grateful for this aspect of the sessions. For example, through the facilitated discussion C3 became aware of P3's illness-related

social deprivation, fear, and end-of-life care preferences, subjects they had been unable to discuss prior to the study visits.

> C3: He doesn't like to talk to me about stuff because he thinks he is stressing me out.
>
> R: Exactly, that was his comment to me [pause] was that you didn't want [pause] that you didn't want.
>
> C3: Yeah, I was amazed when you [R] talked to me, all the things he said to you that he was willing to do, and wouldn't talk to me about [pause] a stranger instead of me.

Clearly surprised that he had been willing to talk about these issues with me, a stranger, she thanked me as we were walking out the door at the end of the second visit. She told me she was grateful for my visits and feeling much more hopeful about his situation.

C5 was also grateful that the visits had broken through P5's silence, something he had clung to steadfastly prior to the study sessions. The discussion enabled C5 to voice her anxiety related to wanting guidance as his substitute decision-maker, and P5 was able to respond to this. Their concerns arose within the matrix of their unique experiential context--their adult son's recent, lengthy ICU admission for a major stroke that resulted in multiple resuscitation attempts with ongoing physical and cognitive sequelae.

> C5: Yes. I liked the way you [pause] got us talking about things that we'd never talked about before.
>
> P5: Somebody always comes around and causes trouble! [laughing]
>
> R: Isn't it amazing [pause] poking our noses in where we don't belong! [general laughter]
>
> C5: No I think it was, it was very [pause] good.

Participants' spoke positively about the study sessions despite all but F2 and F6 initially being resistant to discussing advance care planning. P7 said she purposely avoided thinking or talking about death because she was so terrified of dying, as previously described. After she described her horror to me we moved on and a little later after I mentioned that there was no certainty that her COPD would be terminal she said,

> P7: Yeah, that might not even kill me [pause] now my first husband, he was petrified that he was going to die of cancer [R: yeah?] [pause] do you know what killed him? [pause] sugar diabetes and his heart. [R: So the cancer fear was [pause]] He didn't have cancer of any kind.
>
> R: No [pause] no [pause] Does your cancer worry you in that way?
>
> P7: Sometimes [pause] this spot didn't help. [a lung shadow newly discovered on a recent chest x-ray]

From this point on, she was able to talk about death and dying, but did so on her own terms. She explained her preference to leave all end-of-life care decision-making to her substitute decision-maker (C7), described several negative death/dying-related experiences, and expressed her appreciation for my approach to breaching her silence. Although I had missed/ignored several earlier cues she provided about her fear of death, she made it very clear she needed to be in control of when, how, or even if she addressed this issue. She provided the following feedback that left me in no doubt about this need.

> *P7: There's one thing* [pause] *like when you're talking to somebody don't press in on the fact that they're dying. [R: Yes]* [pause] *Because you don't know how they're going to accept it at first* [pause] *keep that opinion like you did with me* [pause] *about how I would feel about this or that, instead of your own [pause] coming right out and talking about you're dying in a month or two or* [pause]

Summary of "negotiating ambiguity."

The organizing theme, "negotiating ambiguity," was indeed a study in negotiation. Negotiation is related to concepts like cooperation, compromise, concession, conciliation, finding middle ground, give and take, and navigation, suggesting an active process of seeking common ground or agreed upon understanding. The analytic code family created for this process included sub-codes of uncertainty, hope, trust, active listening, communication strategies, creating understanding, and finding common ground. This theme was implicated in participant appreciation as reflected in the four opportunity categories that summarized their feedback about the study sessions. Dynamics of uncertainty, hope, and vulnerability were implied by their gratitude for having a chance to learn about end-of-life care options, consider/document preferences concerning end-of-life care/decision-making, break the silence surrounding the subject, and share illness-related stories and concerns with an interested clinician. The final organizing theme had much to do with addressing these particular dynamics within the study sessions.

Organizing theme 3: being a resource.

Listening to participants' experiences and concerns revealed significant misconceptions, confusion, and knowledge gaps related to COPD, life-sustaining treatments, comfort care, DNR orders, substitute decision-making, and options in advance care planning. "Being a resource" involved addressing these information needs.

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As described in the section on "Reflexivity" under the heading "Rigor" in the previous chapter, as participants shared their experiences with me they also shared ongoing problems and occasionally asked for assistance. The nature of study sessions in qualitative research along with participants viewing me, the researcher, as a clinician may have contributed to their asking me to help them access appropriate resources by arranging referrals and advocating for them within the system. The potential role conflict introduced previously was therefore not just a reality during the sessions, but revealed a significant opportunity in terms of potential improvements to the effectiveness and meaningfulness of advance care planning. "Being a resource" was an important, multi-faceted part of the process and included: a) providing education, b) being an advocate, and c) functioning as liaison.

Providing education.

Education appeared to flow in both directions during the study sessions, and between sessions as well. Some participants read through the print materials between visits and I researched materials to more fully answer questions they had posed. Through the study process and discussions with participants, I learned about their COPD needs, concerns, fears, hopes, vulnerabilities, and end-of-life thoughts and preferences. Participants for their part, asked questions and expressed confusion about a wide variety of subjects related to COPD, co-morbidities, healthcare system, end-of-life interventions, decision-making, and ethics implications. The frequency and breadth of their educational need and desire was even more than I had anticipated. There were a number of recurring topics under this basic theme of education. By far the most significant, in terms of how many participants were confused about it, was the concept of cardiopulmonary resuscitation (CPR). Some asked about it directly, others expressed confusion through their responses to questions I posed. There was a decided gap in knowledge about potential treatments available to them in the event of respiratory or cardiorespiratory failure, even among those who had experienced such episodes in the past. Few understood how/why a medical team would arrive at a decision about instituting or withdrawing various modalities of intervention such as mechanical ventilation. Similarly, there was little awareness of what interventions might be offered under different

circumstances in an Emergency Department, ICU, or medical ward, or their prognostic implications in advanced COPD. Most participants were interested in learning about various scenarios related to ventilatory support, things like non-invasive positive pressure ventilation (BiPAP), time-limited trials of mechanical ventilation versus ventilation with no timeline, and the effects of narcotics on breathlessness. In the following exchange during the second session with P1, I explained a little about BiPAP. P1 had indicated his preference to forgo mechanical ventilation, seemed interested in this as an alternative, but knew little about it.

> R: *No, no, there comes a point when you just can't do the work yourself anymore, the lungs* [pause] *you give them a rest with the ventilator* [pause] *and sometimes they can use things that are not a ventilator. We have something called, um, non-invasive positive pressure ventilation [P1: yeah] where they do it by mask,* [pause] *where it pushes a bit of oxygen in and out for you and they can do that as a trial as well, so if that is something that doesn't seem as bad, you could try that.*
> P1: *Yeah, well, I figure I might let them try that* [pause] *yeah.*

Other topics of interest to participants included the use of narcotics (effects, indications, dosage); withdrawal of life-sustaining treatment, brain death/persistent vegetative state, euthanasia and physician-assisted suicide (differences, meaning, decision-making). In this example, C8 had asked me during the first session about the ethics of euthanasia, physician-assisted suicide, and murder. Between sessions I read up on these issues and returned to C8's question during the second session. The answer appeared to satisfy her concerns.

> R: *Ventilator yes* [pause] *oh, and I wanted to say that to you too, because the last time we talked about it when I was here* [pause] *and there is a difference, cause we talked about isn't it euthanasia when they take the tube out or they unplug the ventilator, that kind of thing* [pause] *and they look at it a little differently because* [pause] *if they never did anything to start with, you would die right away [P:* [pause] *right, mhmm] But if they put you on the machine to begin with, then they're imposing something, they're intervening in a way that supports life that wouldn't go on without that* [pause] *so in a sense it's like a medical treatment that has failed so then you just stop that treatment, so it's not considered euthanasia or assisted suicide to do that. That would be if you said I want you to give me potassium chloride, which is a drug that will stop your heart. That would be physician-assisted suicide, euthanasia basically. So there's a difference, so if you do something that's going to hasten death, that's considered to be euthanasia, if you just intervene and then stop doing that when*

it obviously isn't [pause] *when the person is not getting better, that's the little line that gets walked between those two.*

Many had questions about the purpose, content, and form of advance directives, and how to revise or revoke them if they changed their minds once the directive had been written. C5 was eager to complete an instructional advance directive but was confused about what information was being sought in each section of the CDHA template.

> *C5: I didn't really know what to put down* [pause] *[R: Yeah, it's hard isn't it?]* [pause] *anyway* [pause] *that's just my name [referring to first line of the AD form]* [pause] *"personal values and beliefs to be respected" [reading from the AD template]*
>
> *R: Yeah, a patient I saw yesterday* [pause] *the thing she put down at the beginning, she's Roman Catholic and she said, 'what I really want is for the priest to come and do last rites, that's really important to me.' So that's what she put in the first part.*
>
> *C5: Oh, okay.*
>
> *R: So that kind of thing, if there's anything that you really want them to respect* [pause] *the problem with it is, the default setting is they'll do everything* [pause] *right? The default is we put in a ventilator, we use the paddles to try and start your heart, we put you on drugs to raise your blood pressure, we do everything. Unless you tell us you don't want everything, we do everything* [pause] *that's the way it is, that's the way the system is, that's the default so* [pause] *but I guess the reason we started to do this kind of thing was there were a lot of people who said, 'No I don't want all those heroics. When my time comes, my time comes, that's it.' So.* [pause]

Many knew very little about the principles and challenges of substitute decision-making. C1 and C5 struggled with this and demonstrated difficulty with the idea of trying to make such a decision for their spouses.

> *C5: I told them down there when [P5] was in the hospital and they called me, I said we're not going to have the ventilator or* [pause] *if the heart stops* [pause] *and they were against me, oh yeah, they think that that's murder. [R: Oh yeah, yes]* [pause] *This is what they feel.*
>
> *R: But it isn't.*
>
> *C5: I know it isn't.*

There were several questions about the underlying pathophysiology of COPD; either this had not been well explained to participants or they had forgotten what their physicians had told them. Some asked about resources available for patients and their intimate others living with advanced COPD. And of course there were plenty of questions about the nature, purpose, and eventual application of the study itself.

In providing educational responses, I focused on giving information in a way that was sensitive to participants' needs and education/literacy level, but also respectful of their previous experience and adult learner status. The goal was to make it relevant to their stated concerns, detailed enough to satisfy their needs using accessible language and concepts, but not so detailed as to be overwhelming. Educational responses took many forms. Some were short explanations, others brief scenarios taken from my professional experience with patients and their intimate others living with advanced COPD and/or history with end-of-life ethics consultations. Other modalities drawn on included personal experience, a formal information brochure about advance care planning for patients and family, and an advance directive template developed by the Capital District Health Authority. Educational responses often produced a follow-up request for more clarification suggesting the need to simplify the information or its delivery, or at times to repeat it. Sometimes participants offered their own perspectives and experience with the subject as in the case of F2. Such efforts helped me understand more of the participant's belief or level of understanding about the particular issue.

> C2: *What does Prednisone do anyway?*
> R: *Prednisone is a steroid and it suppresses inflammation.*
> P2: *Yeah, you see I could take those for my lungs and it would just cover it up like a bad date.*
> C2: *Oh, I get you.*
> P2: *And I could get real sick and not know it.*
> C2: *Oh, really?*
> R: *That's one of the down sides of steroids.*
> C2: *She looks terrific when she's taking them* [pause] *so when she's on Prednisone, we don't know that she's sick.*
> P2: *And boy can I go! [P2's sister: the first day she was on them, boy was she high!]*
> C2: *But that's what I didn't like about it* [pause] *it could mask when she was sick.*

At times it was clear that participants did "not know what they didn't know" and these situations prompted more involved responses by me to give context for the explanation.

Participants' feedback at the end of the second visit was positive (C1, F2 - F8) or neutral (P1) and much of it concerned the educational dimension of the sessions. They appreciated the opportunity to learn more about advance care planning and end-of-life

care options (P1/C1, C2, P3/C3, P4, C5), and to consider and/or document end-of-life care preferences (P2/C2, C5, P6/C6). The following is an example related to "learning more." P4, a man of few words and prone to emotionless understatement, expressed his appreciation for the sessions in terms of an opportunity for learning as well as social interaction. He was one of the participants with a reading comprehension literacy issue.

> P4: *It's good [pause] I don't know* [pause] *maybe it's just the company* [chuckling] [pause] *yeah, I'm always glad to see someone from the hospital with new information or going over old or whatever, you know* [pause] *keeps me a little [pause] a little on top* [pause] *I've got such a poor memory.*

C1 expressed her opinion that they had learned from the study sessions. Their sessions had involved considerable discussion of interventions available in the ICU in response to P1's concern about mechanical ventilation engendered by a previous episode of cardio-respiratory arrest and resuscitation. P1's feedback was more about not being confronted with subjects he viewed as emotionally threatening.

> *P1: It was all right.*
> *R: It was okay?*
> *C1: Yeah, we learned a little more.*
> *P1: It wasn't scary or anything like that. [C1: no]*

Clearly participant feedback on the advance care planning discussion as implemented identified the educational component of "being a resource" as particularly valuable.

Related to this, participants also appreciated the educational aspect of the sessions that enabled them to consider and/or document end-of-life care preferences. Although C2 and P2 said they had already been talking about end-of-life care prior to the study sessions, C2 was grateful to explore and clarify her mother's end-of-life care preferences and the reasons behind them.

> *C2: Well, I found it informative because I found out things that* [pause] *Mom wanted that I didn't know that she wanted* [pause] *so I mean that's good for me because* [pause] *when* [pause] *if she was at the point where she couldn't make a decision we wouldn't know what to do.*

C1 was P1's substitute decision-maker. She appreciated the chance to hear more about P1's end-of-life care thinking also. She commented, "Like if I had to make it [decision about life-sustaining treatments] without knowing what he wants it would be a lot

harder." P6 and C6 had already been thinking about death and talking about their goals for end-of-life care. They had a very pragmatic outlook and valued a straightforward approach to the subject.

> *P6: No it* [advance care planning process] *was fine. Really good I think.*
> *C6: You've got* [pause] *you pretty much have to talk about it sometime.*
> *R: It's going to happen to everybody.*
> *C6: Yes.*
> *P6: And I'd rather have it talked to like that.*
> *C6: It's inevitable you know.*
> *P6: When we're able to sit down and talk to him [family doctor]* [pause] *about it and stuff like that* [pause] *with our minds open.*

Between the first and second study sessions, P6 used the advance directive template provided during the first session to record her preferences, which she planned to copy and leave with her family doctor and her children. She also planned to discuss the contents of the document with her children the next time they visited. Thus it appeared that different facets of the educational content of the sessions were meaningful and helpful to participants depending on their particular needs.

Being an advocate.

Two patients (P3, P4) spoke about conditions that were adding significant but potentially needless suffering to their daily lives. Throughout both study sessions, P4 had maintained a very flat affect, speaking in a low monotone. At the end of the second session he expressed a concern that I was very slow to respond to. He had to repeat his concerns about feeling down several times before I realized he was trying hard to get my attention and help with this issue. As an example of a late empathic rupture, it showed the strength of the relationship we had established because despite my inattentiveness he persisted in his effort, which suggested his trust that I would hear him. In the end this episode enriched my understanding of his experience and thus the research data as well.

> *P4: Sometimes I wonder, you know, what the hell goes on with my head, because sometimes I get very melancholy and say, shucks* [pause] *I can sit and watch a show* [pause] *and it's pretty hard not to just out and* [pause] *cry* [pause] *you know* [pause] *and I say, silly boy, but it's*
> *R: Well you probably wouldn't be human if it didn't get to you now and then.*
> *P4: Well they say grown men don't cry.*

> *R: That's right—and probably we'd be a little healthier if they were able to cry a bit more.*
>
> *P4: Yeah, just give in, instead of trying to hold it all back* [pause] *gotta be tough.*

Recognizing that this was a real concern for P4, one that was consistent with his affect and monotonic speech, and having his permission to do so I spoke with his respirologist about the possibility that he might be clinically depressed. During the next clinic session, P4 was assessed and started on antidepressant medication, which greatly improved his mood, fatigue, and quality of life.

Many of participants' current concerns focused on difficulties associated with daily living, things they forgot or chose not to address with any of the physicians involved in their care. The far-ranging nature of the study dialogue provided ample opportunity for these concerns to surface and be discussed. Participants frequently expressed a sense of frustration about the lack of clinical attention to these needs; at times these needs seemed to be their primary concern, one that could and did impact their COPD status. This was certainly the case for P3. His isolation and loneliness appeared to be exacerbating and precipitating breathlessness crises and intense anxiety. His daughter, C3, was very concerned about him, but unable to provide additional daily support. They were both also concerned about his medication--he consistently ran out of his anxiolytic medication because he would take extra whenever he felt himself becoming short of breath and panicky.

> *C3: He's getting a lot of anxiety* [pause] *and it's from being in here* [pause] *that's a concern of mine as well because he's taking his pills when he's not supposed to* [pause] *I've been to the doctor and had his medication into blister packs (P4: Yeah* [pause] *I've got one right here (he shows me the current pack and says he took one this morning already, indicating the Atavan))* [pause] *and he's been messing up on his pills quite a bit* [pause] *every time I come in I check his blister pack (P: I took one this morning around 6:00)* [pause] *ah, you knew I was coming [she laughs]* [pause] *what he does sometimes is* [pause] *his Atavan* [pause] *the Lorezepam for anxiety [R: Yes]* [pause] *he'll run out of these because he'll take more* [pause] *he'll take one out of the top pack and take it in the afternoon 'cause he'll feel like he's having anxiety but then by the time* [pause] *his blister pack comes every Wednesday* [pause] *so by the time Wednesday comes he's two and three out and he needs more* [pause] *and I've been really concerned about him* [pause] *either the doctor can change it and maybe Dad does need them in the afternoon that would be fine* [pause] *but I have to go back and see the doctor.*

In the course of discussing his uncertainty, hope(s), and fears, he acknowledged things were pretty bad as they were and expressed an openness to considering suggestions of an alternate level of care such as assisted living. In the following excerpt I summarized the concerns discussed to that point to clarify what issues P3 and C3 wanted me to follow up.

> R: Okay, [pause] *so the things I think that have been most important up to now have been thinking about getting you into assisted living somewhere where you will have more help, you'll have your food, and you'll have your medication looked after so you wouldn't have to worry about those and C3 wouldn't have to worry about those.* [pause] *Would that seem like a reasonable alternative to you,* [C3]*?*
>
> C3: *As long as it makes Dad feel better.*
>
> R: Yeah [pause] *as long as it's not going to* [pause] *if it makes you feel worse then it's not what we want to do.*
>
> P3: *No, I think it would make me feel a little bit better [R: I do think it would]* [pause] *I'm here all day by myself.*
>
> R: Exactly [pause] *and it won't happen tomorrow, even if we get your name in now.*
>
> P3: *I know, there's a waiting list as long as your arm.*
>
> C3: *And he wants something close by, I know that's his concern, if I was close by I could come all the time* [pause] *but you'd still have people around so then you'd have help all the time, daily* [pause] *or once a week.*

With P3's permission, I described his situation to his respirologist who as mentioned was also a member of my doctoral committee and a c-principal investigator named in the study consent form. After hearing the situation he put in a referral to the unit social worker. Subsequently P3 underwent a formal assessment and happily moved into a more social and supportive long-term care setting. An admission to hospital during this time also gave him a reprieve from his isolation and intense fear of suffocation.

Functioning as liaison.

Functioning as liaison involved a focus on facilitating collaboration--between patients and their intimate others; patients and intimate others with their clinicians; and beyond the research context, among members of the healthcare team. I have already described participants' (particularly intimate others') appreciation of the discussions as a way to breach the silence that some patients had imposed around the subject of their future goals of care. My follow-up discussions with P3's and P4's respirologist exemplified my collaborative efforts address current care concerns relevant to their goals

of care. This focus on promoting collaboration at all levels of the care continuum was the essence of "functioning as liaison." This also exemplified the importance of being prepared for potential role conflict introduced by tension between the demands of being both researcher and clinician. Again because of my focus on patient-centred and relational care ethics, and the CDHA research mandated requirement that a patient's wellbeing come before any research interest of the principal investigator(s) (CDHA, 2007), I chose to err on the side of my obligation to care. As I worked through the interpretation of the data this decision emerged as an important subtheme within the advance care planning process, one that is discussed more fully in the next chapter.

Summary of "being a resource."

This was an organizing theme very much related to increasing participants' capacity to make informed choices regarding their care and continued coping. Education, advocacy, and liaison all related to strengthening this capacity and decreasing their related vulnerability by responding to their unique needs in these areas and helping them connect to much needed resources. Participants' appreciation for the chance to learn about their options and COPD-related questions was connected to the dynamics of this theme.

Summary of Findings.

The overarching theme "advance care planning as collaborative care" speaks to advance care planning understood as a collaborative care process that encompasses but is not confined to end-of-life concerns. The three organizing themes--partnering, negotiating ambiguity, and being a resource--reflect the process and content of this approach. Advance care planning as implemented in the study provided a tangible opportunity to discover, explore, and care appropriately for many different facets of individually expressed illness-related suffering. Some of these concerns could be addressed by appropriate support during the advance care planning sessions, some were dealt with by referral to the patient's physician, and some were a matter of facilitating discussion between the patient and his/her intimate other(s). Viewed as a collaborative, integrated approach to care these findings have significant implications for rethinking the role and paradigm of advance care planning in the context of chronic illness generally, but in COPD particularly.

Chapter Five: Discussion and Conclusions

In this chapter I discuss the study findings and propose a revised understanding of advance care planning grounded in those findings. In the first section of the chapter I return to the current problems with advance care planning in advanced COPD. Within this context, I situate a discussion of the study themes as outlined in Table 2. I then discuss the advance care planning approach based on these themes in terms of the literature concerning patient-centred care, relational care ethics, collaborative care, shared decision-making, and advance care planning in chronic illness contexts. I address the clinical implications of the approach from the perspective of other common paradigms in the advance care planning literature. Using these insights I then return to the study question: *What is required for meaningful and effective advance care planning in the context of advanced COPD?* The final section of the chapter provides a discussion of study limitations, directions for future research, and conclusions.

Advance Care Planning as Collaborative Care

Table 2. Summary of Study Themes

Global Theme	Organizing Themes	Basic Themes
Advance Care Planning as Collaborative Care	Partnering	Creating relational space
		Building therapeutic relationship
		Discerning participants' perspectives
	Negotiating Ambiguity	Exploring fear and hope
		Acknowledging uncertainty
		Addressing suffering
		Engaging hope
	Being a Resource	Providing education
		Being an advocate
		Functioning as liaison

Advance care planning in COPD: a review.

The study was born of a desire to respond to problems related to advance care planning for those living with advanced COPD. Many clinicians hesitate to initiate advance care planning with patients (and their intimate others/substitute decision-makers) citing prognostic uncertainty, potential to erode patients' hope, time constraints, and inadequate communication skills (Blackler, et al., 2004; Crawford, 2010; Curtis, 2000,

2006; Curtis, et al., 2004; Curtis, et al., 2005a; Goodridge, 2006; Gott, et al., 2009; Hardin, et al., 2008; Knauft, et al., 2005; Rocker, et al., 2008; Rocker, et al., 2009; Spence, et al., 2009; Yohannes, 2007). Patients need and desire for timely, sensitive advance care planning discussions that include their family members/substitute decision-makers is evident despite clinicians significant and well-documented concerns (Curtis, 2000; Glass & Cluxton, 2004; Goodridge, 2006; Hansen-Flaschen, 2004; Neerkin & Riley, 2006; Nicolasora, et al., 2006; Seamark, et al., 2007; Sudore & Fried, 2010; Varkey, 2003) and born out in this study. Too often, patients with advanced COPD (many of whom live with significant co-morbidity) are not invited or encouraged to address goals of care until an illness crisis occurs. It seems many physicians are satisfied to equate advance care planning with a single-session "do not resuscitate" or "code status" discussion at these times (Downar & Hawryluck, 2010). Anecdotal evidence attests to the practice and negative effects of tasking junior physicians to obtain this decision (Rocker, 2010). As well, intimate others and/or substitute decision-makers may be left out of such discussions (Crawford, 2010; Gott, et al., 2009; Hines, 2001; Hines, et al., 2001; Murray & Jennings, 2005). It is not hard to see how this crisis-oriented approach might worsen an already stressful situation. It is also ethically questionable given the increased potential for an inadequate or erroneous representation of patients' care values/preferences. Initiating or withholding life-sustaining interventions when a patient prefers the opposite has significant ethics implications related to beneficence, non-maleficence, respect for autonomy, and resource utilization (justice). The findings from the study offer a more patient-centred, ethical, and timely alternative.

Advance care planning in COPD: a collaborative care alternative.

The global theme, *advance care planning as collaborative care*, highlights two key constructs that were central to the process as experienced by participants and the researcher/facilitator. The first is that patients and family members experienced the discussion as "care," the second is that this discussion developed collaboratively, with input from all of us. These points seem particularly relevant in the advanced COPD context given the fragmentation of care and the degree of marginalization and vulnerability reported by so many of these patients and their intimate others.

The "caring" discussion as experienced by participants involved three elements encompassed by the organizing themes: *partnering, negotiating ambiguity,* and *being a resource*. Each of these was developed through a number of facilitating activities. *Partnering* was based on *creating relational space* that led to *building a therapeutic relationship*, which in turn enabled *discerning participants' perspectives*. The second organizing theme *negotiating ambiguity* involved *exploring fear and hope, acknowledging uncertainty, addressing suffering*, and *engaging hope*. The third focus, *being a resource*, required attention to *providing education, being an advocate*, and *functioning as liaison*. Although described separately here for purposes of clarity, these themes represent three intertwining strands of a collaboratively evolving advance care planning discussion.

The related literature on patient-centred care, collaborative care, relational care ethics, and advance care planning in cancer and chronic illness revealed a number of constructs similar to the study themes. Further exploration of these parallels provided the basis for developing a "collaborative care" approach for conducting advance care planning with patients and their intimate others living with advanced COPD. The three organizing themes from the study: *partnering, negotiating ambiguity*, and *being a resource*, shared much in common with four constructs from the literature--finding common ground, managing uncertainty, addressing vulnerability, and creating shared meaning. The basic themes associated with *partnering* corresponded closely to elements in "finding common ground." *Negotiating ambiguity* encompassed most of the elements associated with "managing uncertainty" and "addressing vulnerability." There was also significant overlap between *being a resource* and "creating shared meaning." However, the relational interaction fostered using the study's advance care planning approach resulted in participants feeling cared for in a way that sets this "collaborative care" approach apart from other advance care planning models in the literature. The added focus on caring, engaging hope, reflective praxis, and contextual sensitivity is an adaptation of current patient-centred advance care planning theory particularly well suited to the context of advanced COPD. The potential for enhancing ethical practice and patient, family, and clinician satisfaction with care makes this approach worthy of further exploration to assess its appropriateness for other chronic illness contexts.

Advance Care Planning as Collaborative Care: more than "code status"

1. Partnering: goal - finding common ground

- *creating relational space*
- *building a therapeutic relationship*
- *discerning participants' perspectives*

2. Negotiating ambiguity - goal: managing uncertainty, addressing vulnerability

- *exploring fear and hope*
- *acknowledging uncertainty*
- *addressing suffering*
- *engaging hope*

3. Being a resource - goal: creating shared meaning

- *providing education*
- *being an advocate*
- *functioning as liaison*

Figure 2, a graphic representation of the study's advance care planning approach, summarizes the elements as a three-way (pyramidal) collaborative process.

As with any pyramid, the three-sided approach involving the patient, her/his intimate other, and the facilitator strengthens structural integrity. Developing that structure begins with ***partnering***, incorporates elements of ***negotiating ambiguity***, and adds in ***being a resource*** as required. The resulting interaction is a multi-dimensional collaboration formed from a unique mix of these three dynamics based on the patients and intimate others desires/needs. These will be somewhat different in each case and, even within a given family, are likely to vary from session-to-session as illness progresses and other factors in life change.

As well as three strong sides, the structural integrity of a pyramid requires a solid base. The **home** setting provided the base for the developing structure in the proposed approach. The centrality and size of this element in the graphic give some indication of its significance for the patient/family-centredness of the interaction. However, the graphic also includes a link between the participants in the home setting and the **healthcare team** within the larger **healthcare system**. Failing to connect the two settings can perpetuate the current lack of communication and awareness about patient/intimate others'

preferences related to goals of care and decision-making. In contrast, advance care planning facilitated as a three-way process attending to all the elements and connected to the team beyond the home can be experienced as collaborative care on a number of levels--patient/facilitator, patient/family, facilitator/patient/family, facilitator and healthcare team.

Figure 2. Advance care planning as collaborative care
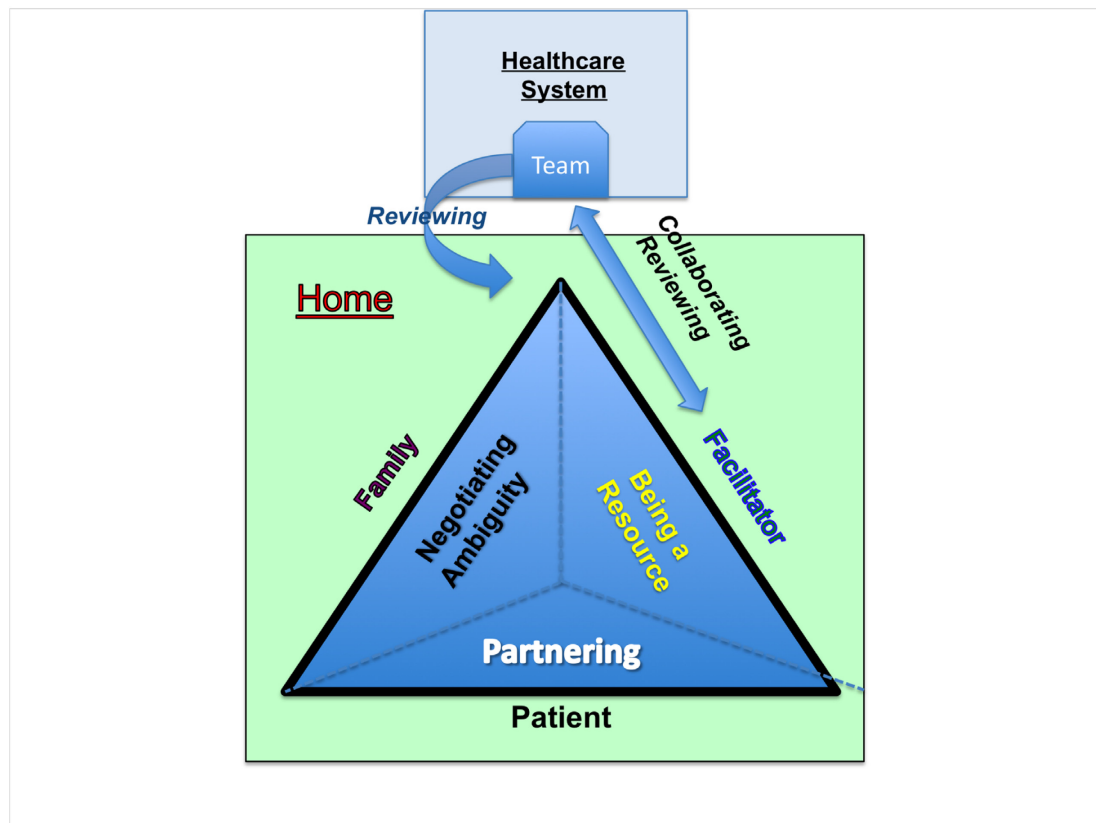
Reclaiming the "care" dimension in advance care planning.

Although the elements of the approach are presented as an ordered list, when done well, these elements are interwoven throughout advance care planning so that the resulting discussion reflects the priorities and style of each patient and her/his intimate others. The concordance between the structure of the discussion and participants priorities and styles depends in large measure on the facilitator's skill in promoting *partnering, negotiating ambiguity,* and *being a resource*. This was not difficult in the

study sessions because participants welcomed a chance to share experiences and concerns with a clinician they saw as interested and caring. By virtue of their illness, its associated isolation, and the generally fragmented nature of their medical care, many felt abandoned and vulnerable, desperate for social contact and clinical support in any form. None of the participants I met with asked me to leave or refused the second visit, even those who seemed most leery about considering end-of-life care. By the end of the sessions all expressed appreciation for the discussions as a chance to learn, be heard, and cared for. It seems that the elements in the approach worked together toward this outcome. The literature provides additional insight into this process and the proposed approach.

Partnering as care.

The activities that facilitated **partnering** included *creating relational space, building therapeutic relationship*, and *discerning participants' perspectives*. The notion of **partnering** implies inherent relational and trust-related dynamics. There are bi-directional implications as well. In the study, advance care planning was not just about *me* (as facilitator) trying to understand *participants* and their experience; it was also about *them* getting to know *me* and something of my experience. My focus was on communicating in a way that enabled this reciprocal give-and-take as a way to share power to some extent and increase our comfort with each other. As this process evolved, trust and relationship strengthened so that participants were able to both contribute and receive information. This shaped the ongoing interaction and helped them more fully understand illness effects in terms of current concerns and relevance to end-of-life care and decision-making. Thus **partnering** enabled us to "find common ground," an element mentioned frequently in the literature on patient-centred care and also referred to indirectly in relational care ethics.

Partnering was an evolving, self-reinforcing dynamic over the course of the sessions. As we talked and participants increasingly shared their stories, we were weaving a relational net comfortable and strong enough to support the more uncertain and emotionally laden advance care planning discussion to come. While weaving that net required input from all, the resulting texture and pattern needed to reflect the patient's and intimate other's perspectives and preferences to promote their engagement. As the person

required to set up the "loom," select the materials, and oversee the weaving process, I focused on fostering **partnering** through identifying, understanding, and integrating these perspectives. This was a process of encouraging, listening to, and not rushing or limiting their input, using it to figure out what was most important to them, and developing a framework based on how and where advance care planning fit best with these issues. The quality of the **partnering** effort, which enabled us to "find common ground," was partially dependent on discerning how ready each set of participants was to contemplate and/or discuss potential end-of-life care and decision-making implications of advanced COPD. Assessing and working with their stage of readiness depended on the use of a relational communication approach.

Creating relational space.

Active listening was the basis of *creating relational space* and the basis of communication throughout the study. Effectively *creating relational space* depended on my ability to *listen attentively*, respond with accurate *empathy*, and relate to participants with *unconditional positive regard* and *genuineness/authenticity*. Empathy refers to being able to *feel into* another's experience through a process referred to as "vicarious introspection" with a goal of understanding what the other is feeling (Orange, Atwood, & Stolorow, 1997; Wolf, 1988). The practitioner listens and checks back using techniques such as partial rephrasing, paraphrasing, analogy, and/or clarifying comments to see if s/he has understood the speaker's meaning (Doehring, 2006; Miller & Jackson, 1995). Empathy was a major aspect of *creating conversational space* to promote the development of **partnering**.

Several researchers have emphasized the importance of empathy as a tool for the clinician to check both her own and the patient's/family's understanding, (McCormack, et al., 2011; Parker, et al., 2007; Seymour, et al., 2010). Empathy as an element of **partnering** required a two-way focus on their understanding of my questions along with my understanding of what they were sharing with me in response. To do this well required attention to verbal input and non-verbal clues such as facial expressions, body language, and the way words were delivered (tone, cadence, intensity, and volume) (Miller & Jackson, 1995). Considered a gift and a skill, an attitude and an approach, accurate and genuine empathy includes a strong sense of interest in and caring about the

wellbeing of the "other" (Abma, 2005; Fan, 2005; Kirchhoff, et al., 2004; Krasner, et al., 2009; Miller & Jackson, 1995; Wolf, 1988). Thus empathy that is accurate and used appropriately can promote a sense of rapport, trust, and relational caring while at the same time enabling increased insight into the experience and feelings of the "other." It is this sense of genuine caring that enables a clinician to "feel into" the experience of the other and discern emotion to guide an appropriate response. Thus competence in the accurate and appropriate use of empathy can facilitate the ***partnering*** process. Lorenz et al (2008) in their systematic review of evidence for improving care at the end of life have documented that a skilled facilitator is the essential element in effective advance care planning discussions. It appears that one of those skills should be competency related to the use of accurate empathy if the clinician is interested in facilitating effective advance care planning discussions in chronic illness contexts.

Another important focus in *creating relational space* required *unconditional positive regard* by the facilitator. Avoidance of judging, blaming, criticizing, shaming, or humiliating the speaker regardless of what that person chooses to divulge is important (Miller & Jackson, 1995). Validating, affirming, reassuring, and/or avoiding negative comments and facial expression/body language demonstrates *unconditional positive regard*. For example, P3 had a habit of sprinkling his conversation with what I considered inappropriate sexual comments. I was also aware of feeling somewhat repulsed by our surroundings (expectorant bucket, cigarette smoke, dirty sheets). Because I wanted him to feel comfortable with me and with the discussion, I worked to repress my negative reactions and chose to respond positively instead. I laughed with him as he shared his experiences and perspectives in his own natural, earthy style. Being aware of and containing my negative feelings enabled empathy and compassion to surface and a stronger therapeutic relationship to develop as the extent of P3's vulnerability, fear, and loneliness became more evident. However, this dynamic highlighted another important facilitator skill--monitoring internal process (referred to in the study analysis as *facilitator issues*) that is also an influential factor in relational communication (Cooper-White, 2007; Doehring, 2006; Kelly, Varghese, & Pelusi, 2003; Krasner, et al., 2009; Meier, Back, & Morrison, 2001; Miller & Jackson, 1995).

Monitoring my internal process was an important part of the bi-directional process of *active listening*--focusing outward to monitor participants' needs and inward to monitor my own internal reactions, which could affect how the discussion unfolded. Emotions, pre-understandings, and assumptions influenced the developing discussion during the sessions--the when, how, and why of my responses to participants. These motivate choices to move the conversation (and the therapeutic relationship) in certain directions and not others (Miczo, 2003). Referred to as countertransference dynamics, Kelly, Varghese, and Pelusi (2003, p.368) describe them as

> *the unconsciously determined responses of a clinician to the specific*
> *characteristics and behaviors of the patient based upon the [clinician's]*
> *previous patterns of significant relationships in his or her life.*

They stress the importance of clinicians monitoring countertransference by being aware of their emotional reactions to individual patients, and to use these to gain helpful insight into these individuals' thoughts and concerns (Kelly, et al., 2003). Such insight provides additional clues for *empathy,* which aid the ***partnering*** dynamic. Countertransference dynamics may also affect clinicians' and patients'/intimate others' health-related understanding and decision-making. A clinician frames information in a particular way (based on often unconscious hopes/goals, uncertainties, negative reactions or judgments), but how clinical information is presented influences patients decision-making (Epstein, 2006; Epstein & Peters, 2009; Kiesler & Auerbach, 2006; Saba, et al., 2006; Salmon & Young, 2005; Thorne, et al., 2006; Thorne, et al., 2007; Thorne, Bultz, & Baile, 2005). The consequences are significant.

> *In emotionally charged situations, preferences may not be elicited as much as*
> *they are constructed--shaped by how information is presented and by the*
> *opinions of family, friends, and the media. (Epstein & Peters, 2009, p. 195)*

It is important to remember that the "what" and "how" of input, or lack of it, from significant others (family, friends, clinicians), influences how people will manage uncertainty (Brashers, 2001) and hope (McGeer, 2004; Simpson, 2000, 2002, 2004).

Hines (2001) points out that clinicians contemplating advance care planning in chronic illness contexts tend to privilege, consciously or unconsciously, their own

agendas. Lack of awareness of internal process or how this can affect communication with patients/intimate others may result in clinicians' unconscious avoidance or manipulation of these emotionally intense discussions. As Knops et al (2005) have suggested, "physician avoidance of discussing a terminally ill patient's thoughts of death is tantamount to 'see no evil,' rather than 'do no harm'" (p.297). The current situation points to clinicians and health educators' apparent lack of regard for and/or training in the sort of reflective practice that would increase their awareness and engagement of this internal process (Krasner, et al., 2009). The study findings suggest that facilitator skill in this self-reflective practice along with increased attention to discerning participants' perspectives may offer an advantage over the current clinician-centred approach to advance care planning (Black, 2007).

The third element in *active listening* was *genuineness*, also an important factor for encouraging rapport and trust (Miller & Jackson, 1995). *Genuineness* speaks to considerations like authenticity, honesty, transparency, integrity, and consistency. Imparted by manner as well as behaviour, it can be enhanced through appropriate sharing from personal experience and perspective (Miller & Jackson, 1995; Yedidia, 2007). Many times in the sessions sharing a personal story demonstrated an empathic understanding of participants' feelings that reduced the power differential and strengthened the therapeutic relationship. As an example, C8 asked me about my understanding of life after death--did I think it was likely that we would meet up with loved ones now dead. He seemed to be trying to make sense of life and death using this perspective. I answered the question from a theological perspective, but also offered my own opinion, which I sensed he wanted. In my answer I was sensitive to his vulnerability in venturing to ask this question and emphasized the considerable uncertainty that surrounds this topic. Both he and P8 appeared to appreciate my answer as validation (as opposed to criticism or deprecation) of how they were making sense of a highly uncertain, but clearly important issue for them. I crafted my response very carefully to be honest about my own sense of the issue without closing any doors his question might be opening, including those related to hope.

Following this exchange he chose to share the painful experience of the unexpected death of their infant son. This was a pivotal shift in our discussion because

previous experience(s) with death and dying is reported to be a facilitator of individuals' openness to considering advance care planning (Fried, et al., 2009; Sudore, et al., 2008). By sharing my own perspective on what is viewed as an essentially uncertain, existential or spiritual issue, I demonstrated my commitment to being open, honest, and non-judgmental--*genuineness*. C8's revelation about the death of their infant son indicated a deepening of rapport, trust, and relationship; this was a family that initially expressed strong reluctance to discussing anything related to death or dying. This sort of development in the discussion (and in discussions with other participants) suggested to me that being *genuine* helped to promote mutuality. *Genuineness* is thought to foster reciprocity, definitely part of the sharing power/ common ground dimension of patient-centredness (Hudson, et al., 2011). *Empathy, unconditional positive regard*, and *genuineness* thus worked together to encourage mutuality, enhance trust, and foster *therapeutic relationship*. This facilitated participants' willingness to begin to share their concerns and perspectives with me, providing clues to their priorities. In the process, rapport and trust continued to develop and were foundational for *building therapeutic relationship*.

Building therapeutic relationship.

Relationship is another concept with an inherent sense of reciprocity. Throughout the study sessions my communication focus was on developing rapport and trust enough to foster a mutually reinforcing relationship to ease tension, increase comfort, and deepen understanding. To monitor this I paid attention to participants' engagement in the developing conversation--their interactions with each other, who was/was not participating, and the depth and focus of the discussion, as well as my own internal processes. Participants' willingness, indeed eagerness in many cases, to share their COPD-related experiences and feelings suggested a developing comfort with the process and trust in me. Given my goal of initiating advance care planning with participants I had never met and for whom this was likely to be a new, not necessarily welcome activity, fostering rapport and trust seemed a logical place to put significant focus early in the process. In return, participants shared their frustration, anger, fear, and hope related to COPD effects, treatment, their intimate others, clinicians, and the healthcare system. As part of the rapport and trust building I also shared some of my COPD-relevant experience

with them, from both personal and professional (ethics and chaplaincy) perspectives. Thus despite the fact that the ***partnering*** could (and should) not be on equal terms (due to their reliance on clinical expertise), it had important dynamics of mutuality woven throughout. My attention to strengthening mutuality and balancing the power aspects of the interaction encouraged *therapeutic relationship*, which in turn encouraged participants to talk about their experiences and concerns.

Discerning participants' perspectives.

Participants' decision to trust me enough to share their experiences opened a window for me to begin to "see through their eyes" (Saha, et al., 2008). *Discerning participants' perspectives* was the third basic theme in ***partnering***, and highly significant in terms of assessing participants' readiness and creating a meaningful framework for the advance care planning discussion. Without sufficient attention to this element, the process would have been irrelevant at best, and harmful at worst. As Epstein et al (2010) have suggested

> *each patient with the same disease will have different sets of concerns, contexts, and health beliefs, some of which have been shaped by discussions with family or coworkers or by information in the media. (p.1490)*

Not surprisingly *participants' perspectives* more often revealed priorities related to their current, rather than future care. The initial study guide question about their COPD diagnosis and its effects was a way to encourage participants to talk about their perspectives and priorities (Briggs, 2004; Briggs, et al., 2004). I chose to use this question from the *Respecting Choices*(R) model where it is used to enable the facilitator to "see through the eyes of the patient" (Briggs, 2004, p. 343). I felt it would be a familiar, relevant, and hopefully non-threatening topic with which to begin the conversation. The first responses gave me significant clues about their quality of life, current challenges, relationships, coping, values, and priorities. While this was the only time I used the conversation guide during the sessions, it was helpful for getting the discussion started and as a check at the end of sessions for me to see if/how well we had covered the topics listed. It provided an opening through which to explore and *discern participants' perspectives*.

The action underlying this theme involved identifying and understanding their concerns, inquiring about and validating beliefs and expectations, and empathetically responding to emotional distress (Fiscella, et al., 2004). *Discerning participants' perspectives* included listening for their preferred decision-making styles, an important aspect to clarify in an effective advance care planning discussion (Fried, et al., 2009; Godolphin, 2009). A shared decision-making approach has been much advocated in patient-centred care, and refers to offering patients (plus intimate others if the patient chooses) whatever level of decision-making involvement they prefer (Makoul & Clayman, 2006; McCormack, et al., 2011; Parker, et al., 2007; Yedidia, 2007). In the study I incorporated elements of this approach including attention to patient factors and decision context (Briggs, et al., 2004), relationship and communication (Lee, et al., 2009; Saba, et al., 2006), patient preferences for information and style of decision-making, and clinician/patient concordance (Kiesler & Auerbach, 2006; Makoul & Clayman, 2006). Clinician/patient concordance is also an aspect of relational care theory, which involves seeking a consensus between the patient and clinician concerning the needs to be addressed as well as the most appropriate approach for addressing them.

My effort to *discern participants' perspectives* was further aided by the venue we chose for the study sessions. I offered to meet with participants in their homes (if they preferred) to increase the likelihood of the process being comfortable, agreeable, and accessible for them. I felt attending to their comfort level was an important aspect of the **partnering** process. Offering to meet with them in their home setting was also a tangible way to help offset the power differential imposed by my inherent professional authority (Bergum & Dossetor, 2005; Christ & Blacker, 2006; D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005; Dubler, 2005; Hebert, 2005; Simpson, 2000, 2002). In hospital and clinic settings the authority vested in professionals by virtue of their expertise and status is clearly visible (white coats, nurses' scrubs, stethoscopes and other equipment). Acknowledging the power imbalance and acting to share power with participants by offering to come to them at home demonstrated respect for their comfort, needs, and preferences (Bergum & Dossetor, 2005; Briggs, et al., 2004; Goldberg, 2005; Scanlan & Kerridge, 2009). I hoped that meeting with them in their own surroundings would make the sessions less intimidating for them.

Meeting in their homes ensured that I (as facilitator) would experience first hand something of participants' circumstances and influences, particularly those related to their vulnerability and/or marginalization. This helped me develop a more contextually based insight into their decision-making styles, considered relevant for enhancing informed choice (Scanlan & Kerridge, 2009). My strong emotions during this contextual immersion suggest that a clinic/hospital venue may have impoverished the discussions and my insights into participants' lived experience, values, and decision-making influences. Finally, meeting in participants' home settings may have facilitated greater privacy and confidentiality, less chance of interruption, and a more relaxed ambience than would have been likely in a clinic or hospital ward. Of course this choice of venue has important implications for a healthcare system that dispenses "care" from a central location based on efficiency and convenience for clinicians but not necessarily for patients and their intimate others. As chronic illness continues to place increasing demands on both human and material resources within the healthcare system, alternate models of care delivery will continue to proliferate and gain credibility. High-quality care for those living with chronic illness,

> *seeks to promote a fuller understanding of the patient's life and preferences, "activation" or "empowerment" of patients, and tailoring of management to patient preferences. (Wagner, et al., 2005, pp. S-8)*

Wagner (2005) points out that these are also elements of the patient-centred care model as well. The Chronic Care Model stresses "the essential roles of an activated patient and a collaborative approach to self-management support" (Wagner, et al., 2005, pp. S-11). It advocates community-based care delivered within a team context that promotes and supports patient self-management to enhance quality of life and health status. Much of this care is envisioned to take place in the home, adding feasibility to appropriateness in terms of home as a venue for advance care planning. Zoffman, Harder, and Kirkevold's (2008) research on clinician/patient communication related to diabetes self-management further supports a home-based shared decision-making approach to enhance practice in this area.

Summary.

Partnering was a process of "finding common ground," a common dimension in both patient-centred, relational care ethics, and collaborative care theory. Three basic themes--*creating relational space, building therapeutic relationship,* and *discerning participants' perspectives*--were foundational to the ***partnering*** process. As an element of patient-centred care, "finding common ground" is associated with appropriate sharing of power and responsibility (Hudson, et al., 2011). In the study, meeting in patients' homes was part of the process of sharing power. *Creating relational space* was based on relational communication that included active listening, empathy, presence, and genuineness. *Building therapeutic relationship* relied on developing trust and rapport and de-emphasizing my professional authority/power sufficiently to enable an environment in which *participants* felt comfortable to share their *perspective*s. Without this I could not have identified the individually meaningful values and priorities with which to frame the subsequent advance care planning discussion. From the perspective of collaborative care theory, two concepts--sharing and partnership--reinforce the idea of locating common ground as the basis of sound clinical encounters, and underscore the importance of the ***partnering*** focus (D'Amour, et al., 2005; McDonald & McCallin, 2010). Such efforts include exploring patients' perspectives, building rapport and maintaining relationship, mindful practice (clinician self-monitoring of internal process), and acknowledging social or emotional clues with empathy (Rao, Anderson, Inui, & Frankel, 2007).

These communication foci identified by Rao et al (2007) echo the interactive elements identified in the study's ***partnering*** theme. It is important to note that these elements, despite being central to patient-centred care, relational care ethics, and collaborative care theory, are still frequently missing in practice contexts of advanced chronic conditions like COPD (Reinke, et al., 2011). The uncertainty that characterizes advanced COPD continues to discourage clinicians from pursuing advance care planning with patients/intimate others even though research including this study has shown that many desire and/or are open to it (Crawford, 2010; Curtis, et al., 2005a; Davison & Simpson, 2006; Goodridge, 2006; Goodridge, et al., 2009; Reinke, et al., 2011; Rocker, et al., 2008; Seymour, et al., 2010; Spence, et al., 2009). Its central role in the lives of patients and their intimate others living with advanced COPD as well as in clinicians' avoidance of advance care planning in this context, make uncertainty a logical and

significant issue to address in any advance care planning model designed for use in this context.

Negotiating ambiguity.

This theme focuses on the issue of uncertainty. It was important to try to understand the role uncertainty was playing for participants in their illness experience and coping. Clinicians who do not make an effort to understand the role of uncertainty in patients and their intimate others illness coping efforts risk undermining important contributors, such as hope, that this uncertainty serves to support (Brashers, 2001). According to Brashers (2001), uncertainty about a particular outcome or issue can be positive, negative, or both, depending on the situation and the individual. Positive uncertainty can help an individual sustain hope by opening up the future as a place of highly desirable possibility (Brashers, 2001; Weingarten, 2010). Similarly, negative uncertainty increases anxiety and fear by casting the future in terms of highly undesirable possibility. Such hope and despair dynamics often co-exist and are common in chronic conditions characterized by high uncertainty and undesirable prognosis (Weingarten, 2010). The underlying illness implication of any advance care planning discussion is inevitably death, which may invoke despair. However uncertainty maintained by ongoing treatment, unpredictable illness trajectory, and individuality of response, makes room for continuing hope of varying sorts and degrees. Identifying a discussion framework that could support the positive while mitigating the negative was central to ***negotiating ambiguity*** in the study. From this perspective, discovering what and how uncertainty mattered to participants provided the basis for developing this framework. *Exploring fear and hope, acknowledging uncertainty, addressing suffering,* and *engaging hope* were the four elements underlying ***negotiating ambiguity***. Exploring fears and hopes provided clues to the uncertainty-related concerns most significant to participants. Many study participants experienced uncertainty as a source of both fear and hope in the face of relentless but unpredictable illness progression.

Most participants initially expressed discomfort with the idea of considering or discussing death and dying, which indicated they felt vulnerable and sensed some "risk" in doing so. This is consistent with the literature that attests to the links between

uncertainty, hope, fear, and vulnerability (McCormack, et al., 2011; Simpson, 2000, 2002, 2004; Street, et al., 2009; Teal & Street, 2009). The issues they preferred to talk about concerned current care needs rather than those related to end-of-life care or decision-making. This is consistent with research showing patients and their intimate others prefer to focus on living rather than dying (Knauft, et al., 2005; Knops, Srinivasan, & Meyers, 2005a). However there is also evidence that patients expect clinicians to raise end-of-life issues in a timely fashion and they appreciate opportunities to talk about related fears and hopes with interested, supportive clinicians (Davison & Simpson, 2006; Davison & Torgunrud, 2007; Fine, Reid, Shengelia, & Adelman, 2010; Heyland, et al., 2006; Liden, Ohlen, Hyden, & Friberg, 2010; Seymour, et al., 2010). *Negotiating ambiguity* was therefore a process of discerning participants' readiness and desire to consider, discuss, and/or learn about end-of-life care implications of COPD. This involved exploring their fears and hopes, current concerns, coping style, and related knowledge.

Exploring fear and hope.

In terms of readiness for advance care planning, uncertainty was a major determinant through its connection to participants' illness-related fears/concerns--fear of suffocation, pain, being a burden to loved ones, and/or dying a slow, undignified death on a mechanical ventilator. Some expressed a sense of uncertainty-related powerlessness or lack of control related to these outcomes. They questioned whether their preferences and decisions regarding end-of-life care would be respected even if they were able to consider, talk about, and/or document them. Not surprisingly most of their hopes--for longevity, self-management, preservation of dignity, and a peaceful death free of suffocation, pain, or lengthy intubation--ran parallel to their fears, indicating the significant role of uncertainty for both hope and fear. This chronic uncertainty included a sense of vulnerability and suffering as well.

In this study *exploring fear and hope* allowed me to discover how participants were reacting to and coping with the unpredictability of COPD. On a positive note, for most participants this uncertainty enabled coping based on a continued hope for longevity, which helped to offset their fear of suffocating to death. On the negative side I frequently heard illness and uncertainty-related anxiety about potentially becoming a

burden to loved ones that accompanied their ever-present fear of suffocation. The subsequent advance care planning discussion responded to this uncertainty through a framework of preparing for the worst while continuing to hope for the best (Back, et al., 2003). For some I framed "preparing for the worst" in terms of negative uncertainty by suggesting that providing guidance about end-of-life care preferences and decision-making could lessen some of the potential burden on intimate others and the potential for mismatched goals of care that might increase suffering. For those experiencing an uncertainty-related loss of control, I framed the discussion (and potential to document preferences) as a way to regain a sense of control by clarifying end-of-life care preferences and decision-making style to maximize the likelihood of receiving care concordant with their wishes. Thus the advance care planning discussions were designed to be meaningful in terms of the fears and hopes of individual participants.

Acknowledging uncertainty.

The significance of uncertainty/ambiguity for patients, their intimate others, and clinicians dealing with advanced COPD, well documented in the literature, suggested the need to sensitively acknowledge and address it. Ignoring it could have undermined any sense of my genuineness and integrity along with participants' trust, our developing rapport, and growing therapeutic relationship. Those researching patient-centred care, shared decision-making, and collaborative care emphasize the necessity of acknowledging and responding appropriately to uncertainty implications as an inevitable part of healthcare (Epstein & Peters, 2009; Haidet, Fecile, West, & Teal, 2009; Street, et al., 2009; Teal & Street, 2009). Similarly, Zelaidt et al (2006) refer to health-related decision-making as a "process of carefully balancing uncertain outcomes." Helping patients and their intimate others acknowledge the uncertainty is also a way of trying to prepare them for an inevitable and continuing aspect of chronic illness (including the possibility of sudden death), an important part of helping them cope (Brashers, 2001; Haidet, et al., 2009; Hines, 2001; Hines, et al., 2001; Street, et al., 2009).

Discussing their fears and hopes with me gave participants a chance to talk about the uncertainty connected to previous ER visits, hospital admissions, and illness exacerbations. Most recognized that this uncertainty was an ongoing part of the illness, which was likely to include future crises, events that increased the relevance of end-of-

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life care planning for them. Many had had experience with this sort of crisis, either as the patient or an observer, and they remembered the stress, uncertainty, and suffering that went with it. Although initially many were reluctant to return to those memories or to consider recurrences, by the end of our time together all were able to reflect on and address the topic to some extent. Becoming aware of tension or emotional discomfort signaled to me that the topic was a source of suffering for participants, which implied a need to respond. *Acknowledging uncertainty* is associated with a risk of introducing or worsening already existing confusion about the illness, treatment, and/or what to expect (Epstein & Peters, 2009). Thus my sensitivity to this risk and readiness to support participants emotionally, spiritually, and cognitively were important aspects of *acknowledging uncertainty*.

Finally, discovering substitute decision-makers' uncertainties was also an important focus in *acknowledging uncertainty*. During our conversations a significant number of intimate others expressed uncertainty, anxiety, and/or confusion with respect to end-of-life care decision-making for the patient. Many lacked confidence in their ability to act as the patient's substitute decision-maker because they were unclear about the patient's preferences. Some had tried unsuccessfully to get the patient to talk about the subject to get a better idea of her/his end-of-life decision-making values, goals, and/or preferences. This finding is consistent with the literature reporting that advance care planning discussions between patients and their substitute decision-makers/intimate others, like those between substitute decision-makers and clinicians, happen relatively rarely (Briggs, 2004; Briggs, et al., 2004; Evans, et al., 2009; Hines, 2001; Sudore, et al., 2008). Because these conversations are infrequent, substitute decision-makers often lack the information they need to make an informed choice consistent with the patient's preferences.

> *Rather than desiring less information in the face of uncertainty, most surrogates want more information, including clear information about uncertainty itself. The act of discussing uncertainty was viewed by some surrogates as a sign that the [physician] was trustworthy (Evans, et al., 2009, p. 52).*

All the intimate others in the study appreciated being part of the discussion of fears, hopes, uncertainty, end-of-life care options, preferences, and values clarification. As in other studies, by the end of the advance care planning sessions they were expressing more confidence in their ability to make decisions consistent with the patient's values and desires (Evans, et al., 2009; Hines, 2001; McCormack, et al., 2011).

The joint discussions meant the patient also heard his/her intimate others' concerns, witnessed the stress they were feeling, and had a chance to respond. Even though these patients had not (and maybe would not have) raised these topics themselves, they were able to address this uncertainty in the context of the study sessions. My presence (as facilitator) may have made this possible by creating a relational space and encouraging intimate others to raise their questions/concerns and by supporting patients emotionally to respond to them. For most patients the discussion of options and values with the substitute decision-maker led to a commitment concerning an instructional or proxy directive, and/or a more in depth discussion of preferences and overall goals of care. Perhaps having a neutral third party breach the walls of silence that had previously kept the subject "off limits" was a sufficient catalyst to enable the discussion to continue between the patient and their intimate other (Sudore, et al., 2008). In any case, it has been established that each discussion of this sort improves the chances that it will continue or be revisited (Garrett, et al., 2008; Rizzo, et al., 2010; Sudore, et al., 2008). Also, it seems that a discussion between the patient and intimate others makes it more likely that they will go on to have the discussion with their clinician and/or document preferences (Sudore, et al., 2008). Therefore it is more likely that study participants would continue to discuss or revisit the topic following our sessions, particularly if invited to do so by their clinicians.

Addressing suffering.

It was natural that uncovering and acknowledging uncertainty in relation to worsening illness, impending death, and dying could result in intense emotion (Epstein & Peters, 2009; Fried, et al., 2009; McCormack, et al., 2011; Spence, et al., 2009; Street, et al., 2009; Teal & Street, 2009). Feelings of relief, fear, grief, anger, frustration, hope, powerlessness, and/or guilt were expressed or shown, and necessitated appropriate emotional support (Epstein & Peters, 2009; McCormack, et al., 2011; Street, et al., 2009).

Theory related to patient-centred care, uncertainty-focused advance care planning, and collaborative care speaks of the necessity of recognizing and attending to patients/intimate others' emotional needs (Bergum & Dossetor, 2005; Brashers, 2001; Epstein & Peters, 2009; Hines, 2001; Hudson, et al., 2011; Mauksch, Dugdale, Dodson, & Epstein, 2008; McDonald & McCallin, 2010; Sharf & Vanderford, 2003; Street, et al., 2009). The quality of clinician responses to the often emotionally laden cues patients/ intimate others present when talking about these issues has been linked to outcomes such as patient satisfaction with care, quality of life, and quality of dying/death (Wright, et al., 2008). Recognizing and addressing emotional suffering is part of active listening (Street, et al., 2009), which is known to have a "supportive counseling" quality (Miller & Jackson, 1995). The sort of relational communication approach used in the study is known to have healing effects (Street, et al., 2009). I used empathy and active listening in the provision of psychosocial/spiritual support during these sessions.

Active listening requires being open to and comfortable with listening for and hearing suffering as a necessary step to addressing it. Research has shown that many clinicians prefer to focus on the medical/technical aspects of an encounter rather than the more emotional patient-centred aspects, often because of constraints and uncertainty (Epstein, et al., 2010; Fine, et al., 2010; Street, et al., 2009). In the study, advance care planning took place over two sessions that lasted on average an hour each, making this approach not practical for a busy physician-based office, clinic, or hospital consultation practice. However, incorporating the approach within the context of a chronic care model based on a more holistic approach to care may improve the feasibility from a time standpoint. Certainly it takes time to develop trust and a strong therapeutic relationship, but not as much time as may be supposed (Briggs, 2004). Within the study context, trust was established early in the process and strengthened throughout the sessions. Patients need to feel "safe" in order to disclose their feelings and trust that the facilitator is competent and able to support them during these deeply emotional, vulnerable moments (Street, et al., 2009). Skilled facilitators are able to quickly develop this sort of interaction with patients and their intimate others by recognizing the need for and using an appropriate relational style.

Liden et al (2010) describe two interactive frameworks from which to choose depending on the patient's particular needs--the "patient-professional" frame and the "person-person" frame. The first tends to correspond to the sort of medical/technical focus preferred by many clinicians; it plays up the power differential and is more about information relay than partnering (Briggs, et al., 2004; Liden, et al., 2010). It is still a valid patient-centred response for those who would rather not acknowledge or explore emotion. In contrast, the "person-person" frame offers a more equitable power sharing as the clinician seeks to develop a sense of shared understanding by connecting with the patient on a human/emotion level. This frame is similar to the ***partnering*** focus in the study. During the study discussions I used "presence" and empathy to discern how to respond to participants and then to provide the required support. In most cases this involved an expression of shared humanity, compassion, and understanding, all of which are known to strengthen rapport, trust, and the therapeutic relationship (McCormack, et al., 2011; Parker, et al., 2007; Reinke, et al., 2011; Street, et al., 2009).

"Presence," an element of active listening, was a way of *addressing suffering*. "Presence" is a way of accompanying (by being attentive to) and not abandoning patients and their intimate others, and thus tends to be experienced as support during emotionally difficult parts of clinical interactions (Epstein, 2006; Franks, 2010; Sinclair, et al., 2006; Weingarten, 2010). It was an indication of my interest in and commitment to their wellbeing, an important factor given many participants' growing sense of isolation and abandonment by family/friends and sometimes clinicians. Consistent with the "whole person/bio-psychosocial perspective" dimension of patient-centred care, being "present" to participants in the sessions included responding to their emotions with appropriate empathy, validation, and/or support (Epstein, et al., 2010; Epstein & Peters, 2009; McCormack, et al., 2011; Street, et al., 2009). In addition to psychosocial issues they frequently expressed spirituality/existential concerns that also called for appropriately sensitive responses, a finding consistent with others (Canada, et al., 2008; Galek, et al., 2005; Liden, et al., 2010; McCord, et al., 2004; Reinke, et al., 2011; Sinclair, et al., 2006). Most participants referred to faith issues at some point during the sessions, particularly when speaking about hope, coping, and trying to make sense of the present

and the future. In addressing this emotional, social, and/or spiritual/existential suffering I worked to preserve the possibility of hope their expressions of uncertainty conveyed.

Engaging hope.

Hope can be considered a positive expression of both an emotional and behavioral (agentic) response to uncertainty (Brashers, 2001). Anxiety, fear, and/or frustration are corresponding negative responses to uncertainty (Brashers, 2001), but positive and negative tend to co-occur as hope exists simultaneously on many levels (Cellarius, 2008; Herth & Cutcliffe, 2002; Nekolaichuk & Bruera, 1998; Nekolaichuk, Jevne, & Maguire, 1999; Ruddick, 1999; Simpson, 2000, 2004). These appraisals and emotional responses tend to motivate individuals to employ particular uncertainty management strategies to cope (Brashers, 2001; Liden, et al., 2010; McCormack, et al., 2011). Although the scientific method underlying our biomedically-oriented healthcare system seeks to reduce uncertainty and enhance predictability, not all patients and intimate others appreciate this approach (Brashers, 2001). The uncertainty and unpredictability of outcomes in chronic conditions like COPD actually provide room for possibility and thus for hope (Back, et al., 2003; Davison & Simpson, 2006; Milne, et al., 2009; Morse & Penrod, 1999; Simpson, 2000, 2002, 2004; Thorne, et al., 2006; Thorne, et al., 2007). For example, P4 described an episode that angered him when he was hospitalized for a serious COPD exacerbation. A visiting home care nurse had responded to his comment that he was not ready to die yet by telling him that this was "as good as it was likely to get." He was furious with her. Clearly he viewed uncertainty as a way to maintain hope despite the implications of worsening illness. Realizing that uncertainty filled this role for him helped me understand his reluctance when I first mentioned advance care planning. I was able to use this insight to approach the topic through his hope for longevity and desire to avoid intubation.

The work of Kaethe Weingarten (2000, 2004, 2007, 2010) was pertinent to engaging and working with participants' hopes and "addressing vulnerability." Weingarten describes her approach as "doing hope," a collaborative interaction with clients to pursue what she terms "reasonable hope" (Weingarten, 2000, 2007, 2010; Weingarten & Worthen, 2009). "Reasonable hope" to Weingarten (2010) is a relational, active stance that embraces uncertainty by seeing the future as open and malleable. It

explores goals and possible pathways for reaching them without downplaying the co-existence of doubt, despair, and contradictions (Weingarten, 2010). This latter was akin to the process of identifying and acknowledging uncertainty and suffering I used when doing advance care planning. It is an important focus because hopefulness has been associated with tangible benefits including better problem-solving, handling challenges, and coping with illness and disability (Weingarten, 2010). *Engaging hope* seemed a positive and relevant way to support and help participants address the vulnerability of worsening illness because it was a significant factor in their coping repertoire.

The "doing hope" approach entailed what Weingarten (2010) refers to as radical listening, bearing witness, accompanying, and resisting any urge toward indifference. My choice of active listening, presence, empathy, and unconditional positive regard was very similar. For example using active listening, empathy, and positive regard I came to understand that P3's continued focus on his present situation indicated that his "current needs" were the source of his debilitating fear and despair, and had implications for advance care planning. This insight led to a discussion framework in which we were able to identify and engage new, more hope-enhancing goals (healthier diet, smoking cessation, oxygen therapy, change in anxiety medication, social connections, help with activities of daily living) and some pathways (Meals on Wheels, assisted living arrangements, referrals for Home Care and medication changes) for achieving them. P3's increasing sense of vulnerability due to illness losses and inadequate living conditions was at the root of his suffering and struggle to maintain hope. As Sorlie et al (2006, p.1245) have suggested,

> *This [vulnerability] may explain why so many patients feel that they need more time to talk with their health care providers. They may be indirectly trying to express their need to discuss their fears as well as such existential ideas as their own mortality and death.*

Once his most pressing needs vis-á-vis vulnerability had been addressed P3 was willing to explore advance care planning decision-making, quickly delegating authority to C3 to make all such decisions for him. Addressing participants' fears, hopes, and resulting vulnerability was an essential element in the study approach to advance care planning. Most located this vulnerability in current concerns, but invariably imbedded in these

concerns and hopes were vulnerability implications related to fear of future suffering and dying/death.

Assessing participants' readiness to move from their current concerns to the vulnerabilities implied by worsening illness and possible end-of-life crises was dependent on natural conversational openings and emotional cues (Carr & Khodyahov, 2007; Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). Based on my assessment of readiness I established a conversational pace sensitive to participants' comfort, with a focus on sustaining rather than diminishing trust as well as hope. We broached advance care planning topics such as substitute decision-making, care options, and preferences only when participants offered cues related to this. I did not attempt to rush or force these issues. For example as previously mentioned P7 gave clear signals that she was uncomfortable with any direct discussion of death or related issues. However, she eventually raised the topic during the final stage of visit two when I asked for her suggestions for improving my approach to advance care planning. After saying she appreciated the approach I had taken with her (not forcing her to confront or talk about dying) she referred to her strong faith, but her comment hinted at a fear of dying. She admitted to having an intense fear and described the episode of cardiorespiratory distress in which a nurse's callous question about "unplugging" her had clearly heightened both her suffering and ongoing sense of vulnerability and mistrust. I realized how important it had been to allow her to engage the topic on her own terms and in her own time.

Participants' feelings of vulnerability certainly affected their readiness in relation to considering advance care planning considerations, but also offered an opening to frame the discussion in a way to address this vulnerability. Much of the literature concerning patient-centred communication, shared decision-making, and advance care planning in chronic illness settings refers to uncertainty and vulnerability related to the issue of readiness or "timing" (Barnes, et al., 2007; Carr & Khodyahov, 2007; Fried, et al., 2009; Kiesler & Auerbach, 2006; Parker, et al., 2007; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004; Yohannes, 2007). Thus an important aspect of ***negotiating ambiguity*** was discerning participants' readiness and framing subsequent discussion with this in mind.

Summary.

Negotiating ambiguity was akin to the "managing uncertainty" dimension of patient-centred care (Epstein, et al., 2010; McCormack, et al., 2011; Saha, et al., 2008; Teal & Street, 2009; Wagner, et al., 2005) and shared decision-making (Godolphin, 2009; Saba, et al., 2006; Stewart, 2001; Woolf, et al., 2005). All involve identifying, acknowledging, and working with uncertainties most important to the participants. Understanding the role of uncertainty for participants helped me frame the subsequent advance care planning discussion.

> *This skill [negotiation and collaboration] during the . . . [medical] encounter*
> *requires the [physician] to operate with the utmost awareness and adaptability*
> *to negotiate a shared understanding with the patient and to reach agreement*
> *(Teal & Street, 2009, p. 540)*

In the study this continued the process of relational engagement and active listening, but with a focus on discovering and acknowledging the salient ambiguities from participants' standpoint and establishing common ground. I explored their fears and hopes about the future as a window into the uncertainties that most concerned them. Mostly I listened for this in their experiences of their own illness crises or as witnesses to others' end-of-life struggles. Because most seemed unfamiliar with thinking about hope and fear when directly questioned about it, I chose to explore these topics indirectly through the illness experiences they shared with me. This sort of discussion can and did provide a natural segue into their current concerns and on into those related to end-of-life. Very often these natural conversational "doorways" were accompanied by emotional vulnerability that called for sensitive, empathic response.

Being a resource.

The focus of ***partnering*** was on identifying issues most important to participants and building a strong enough relationship to address these issues in the context of considering end-of-life care and decision-making preferences. In contrast, ***being a resource*** had a more educational focus to help participants consider, understand the implications of, and articulate their end-of-life care and decision-making preferences. This focus involved clarifying participants' understanding of these topics, my

understanding of their information needs, decision-making, and preferences, and their healthcare team's understanding of the resulting end-of-life care plan (if any). Thus ***being a resource*** relied on three main activities--*providing education*, *functioning as a liaison,* and *being an advocate*.

Providing education.

Many participants were unaware they were lacking critical pieces of information they needed for a fuller appreciation of their illness situation and its implications in terms of considering options related to current and future goals of care. *Providing education* was about filling in these gaps and respectfully correcting misunderstandings while being sensitive to decision-making styles, information needs, hope, and comfort levels (Briggs, 2004; Briggs, et al., 2004). As part of this focus I encouraged participants to ask questions throughout the sessions right from the informed consent process through to the final moments. *Providing education* involved offering information in support of creating shared meaning, a related concept from the literature. I tried to respond clearly, simply, and accessibly to direct questions, an educational approach recommended for improving the quality of clinical encounters (Epstein & Peters, 2009; Fiscella, et al., 2004; Fraenkel & McGraw, 2007; Frank, 2011; Liden, et al., 2010; Street, et al., 2009; Teal & Street, 2009; Zeliadt, et al., 2006). Beginning with a consideration of illness-related experience, changes, and difficulties and moving into fears, hopes, and advance care planning, participants were invited to revisit their past and reflect on the present as a way to increase insight into the relevance of considering their future (Weingarten, 2000). Increasing such relevance has been identified as a factor for enhancing patient/family readiness to engage in advance care planning (Westley & Briggs, 2004). Correcting misconceptions and providing information to address knowledge gaps helped participants adjust their perception of the relevance of end-of-life care planning in some cases.

Responding to spontaneously occurring "teachable moments" related to questions, confusion, or misconception called for clear explanations tailored to the needs of individual participant(s). Figuring out what information was needed and how to present it depended on developing a sense of participants' related beliefs, values, and communication styles--these perspectives were influential for creating shared meaning. Individuals draw from various sources, incorporating what resonates with their

experience, values, and hopes, and ignoring what seems irrelevant or discordant (Epstein & Peters, 2009; Frank, 2004; Street, et al., 2009; Zeliadt, et al., 2006). *Providing education* required me to monitor participants' understanding and identify needs for further information or a different approach to an explanation. This is an important but frequently neglected step in this sort of process (Fiscella & Epstein, 2008; Rao, et al., 2007; Saha, et al., 2008). It was also important to give information in a way that was sensitive to participants' education/literacy level, their previous experience, and adult learner status (Fraenkel & McGraw, 2007). Two patients in the study mentioned literacy-related problems. Others were unclear about what they were being asked for in the advance directive template component of the print resources I left with them. It is not uncommon for patients and their intimate others suffering with COPD to also be contending with low education levels that may contribute to such difficulties (Salvi & Barnes, 2009).

Print resources were part of *providing education*. A copy of the March 2007 CDHA Patient and Family Education document, "Let's Talk about Advance Directives," (Appendix C) was left with each family. This resource was provided during the first session if we discussed the topic of end-of-life care planning during that session; otherwise I left the brochure as part of the second session. The blank advance directive template included in the booklet was part of the advance care planning discussion when a participant wanted to review what s/he had written or asked for clarification about the meaning of certain items. While this was certainly a positive aspect, there was also a literacy downside. For example, C5 found this template almost incomprehensible, not because she couldn't read it, but because the phrasing of the questions made no sense to her. However, helping her make sense of what was being asked in each item enabled her to reflect on and understand her own experience in new ways. Our combined effort facilitated the creation of "shared meaning," an aspect of patient-centred advance care planning (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010). Watching participants struggle in this way made it very clear that literacy is about much more than reading and writing. It encompasses cultural aspects in broadest sense (Fiscella & Epstein, 2008; Saha, et al., 2008; Surbone, 2004). Ethnicity, family, community, gender, health beliefs, relationship, views of authority, to name a few, all affected the relevance and

accessibility of particular resources for those they were designed to serve (Fiscella & Epstein, 2008; Saha, et al., 2008; Sudore, et al., 2008). I offered information to correct misconceptions, but always with hope in mind. Otherwise I only provided information in response to participants' requests. For example, none of participants expressed any concern or question about their likely COPD prognosis, and all expressed a hope to keep living. Thus providing information/education appeared to be helpful for creating shared meaning when it was delivered in way suited to their needs.

A significant proportion of those living with COPD are "socially disadvantaged" on the basis of multiple co-morbidities, low socioeconomic status, low education levels, and damaging lifestyle behaviours such as smoking and substance abuse (Fiscella & Epstein, 2008; Parnell, 2001; Salvi & Barnes, 2009; Wong, Gan, Burns, Sin, & van Eeden, 2008). This was the case for all the study participants, and was even more relevant for the few who were also dealing with more traditional literacy difficulties, which demanded even greater sensitivity in regard to *providing education* to facilitate advance care planning (Sudore, et al., 2008). Social determinants of health and cultural influences are known to be important factors to consider when trying to communicate information effectively (Saha, et al., 2008; Street, et al., 2009; Sudore, et al., 2008; Woolf, et al., 2005) and provide ethically appropriate/sound care (Neerkin & Riley, 2006; Woolf, et al., 2005). Social disadvantage can increase the need for information to be provided in a simple, accessible form followed by checking more frequently for understanding (Fiscella & Epstein, 2008).

> *The mismatch between patients' needs and the time and resources available to address those needs is greatest for socially disadvantaged patients, thereby exacerbating disparities in access to, process of, and outcomes of health care (Fiscella & Epstein, 2008, p. 1849).*

Taking the time to check understanding and whether the information shared is actually desired can also enhance rapport, trust, and thus the therapeutic relationship. Participants' confidence and trust in a clinician can be preserved (or lost) in part by the way educational/informational responses align with their needs and preferences (Frank, 2011; Gravel, et al., 2006; Kiesler & Auerbach, 2006; Makoul & Clayman, 2006; McCormack, et al., 2011; Saba, et al., 2006; Salmon & Young, 2005). To help clarify understanding in

some cases I shared a pertinent story from my experience. This served the dual purpose of providing needed information to participants in an accessible, memorable form while demonstrating genuineness which helped address vulnerability and strengthen the therapeutic relationship (Miller & Jackson, 1995; Yedidia, 2007). Honesty, openness, and sensitive disclosure matter when sharing information, and were also an important focus during advance care planning in the study (McCormack, et al., 2011).

Providing information to help participants understand the topic of advance care planning, consider its relevance to their own situation, and reflect on their related preferences were all part of *being a resource*. Facilitators should be knowledgeable in these areas (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Parker, et al., 2007). This emotionally intense task is made more challenging by the fact that few individuals have considered or are aware of preferences concerning end-of-life care, and those they have are likely to fluctuate with illness progression (Epstein & Peters, 2009; Hines, 2001; Hines, et al., 2001). In the context of end-stage COPD with its not insignificant risk of mortality, it seemed important to try to gently raise this awareness for participants. Being asked to think and talk about things like hopes, fears, uncertainties, and end-of-life care issues was clearly not something most participants had much experience with. Using the fears and concerns they mentioned I encouraged further discussion that eased us into future implications. Finally I encouraged patients and their intimate others to think about these implications in terms of their end-of-life care preferences and decision-making if they were amenable. In this way we worked toward creating shared meaning related to their advance care planning needs, concerns, and values.

Helping them clarify their preferences for a particular style of decision-making (more autonomous, clinician dominated, or shared) was very much a part of ***being a resource*** to create shared meaning. We talked about who would make decisions for the patient if s/he was unable to do so for her/himself, and the likelihood that such a scenario might happen. Even in the small group of study participants, some preferred to leave all decisions in the hands of their substitute decision-makers, others wanted to dictate down to the last detail, while some trusted their doctors to do what was best for them. Just assuming that patients/intimate others desire an equal partnership decision-making model

can result in discussion that proceeds at cross purposes, produces mismatched goals, and results in significant dissatisfaction and mistrust (Salmon & Young, 2005). It is known that patients who prefer to leave such decisions in the hands of their clinicians are also less likely to engage in advance care planning and thus seldom have a chance to indicate this preference (Carr & Khodyahov, 2007). In all likelihood patients will not receive the sort of decision-making approach they prefer. Sorting out these preferences provided valuable guidance to substitute decision-makers for making decisions if needed in future crises. Creating shared meaning thus included talking about preferred decision-making style and care preferences, along with preferences for recording (or not) these outcomes (Kiesler & Auerbach, 2006; Salmon & Young, 2005). The outcomes of these discussions would then need to be shared with members of the patient's care team to promote appropriate follow-up and respect for their preferences.

Being an advocate.

This involved creating bridges between patients and their physician with respect to current health concerns. For example I spoke with one patient's physician about the possibility that patient had undiagnosed clinical depression which could then be addressed by the appropriate clinician. Thus *being an advocate* enabled what McCormack et al (2011) refer to as "tangible help." This can take a number of different forms including referral, medication, support groups, counseling, and/or enrolment in physical or occupational therapy programs (McCormack, et al., 2011). Referring participants to clinicians more skilled at responding to their current needs was an expression of caring and commitment I hoped would reassure them about ongoing team involvement, competence, and non-abandonment (Back, et al., 2009; Curtis, 2006; McCormack, et al., 2011). Fear of abandonment and not knowing who will be caring for them in future crises are significant issues for those living with advanced COPD (Heyland, et al., 2006; Heyland, et al., 2010).

Being an advocate was an important contributor to strengthening the therapeutic relationship with some participants. It entailed helping them access desired or needed resources, including additional support for advance care planning follow-up for those indicating this preference. For example C5 was still working on her instructional

directive and welcomed the news that she could request more support from EMP personnel in regard to completing it. In some cases I acted as an advocate for a participant within the broader healthcare system (Black, 2007; McCormack, et al., 2011). For example, I advocated on the patient's behalf with his physician by suggesting an assessment for additional home support, something the healthcare team had not considered and were unaware of his increasing need in this area. It is important also to recognize that as Seymour et al (2009) have pointed out, those clinicians most familiar with the patient and family and their end-of-life care needs are most appropriate for this advocacy role. Advocacy is strongly associated with the notion of trust, so my advocacy efforts that followed initial study discussions helped strengthen trust and growing therapeutic relationships.

Respect, another element related to advocacy and trust, has been linked to attending to the patient-as-person and person-as-patient, and to the relational nature of these encounters (Beach, et al., 2007; Bergum & Dossetor, 2005; Epstein, et al., 2010; Scanlan & Kerridge, 2009). Respect is an especially important focus in advocating for those experiencing marginalization, disadvantage, and stigma, which is especially common for those living with advanced COPD. The current lack of access to helpful information and support services for many patients and intimate others living with COPD makes the advocacy role relevant on a systemic as well as individual clinician level (Blackler, et al., 2004; Habraken, et al., 2008; Hasson, et al., 2009; Spence, et al., 2009). Addressing suffering through psychosocial/spiritual support and more tangibly through *being an advocate* within the system was thus an important aspect of ***being a resource*** for advance care planning in the study.

Functioning as liaison.

This activity focused on improving understanding and capacity related to patient preferences for care and decision-making. This focus involved fostering discussion between patients and the intimate others they name as their substitute decision-makers, and then emphasizing collaboration with and within the patient's healthcare team. Engaging participants in the emotionally challenging process of considering and/or formalizing advance care planning preferences is a wasted effort if these preferences are

not communicated to and honoured by those responsible for acting on them (substitute decision-makers, physicians, other clinicians) and up-dating them periodically according to patients' desires (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Fried, et al., 2009; Knops, et al., 2005b; Parker, et al., 2007; Westley & Briggs, 2004). The research focus of the study advance care planning process meant I was not a member of patients' healthcare teams and thus rarely had access to them. During the study sessions I encouraged patients to talk about our discussion with their family doctor, other members of the healthcare team, and in the case of P4, intimate others. I also suggested they make copies of any resulting advance care planning documents for their family physician, substitute decision-maker, and their medical record. This is also a way of sharing responsibility and power in line with patient-centred care (Hudson, et al., 2011).

The literature describes ongoing difficulties with uncertainty concerning team roles and responsibilities for initiating and following up on advance care planning discussions with patients and intimate others (Crawford, 2010; Seymour, et al., 2010). This is also a concern in terms of inter-professional collaborative care more generally, which has serious implications for those living with complex co-morbidity and care needs common in advanced chronic illness (D'Amour, et al., 2005; Hebert, 2005; McDonald & McCallin, 2010; WHO, 2010). To be effective, any approach to advance care planning should include fostering collaboration with the patient's healthcare team as exemplified by the *functioning as liaison* element of the study approach.

Summary.

Being a resource relied heavily on *providing education* in a user-friendly manner adapted in line with participants' needs, education/literacy levels, and experience. The teaching covered topics such as COPD, life-sustaining interventions and possible end-of-life scenarios, decision-making issues, and ethics questions. It was woven throughout the sessions in response to questions, confusion, and relevant misconceptions. Other components included *being an advocate* and *functioning as liaison* to ensure follow-up by appropriate clinicians to address session outcomes related to current issues and end-of-life care decision-making. These were important links to ensure the process aligned with both patient/family-centred and collaborative care.

Summary of collaborative care approach.

Study findings reflected in the global theme and model, *advance care planning as collaborative care*, are germane to current gaps related to this clinical practice as it exists in the context of advanced COPD. Much of the infrequency and inconsistency of advance care planning for patients and their intimate others centres on their clinicians' uncertainty about such discussions. The study approach, organized around three activities based on patient-centred care principles: *partnering, negotiating ambiguity,* and *being a resource*, provided a positive way to work with this uncertainty. The approach calls for a facilitator skilled in relational communication to identify, acknowledge, and explore the role of uncertainty with patients and their intimate others. Through active listening, building rapport and trust, soliciting their input, exploring fear and hope, offering psychosocial/spiritual support, and providing access to needed resources, the facilitator offers patients and their intimate others a meaningful framework within which to re/consider their end-of-life care values and preferences. But it was combining all the process elements in a way that was sensitive to each patient's and intimate other's priorities and style that resulted in advance care planning each could appreciate. The home setting was a constant, a familiar backdrop against which the unfamiliar discussion process could develop in a way that was sensitive to requirements of each group of participants. Doing advance care planning in participants' homes seemed to optimize their comfort while providing the facilitator with important contextual clues to guide the process of combining the discussion elements sensitively. Most often we sat at the kitchen table, a traditional family gathering place symbolic of care based on the sharing of food, talk, and nurturing interaction. Thus conducting the discussions in participants' homes grounded them in a basic, familiar, and important patient/family-centred setting of "care."

Participants' appreciation suggested the activities contributing to the discussion led to an interaction that was caring, collaborative, and respectful of hope. It suggests further that advance care planning based on an evolving, personally-adapted relational approach can be more than a means to an "end" in terms of advance directives. While this documentation has often been the goal of such discussion, the study indicates that other outcomes may be more important to participants (patients/intimate others/substitute

decision-makers) and perhaps more possible. As suggested by Hobbes (2009), the discussion itself can be a valuable "end" and should be a primary goal of any revised advance care planning approach that purports to exemplify patient-centred care.

Role conflict revisited

Given the therapeutic nature of the interpersonal communication techniques I used in *partnering* to foster relational rapport and trust, the psychosocial and spiritual support in response to distress in *negotiating ambiguity*, and the information, advocacy, and liaison I provided as part of *being a resource*, there is a need to revisit the issue of role conflict introduced in Chapter 3. Because the intervention aspect of my study included asking participants about their experience of worsening COPD, I anticipated I might hear about ongoing concerns related to their illness. The possibility that participants might reveal a serious medical issue or ask for my help with a clinical problem outside the scope of traditional advance care planning discussions or my own professional practice occurred to me as well. I realized that I would feel obligated to respond to the stated need, but would feel constrained by the purpose and privacy/confidentiality issues associated with the research context in which those needs were identified. In addition, the study participants were considered to be members of a "vulnerable population" and classified as such in my REB submissions, which heightened my vigilance for being sensitive and caring. Although not discussed explicitly in these terms in the study consent form or the materials I submitted to the REBs, I was aware of this possibility for tension between my roles as a researcher and a clinician firmly committed to a study design shaped by and founded on relational care ethics.

> *It is part of being an artful qualitative researcher to know one's place on that continuum, to have a complex and in-depth understanding of both the issues and the current literature of the subject at hand, and to have the means and connections whereby the participant may be assisted with outside referral and resources as needed (Eide & Kahn, 2008, p. 200).*

However the study was more than simply an investigation of participants' lived experience--it was an investigation of the lived experience of a particular intervention. That intervention was an aspect of the study and was based on clearly articulated patient-

centred, relational care principles. I felt therefore that not responding to participants' requests or distress would violate the integrity of the research design. It was always part of the study design that I would respond to participants' psychosocial or spiritual distress in the moment. As for other types of clinical issues participants might raise, I planned to note their concerns, talk these over with them at the end of the sessions, and if they wanted me to, with their permission, make an appropriate referral. In the study as implemented this situation arose with two participants--in both cases I had their verbal consent to make a referral to their treating respirologist. Having both their request for help and their consent were the primary factors, but in addition their respirologist was one of the co-principal investigators of the study and so named in the consent form. He was also a member of my doctoral supervisory committee and thus privy to all the study data. I believed that responding in this way was thus appropriate ethically, professionally, and from a research perspective given the study design. The fact that actively "caring for" participants emerged as a valued and unique element of the study approach provides additional support for the choice I made.

Collaborative care approach versus models.

The two most frequently mentioned advance care planning models in the literature, *Respecting Choices*[(R)] and "stages of change" models, also have a patient-centred focus. *Respecting Choices*[(R)] is based on Pierce and Hicks' (2001) interactive decision-making model and Donovan and Ward's (2001) representational approach to patient education (Briggs, 2004; Briggs, et al., 2004) while the Transtheoretical Model is based on Prochaska's (1997) "stages of change" theory (Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). All three approaches share features arising from their central focus on patient-centredness, but there are also several features unique to the proposed "collaborative care approach."

Commonalities.

All the patient/family-centred advance care planning approaches shared some version of the following elements.

Skilled facilitator.

Perhaps the most important shared element is the emphasis on the need for a trained, skilled healthcare professional with sufficient time and interest to facilitate the sessions. References to this individual's skills included the ability to initiate the discussion with the patient and his/her intimate other/substitute decision-maker, assess his/her readiness for the discussion along with his/her illness knowledge and beliefs, listen attentively, identify patients'/intimate other's perspectives, and be willing to cultivate a therapeutic relationship in which they feel supported sufficiently to consider difficult issues and decisions (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; McCormack, et al., 2011; Parker, et al., 2007; Reinke, et al., 2011).

Communication approach.

Relational communication--active listening, empathy, genuineness, positive regard--to build rapport and trust, therapeutic relationship, and discern patients' and family members' perspectives is considered essential for the discussion (Au, et al., 2011; Briggs, 2004; Briggs, et al., 2004; Davison & Torgunrud, 2007; Detering, et al., 2010; Fried, et al., 2009; Knops, et al., 2005a; Reinke, et al., 2011; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008).

Addressing uncertainty.

All mention the need to recognize/acknowledge the uncertainty inherent in medicine generally, but especially in prognostication (particularly in chronic illness settings) and predicting the content and timing of end-of-life scenarios (Au, et al., 2011; Barnes, et al., 2007; Davison & Torgunrud, 2007; Fried, et al., 2009; McCormack, et al., 2011; Parker, et al., 2007; Sudore & Fried, 2010; Sudore, et al., 2008).

Inclusion of the substitute decision-maker.

The various models highlight the importance of including the patient's substitute decision-maker/intimate others during the discussion (with the patient's permission) to decrease their uncertainty (Briggs, 2004; Briggs, et al., 2004; Davison & Torgunrud, 2007; Detering, et al., 2010; Parker, et al., 2007) and to increase the likelihood that these discussions will continue (Fried, et al., 2009; Sudore & Fried, 2010; Sudore, et al., 2008).

Timing.

Attention to readiness, timing, and/or acceptability factors for advance care planning is commonly mentioned (Barnes, et al., 2007; Detering, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008), as is incorporating follow-up sessions to accommodate the likelihood that participants' priorities and preferences will shift as illness worsens (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Fried, et al., 2009; Knops, et al., 2005a; Parker, et al., 2007).

Information/education.

All models spoke about the importance of providing information to address patients/intimate others' knowledge and awareness gaps, confusion, and/or misconceptions (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Davison & Torgunrud, 2007; Detering, et al., 2010; Fried, et al., 2009; Parker, et al., 2007; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). In addition to knowledge, most models highlight the need for adult education strategies and attention to literacy level, needs, understanding, and preferred learning styles without using euphemisms, jargon, or complex language (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Knops, et al., 2005a; Parker, et al., 2007; Rizzo, et al., 2010). Some advocate the use of a conversation guide to ensure that information needs are explored and responded to systematically, a framework for advance care planning information relevant to participants' beliefs and values is developed (Briggs, 2004; Briggs, et al., 2004), and advance care planning information is adapted to be relevant/meaningful to participants' particular stage (Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008). Print and video resources to augment education efforts are also mentioned in connection with a number of models (Briggs, 2004; Briggs, et al., 2004; Davison & Torgunrud, 2007; Detering, et al., 2010; Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008).

Collaboration.

Consulting with and sharing information with other team members to increase awareness of patients' preferences and the likelihood they will be respected when the time

comes is advocated (Au, et al., 2011; Davison & Torgunrud, 2007; McCormack, et al., 2011).

Unique elements.

While the models have many elements in common, there are several additional features that set the study's collaborative care approach apart and make it particularly suitable for use in the COPD context (and perhaps other chronic illness contexts). The most significant include: focus on caring, engaging hope, reflective practice, and contextual sensitivity.

Focus on caring.

Several articles on advance care planning mentioned "caring" as a positive incidental outcome of the process according to participants when discussions were done from a patient-centred, shared decision-making perspective (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Parker, et al., 2007). In contrast, *caring* was foundational to the collaborative care approach implemented in this study in the context of advanced COPD. Using principles of patient-centred care (Epstein, et al., 2010; Fiscella, et al., 2004; Hudson, et al., 2011; McCormack, et al., 2011; Saha, et al., 2008; Stewart, 2001; Yedidia, 2007), relational care ethics (Bergum & Dossetor, 2005; Tronto, 1993), and advance care planning principles developed using Problematic Integration theory in a chronic illness setting (Babrow, 2001b; Babrow & Mattson, 2003; Brashers, 2001; Hines, 2001; Hines, et al., 2001) the design of the study approach sought to maximize participants' sense of being cared for during the interaction. Care-related principles from these theories guided the study approach: relational communication, building a therapeutic relationship, negotiating shared understanding, engaging hope, and providing psychosocial/spiritual support.

Patients and their intimate others living with advanced COPD tend to be marginalized, left to cope largely on their own, and often feel abandoned, isolated, and vulnerable (Curtis, 2006; Ek, et al., 2011; Goodridge, 2006; Goodridge, et al., 2009; Rocker, 2004; Rocker, et al., 2008; Rocker, et al., 2009; Simpson & Rocker, 2008a; Simpson & Rocker, 2008b; Simpson, et al., 2010). Thus I theorized that to be truly patient/family-centred advance care planning in this context should be attentive to this

possibility. related to. In contrast, some centres using the *Respecting Choices*[(R)] model have chosen to use a workbook which participants work through on their own to identify and document personally relevant values and preferences related to future care decision-making (Simon, Raffin Bouchal, & Murray, 2008). While this may be a less labour intensive (for staff) approach, it does little to acknowledge concerns related to isolation, marginalization, and/or literacy so common in those living with advanced COPD. I felt that meeting with patients and intimate others in their own surrounding and facilitating the discussion face-to-face was one way to do so and the study approach seems to have succeeded in this effort as indicated by participant feedback. Most expressed appreciation for the study sessions in terms of the meetings providing a chance for them to talk about their concerns with an interested and respectful clinician. I interpreted this feedback as an indication that the relationship we developed during the discussion was experienced by them as a positive caring one able to support them through the emotional ups and downs. I also suggest that this intentional focus on caring/feeling cared for contributed to their willingness to risk considering end-of-life care implications of advanced COPD with me.

I believe using their homes as the study venue also enhanced the sense of caring and thus their willingness to enter into advance care planning. Choosing to meet in participants' homes was a major departure from other models, although the *Respecting Choices*[(R)] model speaks of developing a community-based alternative (Hammes, 2003) and in the UK Seymour et al (2010) describe an approach being explored by community nurses. As discussed earlier in this chapter, having the advance care planning discussions in participants' homes enabled me to experience their circumstances, facilitated the sharing of power, increased accessibility and comfort, and decreased formality, all of which may have enhanced the patient-centredness of the evolving relationship and interaction. Although nothing in the approach precludes holding the discussion elsewhere, contextual information is known to influence communication, which means participants' home settings likely added a different, perhaps more "personal" dimension to the discussion. Being able to observe and interact with people in their home surroundings may prompt questions and insights that might never surface in a clinical setting where structure and expectations are more formal, unfamiliar, and time-constrained. Meeting in patients' homes was a highlight of the approach.

Developing a chronic care paradigm that incorporates advance care planning is a current focus in healthcare circles given the rise in the prevalence and cost (human and financial) of chronic conditions and co-morbidity in the aging population (Black, 2007). Wagner's (2005) Chronic Care Model (CCM) along with patient and family self-management theory (Bourbeau, et al., 2003; Bourbeau & Nault, 2007; Bourbeau, Nault, & Dang-Tan, 2004; Zoffmann, et al., 2008) promote care in the community setting as a route toward balancing patient-centred and evidence-based practice with efficiency and effectiveness. Such a paradigm shift will surely be welcomed by and benefit those living with advancing COPD and formal care that tends to be fragmented, episodic, and hard to access. I operationalized patient-centred and relational care ethics care principles through partnering, negotiating ambiguity, and being a resource for participants. Focusing on participants' lived experience of illness, identifying their perspectives, exploring their fears and hopes, addressing their uncertainty and suffering, and engaging their hope, meant "care" was woven through the entire fabric of our interaction. Indeed, the approach resurrects the "care" element in advance *care* planning by treating it as an end in itself (part of the fabric of ongoing care) rather than solely as a means to an end (advance directives). Being committed to discovering participants' current concerns and discussing ways to address these was key to gaining their trust, building a therapeutic relationship, and creating an individually meaningful framework in which to ground the discussion of setting goals of care for end of life. Several authors mention this need to ground advance care planning in the regular care continuum (Black, 2007; Briggs, 2004; Briggs, et al., 2004; Parker, et al., 2007; Reinke, et al., 2011). Black (2007) also speaks about the need to make advance care planning specific to the concerns and conditions commonly associated with particular illnesses. Finally, collaborating with other team members extends the relational communication approach, is part of *being a resource*, and is a necessary step in the advance care planning process if discussion outcomes are to be acted on appropriately.

Engaging hope.

As an aspect of emotional support, my focus on "engaging hope" was unique to the study approach. Several other models refer to the need to respect patients' hope(s) by communicating in ways that balance realism with promoting/maintaining hope (Barnes,

et al., 2007; Detering, et al., 2010; Parker, et al., 2007). Briggs (2004) included questions about fears and hopes in her advance care planning interview, but did not have this as a particular focus. Part of clinicians' reluctance to initiate advance care planning with patients suffering with advanced COPD is based on their concern about damaging patients' hope. However, it is difficult to assess this without knowing what these hopes are. Therefore in the study I sought to identify and work with (engage) participants' hope(s) and shaped the discussion framework for this purpose. To do this I explored fears as well as hopes, and used these to develop a framework for advance care planning that would be relevant/meaningful for participants in terms of their particular hopes, fears, and uncertainties. Through attentive listening I sought to be present to participants, bearing witness to their suffering, identifying clues to their hope(s), and offering support for hope-related goals. These are also key elements in Weingarten's (2010) "doing reasonable hope" approach to family-centred counseling. Akin to McGeer's (2004) process of peer scaffolding, the study approach is a process in which participants' hope can be strengthened through the thoughtful support of significant others, in this case the advance care planning facilitator/clinician. Done well the process can aid patients and their intimate others living with advanced COPD to construct a care plan able to accommodate, cope with, and help make sense of their fears, concerns, and hopes related to future health status and care.

Other authors also mention the "sense-making" dimension, suggesting it is an aspect of the active or agency dimension of hope (McGeer, 2004; Simpson, 2000, 2002, 2004; Weingarten, 2010). Thus engaging participants' hope via advance care planning discussion provided them with a chance to consider and try to "make sense" of past, present, and a possible future related to their illness, quality of life, dying, and care values and preferences (Weingarten, 2010). Connections between meaning-making and hope were evident in our discussions as well, and were often grounded in considerations of existential/spiritual/faith-based concerns. Being able to provide spiritual/existential support was thus an important aspect of engaging hope uniquely expressed in the model.

Beyond sense-making, engaging hope was about helping participants maintain a positive perspective on future illness uncertainty and seek goals consistent with this and ways to achieve them (Weingarten, 2010). "[D]oing reasonable hope, is oriented to the

here and now, toward actions that will bring people together to work toward a preferred future" (Weingarten, 2010, p. 8). Helping patients identify and clarify meaningful care goals and plans to help achieve them can help to calm fears, lower stress, and increase hope (Weingarten, 2010). Exploring fear and engaging hope in advance care planning can provide patients living with advanced COPD a chance to discuss their emotions (fear, anxiety, anger, guilt, hope) and desires with intimate others and/or substitute decision-makers. This may help address ongoing emotional trauma, hopelessness, and uncertainty.

Engaging hope also involved helping participants access additional resources, an important aspect for this population that tends not to know about such resources or may assume there is nothing that will help (Booth, et al., 2003; Elkington, et al., 2004; Habraken, et al., 2008; Pinnock, et al., 2011; Simpson & Rocker, 2008a). Efforts in this regard included ensuring intimate others/substitute decision-maker(s) were part of the discussion and acting as liaison and advocate for patients/intimate others with the healthcare team and system. Engaging hope positively in these ways as part of advance care planning discussions can help to counter the current healthcare tendency that equates hope with cure, implying that chronic/incurable illness such as COPD precludes hope. For many clinicians, hope, though often unrecognized and/or unacknowledged, is rooted in this rather narrow, limiting perspective that can profoundly diminish patient-centredness.

Reflective praxis.

The collaborative care approach addresses the negative effect this lack of self-awareness on the part of many clinicians can have on communication with patients and intimate others, especially in deeply emotional discussions like advance care planning. While a trained skilled facilitator is central in other models, the study approach requires additional expertise in applied self-awareness and reflection. A major component of my training as a spiritual care clinician was developing self-awareness related to competent reflective practice and psychosocial/spiritual counseling/support (Cooper, Aherne, & Pereira, 2010; Cooper-White, 2007; Doehring, 2006; Miller & Jackson, 1995). Much of this training was done from a "praxis" perspective, which connotes a "combination of reflection and action to effect transformation" (Weaver & Olsen, 2006, p. 461). Within the context of spiritual care education, this pursuit of a "praxis" orientation involved

becoming proficient at using an action-reflection-action-reflection cycle applied in professional practice settings. Continual encouragement and supervision of my reflection related to both the motivation behind my actions (self-awareness, internal process) and the effects of those actions (on others and myself) increased my capacity for and commitment to being a more thoughtful, sensitive, insightful practitioner. I relied heavily on my ability to monitor, interpret, and utilize my inner process particularly in terms of transference, countertransference, and projection identification dynamics, in developing the *partnering*, *negotiating ambiguity*, and *being a resource* elements of advance care planning in the study.

While most models emphasized the appropriateness of using skilled, non-physician facilitators to initiate advance care planning, none mentioned spiritual care clinicians in this context. However, developing proficiency in reflective praxis remains a central element in spiritual care education, practice, ethics, and peer review. This proficiency includes exploring and responding to spiritual/religious concerns of clients/patient, intimate others, colleagues, and peers. In the study, all participants raised issues related to religious/spiritual or existential concerns. Comfort and expertise in dealing with such questions and the suffering frequently associated with them is therefore an important aspect of the study approach. The ability to provide good emotional and existential/spiritual/religious support is also a key skill involved in *negotiating ambiguity* and *partnering*.

Contextual sensitivity.

Other models were developed primarily within a cancer context, although the *Respecting Choices*[(R)] approach has been adapted for use in other chronic, life-threatening illnesses such as congestive heart failure and chronic renal failure (Briggs, 2004; Briggs, et al., 2004; Westley & Briggs, 2004). While the literature attests to the need for better quality end-of-life discussions for those living and dying with cancer, there is an acknowledgement that in this context patients and their families are more likely to have at least considered the possibility of dying (Au, et al., 2006; Blackler, et al., 2004; Curtis, et al., 2005a; Curtis & Rocker, 2006; Edmonds, 2001; Elkington, et al., 2005; Gardiner, et al., 2009; Goodridge, 2006; Habraken, et al., 2008; Neerkin & Riley, 2006; Rocker, et al., 2007). This is not the case for COPD patients and their intimate others who are often

unaware of the likely implications of their illness and thus tend to consider their worsening quality of life as simply part of aging (Habraken, et al., 2008; Pinnock, et al., 2011). Thus there are some contextually unique and salient features of living with advanced COPD that need to be addressed in the advance care planning approach if it is to be meaningful and effective for these patients, their intimate others, and clinicians caring for them at the end of life.

Features that set advanced COPD apart from other chronic illnesses tend to include increasingly severe (often refractory) breathlessness, lung infections, complex medications and dosing schedules, loss of mobility, independence, meaningful activity, relationships and social contact, self-efficacy and a sense of control in life, dependence on family/friends and home oxygen (for many), and stigma. These effects result in considerable vulnerability. Many feel abandoned by the healthcare system, not worthy of consideration, or do not realize there could be other care options to enhance their quality of life (Ek, et al., 2011; Habraken, et al., 2008; Pinnock, et al., 2011). I wanted to address participants' vulnerability, encourage their voice, and leave them feeling valued, respected, and more in control through my approach to advance care planning. This desire resulted in a patient/family-centred care design that focused on relational communication and building trust through a good therapeutic relationship. The advance care planning models advocated by Briggs et al (2004b) and Sudore et al (2008) embrace a somewhat preset series of topics, verbal and/or written, to achieve the goal of "preparing patients and their families for . . . decision-making [about future treatment for an end-of-life crisis]" (Briggs, et al., 2004, p. 47). Their reported discussions took place in clinical settings and over the phone, not in patients' homes.

In contrast I wanted to encourage patients' and intimate others' trust, comfort, and voice. I envisioned a discussion framed around the issues raised by participants rather than one based on a series of preset stages or facilitator assumptions/goals. Stage three reported by Briggs et al (2004b) included the question, "Can you see that by not fully understanding your medical condition or its possible complications, you might not see the reason for planning ahead for the future?" (p.52) The implied assumption is first of all, that one can have "full understanding" of an uncertain medical condition, and second, that this is the one credible reason "for planning ahead." These assumptions and the resulting

question seemed patronizing and inconsistent with a patient-centred approach, which would advocate for a question such as, "Do you see any reasons for planning ahead for your care?" Although my goal was also to have participants consider the end-of-life implications of COPD and their preferences related to care and decision-making, I envisioned a patient/family-centred approach as requiring me to identify and respond to their goals rather than my own if both could not be accommodated. Often their goals related to current care concerns and so we spent considerable time early on discussing this perspective and possible options. This underscores the importance of *being an advocate* and *functioning as liaison*. Ultimately, the study approach was about finding a way to incorporate both our goals--"advance care planning as collaborative care."

To do this I adapted Briggs et al (2004b) introductory questions about the current illness situation to begin the discussion and to understand participants' emotional experience of the illness and its frequent concomitant co-morbidities. I provided psychosocial/spiritual support in the form of empathy, positive regard, compassion, reassurance, or affirmation targeted to their particular suffering. Much of their suffering had an anticipatory aspect connected to ongoing uncertainty and fear of pain and dying from suffocation. Framing advance care planning as a way to minimize the likelihood of this sort of suffering was a way of addressing the fear and its associated hope. Growing dependency on loved ones for help with activities of daily living left many concerned about becoming a burden to these individuals. Advance care planning framed as a way to address this issue provided a welcome alternative for some and strengthened their hope for a peaceful death. Similarly I framed advance care planning as a way to regain a sense of control for those for whom this was a central concern. Positive regard, attentive listening, and genuineness helped to convey an honest sense of interest that offset the sense of stigma, worthlessness, and guilt so many experienced because of their smoking history. Thus psychosocial support, illness-related information, and advance care planning options were provided to address their particular fears, hopes, and suffering expressed in different terms by each patient and family. However, the agenda going into each session was very open and we did not move through any preset topics beyond the initial one.

Negative social determinants of health are another contextual feature for many living with advanced COPD. All the study participants were contending with poverty, low levels of formal education, and significant co-morbidity and a long history of smoking. Many also had a history of substance abuse, poor nutrition, and lack of exercise combined with negative experiences of formal healthcare. Factors such as low education level, employment status, poverty, and co-morbidity can and do affect how/whether patients' and families' communicate with clinicians (Kiesler & Auerbach, 2006; Rizzo, et al., 2010; Saba, et al., 2006; Saha, et al., 2008; Salmon & Young, 2005; Street, et al., 2009; Teal & Street, 2009). They may be reluctant to ask questions or seek clarification from clinicians if they do not understand health-related information or its implications. They may be reluctant to seek information in the first place, assuming instead that clinicians will tell them whatever is important for them to know (Davison & Simpson, 2006; Davison & Torgunrud, 2007). Many have experienced the healthcare system as abandoning, judgmental, and unhelpful especially with respect to identifying and accessing needed resources (Booth, et al., 2003; Guthrie, et al., 2001; Gysels, et al., 2007; Gysels & Higginson, 2009, 2010; Simpson & Rocker, 2008a; Simpson, et al., 2010). The study approach attempted to counter this history.

In addition, advance care planning information brochures and templates tend to have reading levels significantly higher than that of many patients and families, and often include complex legal and medical terms (Mueller, Reid, & Mueller, 2010; Sudore, et al., 2007). "The combination of limited literacy and poor advance directive design results in a mismatch that may jeopardize decision-making around end-of-life care" (Sudore, et al., 2007, p. 166). As Sudore et al (2008) have pointed out, patients and intimate others are more likely to take action if they understand the information they are receiving (Sudore, et al., 2008). Enhancing such understanding may ultimately depend more on better quality and more frequent oral communication (between patients and intimate others, and between patients, intimate others, and clinicians) than on adjunctive print materials. Oral forms of communication are often preferable and more efficacious for those with literacy or language difficulties and/or lower levels of formal education (Sudore, et al., 2008). And just as importantly, more meaningful and effective end-of-life decision-making outcomes tend to result when such conversations occur between patients and their

intimate others (Detering, et al., 2010; Garrett, et al., 2008; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004).

Summary.

The approach shares a number of patient-centred elements with the two common approaches to advance care planning: *Respecting Choices*[(R)] and "stages of change." Commonalities across the three models included: a skilled facilitator, relational communication, addressing uncertainty, including the substitute decision-maker, attention to readiness, relevant information/education, and collaboration. However, there were several differences that made the study's collaborative care approach uniquely appropriate for the context of advanced COPD, and possibly other chronic illnesses. These elements included: a focus on caring, engaging hope, reflective praxis, and contextual sensitivity. These features extended the patient/family-centredness of previous models and resulted in an advance care planning discussion that left participants feeling cared for and appreciative despite initial wariness. The approach is consistent with the literature on patient-centred care and shared decision-making, relational care ethics, collaborative care, and advance care planning research in chronic illness.

Interestingly, data from "INSPIRED," a CDHA pilot program of home-based education, emotional support, and advance care planning for patients and their intimate others living with COPD, provides further support for the collaborative care approach. In the first six months, participating patients and their intimate others completed pre- and post-intervention questionnaires and qualitative interviews. Team members initiated COPD education and worked to optimize self-management, care coordination, and psychosocial/spiritual support. As part of this effort advance care planning discussions were initiated using the collaborative care approach within the program's care continuum. Outcomes of these conversations varied depending on the patient's stage of readiness. However, all patients and their intimate others have appreciated the care provided by the team including the advance care planning segments (Booth, et al., 2011; Rocker, 2011 in press).

The Study Question Revisited

What do these findings contribute to answering the question that guided the study, *"What is required for meaningful and effective advance care planning in the context of advanced COPD?"* To answer this, meaningfulness and effectiveness are considered from the perspective of the participants and the healthcare system in which the process arose.

Meaningfulness.

In assessing the meaningfulness of advance care planning in the study, I considered the perspectives of both the participants and the facilitator/researcher. However, because principles of patient-centredness were central to the study design, participants' views of meaningfulness were considered more significant. From their perspective, they were appreciative of advance care planning that: a) fostered a feeling of being cared for, b) provided a chance to learn more about COPD, end-of-life care interventions and decision-making options, c) to consider/discuss preferences and values related to these, and/or d) overcame the silence between patient and intimate others regarding this subject. I interpreted these--caring, learning, considering goals of care preferences, and breaking the silence--as elements of meaningful advance care planning according to participants. From the facilitator's perspective, meaningfulness resided in participants' appreciation, their feelings of being cared for, and the goals of care outcomes of the discussions. I interpret this meaningfulness in terms of "patient-centredness."

Caring.

Most participants appreciated the advance care planning sessions as a chance to talk about illness concerns and experiences with an interested clinician. They welcomed the "caring" aspect of the sessions. From a purely common sense perspective, it is not surprising that advance care planning initiated according to the "collaborative care" approach was experienced as "care" by seriously ill patients and their intimate others living with advanced COPD. A clinician spent time in their homes listening carefully and supportively to their uncertainties, fears, and hopes as part of a process of soliciting their preferences regarding end-of-life care and decision-making. She then made sure that

another member of the healthcare team was aware of and understood the outcomes of these discussions. It is not hard to imagine that such a process would have a positive impact at a number of levels, not the least of which might be patient and intimate other satisfaction with "care" in that moment, and ideally at the end-of-life. Many COPD patients are starved for social contact and dialogue (Ek & Ternestedt, 2008). Delivering advance care planning using a framework of "collaborative caring" is an approach viewed by many as a way to increase meaningfulness (Barnard, 2002; Gott, et al., 2009; Hickman, et al., 2005; McCormack, et al., 2011; Quill & Cassell, 1995; Spence, et al., 2009; Weiner & Efferen, 2005; Weiner & Cole, 2004). Active listening, building a therapeutic relationship, discerning participants' perspectives worked together to establish an atmosphere of personalized, respectful caring that enabled participants to consider and talk about personally meaningful elements of advance care planning (Anderberg, Lepp, Berglund, & Segesten, 2007).

Learning.

Participants appreciated the chance to ask questions and receive information about issues such as worsening COPD and on-going care concerns, end-of-life care interventions and ethics, and issues related to decision-making like documentation and changing one's mind. They had wide-ranging questions and interests that called for the facilitator to have corresponding knowledge in these areas as well as adult education competence.

Considering goals of care preferences.

Meaningful advance care planning also provided a chance for participants to clarify their goals of care preferences and talk about fears and concerns such as prolonged dying, suffering, being kept alive on a "breathing machine," suffocation, becoming a burden to intimate others, physician-assisted suicide, euthanasia, life after death, cremation, and the details of CPR.

Breaking the silence.

A number of intimate others had tried to talk with the patient about his/her goals of care preferences and values prior to the study sessions, but their attempts had not been

successful. The presence a 'neutral third party' (facilitator) to sensitively encourage and support participants to engage in such conversations was welcomed by many as a meaningful contribution to their care and as a chance to learn, consider long-term goals of care, and break the uncomfortable silence some patients had imposed around the topic.

Patient-centredness.

Meaningfulness in terms of my (researcher/facilitator) perspective was related to my goals for the study. I wanted to foster a non-coercive patient/family-centred discussion respectful of participants' stage of readiness, comfort level, values/beliefs, and needs. I worked to make the resulting discussion a relevant one for the patient and intimate others to consider advance care planning preferences related to decision-making style and/or end-of-life care. Exley (2005) has characterized this population as the "disadvantaged dying." Many of these patients and intimate others are contending with significant vulnerability due to low socioeconomic status and education levels, high co-morbidity, social isolation, constraints due to breathlessness, immobility, and long-term oxygen therapy, fear of death and suffering due to unpredictable exacerbations, and social and medical stigma associated with smoking (Goodridge, 2006; Goodridge, et al., 2009; Reinke, et al., 2011; Rocker, et al., 2008; Rocker, et al., 2009; Seamark, et al., 2007; Simpson & Rocker, 2008a; Simpson & Rocker, 2008b; Simpson, et al., 2010). Because of this potentially profound, often unacknowledged vulnerability and related suffering, increased attention to patient/family-centred care by clinicians may be particularly welcome and helpful. While a more individualized caring focus might improve effectiveness in healthcare encounters generally, it is certainly relevant for emotionally intense interactions like advance care planning, especially for those living with the vulnerability and isolation of advanced COPD. The "collaborative care" approach was meaningful from this perspective because all were able to engage to some degree and felt satisfied with the process. This was suggested by participants' appreciation of the sessions and me as facilitator/researcher, along with the fact that these discussions encouraged consideration (in some cases documentation) of their goals of care preferences.

Effectiveness.

Effectiveness of advance care planning in the study depends on the criterion used to assess it. From a more traditional standpoint, effective advance care planning strives for useful advance directive documents to guide end-of-life decision-making for clinicians. However, problems of vagueness, inapplicability, and inaccessibility have plagued advance directives suggesting other outcomes may be more worthy of consideration in terms of effective advance care planning (Barnard, 2002; Barnes, et al., 2007; Hawkins, et al., 2005; Hickman, et al., 2005; Jordens, et al., 2005; Rizzo, et al., 2010; Seymour, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Weiner & Efferen, 2005; Weiner & Cole, 2004; Westley & Briggs, 2004). Support is building for outcomes such as patients considering and learning more about end-of-life care interventions and decision-making implications, patients and intimate others discussing these subjects, related values, and preferences, patients/intimate others talking these issues over with clinicians, and revisiting the discussions periodically as illness progresses (Detering, et al., 2010; Parker, et al., 2007; Sudore & Fried, 2010; Sudore, et al., 2008). There is also evidence to suggest that such discussions increase the likelihood that patients will revisit the topic with intimate others and/or clinicians, and may go on to complete an instructional and/or proxy directive (Garrett, et al., 2008; Havens, 2000; Sudore, et al., 2008). Thus each time an advance care planning discussion occurs helps increase awareness and clarification of related preferences for patients, intimate others, and eventually clinicians (Sudore, et al., 2008). Outcomes such as patients considering the topic and eventually discussing it with intimate others may be as or more important than advance care directives in terms of guiding end-of-life decision-making. Interestingly, when the "collaborative care" approach is judged on the basis of these more current standards of effectiveness, its meaningfulness as described above is closely linked to its effectiveness.

Documentation.

Using a traditional criterion of completion rates of advance directives, the study approach was only minimally effective. Two participants completed or were in the process of completing an instructional directive. One finished her directive prior to the

end of the second visit and had plans to discuss it and share copies with her family doctor and three children. For the other it was a work-in-progress when the second study session ended, but she was intent on finalizing it with the help of Extramural Program staff. Several others were still actively considering completing such a document at the end of the sessions. Each of them had chosen a substitute decision-maker and one took the CDHA template home as a possible tool for guiding his substitute decision-maker. One had clarified her wishes with her substitute decision-maker and was planning to formalize this via a proxy directive. Another had named his daughter as substitute decision-maker and planned to document this via a durable power of attorney for healthcare decisions, another was considering finalizing her wishes via a proxy and/or instructional directive to give to her physicians. The remaining participants were satisfied that their substitute decision-makers (a spouse in each case) understood their wishes/values with respect to end-of-life care and decision-making. Documentation of these preferences seemed superfluous to them. Only two formal instructional/proxy directives were completed despite all participants having considered and discussed these options to some extent during the sessions. Given the reasons for their appreciation of the sessions, the frequency of completing advance directives seemed not to be the best way to assess the effectiveness of the advance care planning approach for these participants.

Considering and learning about end-of-life care issues.

The study approach was more "effective" when effectiveness is based on advance care planning being sensitive and responsive to participants' needs and readiness. The collaborative care approach centred on creating opportunities and a hospitable environment for participants to think and learn more about end-of-life care issues as well as their goals of care and decision-making preferences. Information based on their questions, concerns, and misconceptions was provided in a user-friendly format that included accessible language, stories, and relevant examples. Topics addressed included COPD-related, life-sustaining interventions along with a consideration of burden/benefit, decision-making logistics and legal/ethical considerations. This was an important aspect of trying to enhance participants informed choice concerning their end-of-life care and decision-making preferences. Trying to enrich participants' understanding of the end-of-

life implications of advanced COPD was also part of being attentive to their stage of readiness to consider advance care planning. In terms of engaging participants in a patient/family-centred reflective process consistent with their current stage/readiness and preferred style of decision-making, the study approach was effective (Barnes, et al., 2007; Rizzo, et al., 2010; Seymour, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Weiner & Cole, 2004; Westley & Briggs, 2004).

Informing intimate others/substitute decision-makers.

The study approach included at least one intimate other named by the patient in all but one case. Thus it facilitated a discussion between the patient and her/his substitute decision-maker(s)/intimate other(s), a step highly recommended by many studies to increase effectiveness (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Rizzo, et al., 2010; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). In terms of increasing the likelihood of patients going on to document their end-of-life care preferences and/or discuss them with clinicians, having an advance care planning discussion with intimate others is a positive factor, suggesting another way the study approach could be deemed effective (Detering, et al., 2010; Garrett, et al., 2008; Sudore, et al., 2008). Furthermore, this sort of discussion is thought to help substitute decision-makers understand patients' preferences/values, and therefore have less stress/more confidence in making a decision if called upon to do so (Briggs, 2004; Briggs, et al., 2004; Detering, et al., 2010; Fried, et al., 2009; Parker, et al., 2007; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). Advance care planning in the study could be considered effective from this standpoint as well.

Two situations not encountered with study participants are important to highlight when considering advance care planning effectiveness in relation to inclusion of intimate others. One concerns those patients who have no intimate others to be involved in their care/decision-making. By chance, all study patients had intimate others involved with their day-to-day care and support. Previous research has led to the understanding that including these individuals in the advance care planning discussion is important so that they will be aware of the patient's preferences concerning end-of-life care and decision-making. However, as our population ages and family dynamics shift, a significant

number of patients with advanced COPD may not have intimate others involved in their lives. For these patients effective advance care planning should include a focus on identifying who could make these sorts of decisions for them should they become incapacitated in an end-of-life crisis. Helping them understand desirable qualities in a substitute decision-maker would be the first step in helping them consider and choose someone to fill this role. Making them aware of the hierarchy of legal substitute decision-makers set out within a regional jurisdiction would be an important step as well. Effective advance care planning in this situation would also include ensuring that the individual selected is aware of the patient's preferences, ideally through taking part in the discussion. Finally, it would be important to document this individual's identity as the substitute decision-maker in the patient's hospital health record and with her/his primary care physician. All of these topics could be easily included in the "collaborative care" approach.

The second caveat concerns scenarios in which patients experience conflicted relationships with or among their intimate others. This sort of relational strain seldom engenders trust and may be more likely to escalate rather than disappear during the stress of an end-of-life crisis. Thus again it would be important to help the patient select a trust-worthy substitute decision-maker who is willing to make a decision about end-of-life care in accordance with the patient's preferences/values. The "collaborative care" approach would be adapted to include the same steps as those listed for patients who have no intimate others.

On-going process.

Although the study did not include any follow-up to assess whether patients and intimate others went on to raise these topics with their clinicians, encouraging them to do so was an aspect of our discussion. Because preferences may shift as illness progresses effective advance care planning builds in recurring discussions with patients and intimate others to up-date preferences as needed (Barnes, et al., 2007; Briggs, 2004; Briggs, et al., 2004; Fried, et al., 2009; Hines, 2001; Parker, et al., 2007; Sudore, et al., 2008; Wittink, et al., 2008). In the study the "collaborative care" approach included at least two discussions, but ideally would include continuing follow-up as part of the regular care

continuum. The facilitator's *functioning as liaison* role in the approach is a purposeful step to increase the possibility that other clinicians will revisit these discussions with patients and their intimate others.

Summary of meaningfulness and effectiveness.

In the study, advance care planning focused on 'caring' using a patient-centred approach to *partnering* that included relational communication to discern participants' perspectives and develop a strong trusting therapeutic relationship. The facilitator worked at *negotiating ambiguity* and *being a resource* in response to participants' emotions, concerns, and needs. According to their feedback, all were satisfied with the approach, including having me, an unknown (to them) clinician facilitate the discussion. All were appreciative and none offered suggestions for changes, suggesting the highlighted elements (partnering, negotiating ambiguity, being a resource) enabled advance care planning acceptable to them. None said they would have preferred their own or another physician as facilitator, suggesting the possibility that clinicians other than physicians are acceptable advance care planning facilitators for patients and intimate others living with advanced COPD. Although there were no direct comments about using their homes as the venue for the discussions, six of the eight patients used oxygen throughout the sessions, a treatment modality more comfortably accommodated in this setting. The fact that most had no access to a vehicle, depended on the comfort of continuous oxygen, and became very short of breath with minimal exertion indicated that this venue likely made the sessions easier for them. As a body of evidence, these findings have significant implications for facilitating advance care planning that is meaningful and effective for those living with advanced COPD, and possibly other chronic illnesses. Assessing meaningfulness and effectiveness at other levels--clinician, team, healthcare system--was beyond the scope of this study, but is an important focus for further research.

Clinical implications of the "collaborative care" approach.

The "collaborative care" approach of advance care planning brings certain implications to the clinical arena of chronic illness care.

What the approach adds.

Like other patient/family-centred models, the "collaborative care" approach begins with a clinician facilitator who is a skilled relational communicator, team collaborator, health educator knowledgeable about COPD, life-sustaining interventions, decision-making concerns, and ethics. However, the approach incorporates several new elements uniquely significant in the advanced COPD context:

1. focus on caring, including psychosocial and spiritual/existential support
2. engaging hope
3. facilitator reflective praxis
4. contextual sensitivity, including meeting in patients' homes

With these additional elements the approach appears to have enabled advance care planning that preserved hope(s) and facilitated a feeling of being cared for in participants, many of whom had been feeling short-changed in this regard. These additional elements may enhance the study approach's adaptability to other chronic illness settings.

Resource implications.

Some patients may opt for comfort care and fewer/shorter duration life-sustaining interventions when they understand the clinical implications of these options and have the chance to make a more informed choice (Wright, et al., 2008; Zhang, et al., 2009). As well, there may be more concordance between end-of-life care delivered and patients' actual preferences if their intimate others/substitute decision-makers and/or clinicians are aware of these preferences. Such concordance is more consistent with respect for autonomy and can enhance satisfaction with care. Without timely, high quality advance care planning discussions patients' goals of care are unlikely to be known and concordance is unlikely to improve (Crawford, 2010; Detering, et al., 2010; Gysels & Higginson, 2010; Pinnock, et al., 2011; Reinke, et al., 2011; Spence, et al., 2009). Default initiation of life-sustaining interventions is not uncommon in such situations, and has significant ramifications financially, ethically, and for satisfaction with care. The study approach has potential to address these issues.

Six out of eight patients in the study favoured comfort care after they understood the details of cardiopulmonary resuscitation, mechanical ventilation, and other life-

sustaining interventions. Some remained open to undergoing a limited time trial of mechanical ventilation for potentially reversible respiratory failure. For most the priority was to do whatever was necessary to avoid <u>awareness</u> of suffocation, pain, and any attendant suffering. Thus most opted to err on the side of sedation and earlier death rather than awareness and prolongation of extreme breathlessness/dying. Most embraced a "comfort care" focus as their overriding value related to life-sustaining interventions. This suggests the likelihood that effective, meaningful advance care planning discussions enable patients to better assess their options and make a more informed choice consistent with their values, increasing the potential for care concordant with their wishes, greater satisfaction with care, and better stewardship of finite, scarce resources. As an example, the CDHA "INSPIRED" home-based program of follow-up care for those living with advanced COPD includes advance care planning discussions based on the "collaborative care" approach. Early data suggest a more than 50% reduction in ER visits and hospital admissions for enrolled patients, many of whom have opted for "comfort care" often with a short trial of mechanical ventilation. These resource implications are major, but so too is the potential that patients will receive end-of-life care more consistent with their values and preferences. All of this bodes well for patients, their intimate others, the resource-strapped healthcare system responsible for their formal care, and the over-burdened taxpayers who fund it.

Ethics implications.

There are clear ethical dimensions to these decisions as well, particularly related to patients' and intimate others' understanding of what they are being asked to consider. Only when they understand potential options ramifications can they make a more truly "informed" choice. The study approach highlighted issues that currently militate against this. The readability level of current print materials that are often part of advance care planning discussions continues to be too high (Mueller, et al., 2010; Sudore, et al., 2007). Mueller, Reid, and Mueller (2010) examined the reading level of the government-sponsored advance directive materials made available to the general public across 50 US states. Of the 62 forms they assessed, the average readability level was 11.9, exceeding the recommended level (fifth grade or lower) by an average of 6.9 grade levels (Mueller,

et al., 2010). Sudore et al (2007, 2010) emphasize the importance and implications of redesigning these adjunctive materials in line with the literacy and language/ethnicity requirements of the intended audience. Without attention to this it remains likely that many patients and their intimate others will be unable to comprehend what they are being asked to consider and make decisions about. Without such comprehension, any consideration and/or discussion (plus or minus documentation) related to informed choice about end-of-life care will be inadequate.

Several study participants struggled to understand the meaning of the questions in the advance directive template included in the March 2007 CDHA Patient and Family Education brochure "Let's Talk about Advance Directives," (Appendix C). Given the low education level of many patients with COPD, this readability issue merits further attention by those involved in advance care planning with this population. The potentially positive resource implications of ensuring patients and their intimate others have a better understanding of life-sustaining interventions and the personal implications of related choices makes it expedient that we attend to improving readability of adjunct materials.

On this same note, from the results of this study and many others it is becoming increasingly clear that "informed choice" pursued through advance care planning involves something more than reading pamphlets and/or completing documents (Detering, et al., 2010; Fried, et al., 2009; Garrett, et al., 2008; Rizzo, et al., 2010; Schickedanz, et al., 2009; Sudore & Fried, 2010; Sudore, et al., 2008; Westley & Briggs, 2004). The inappropriate readability level of print material points to the fallacy of relying heavily on such resources in advance care planning. Face-to-face patient-centred discussions in which participants' understanding can be sensitively assessed and enhanced appears to be appreciated and more efficacious.

In terms of beneficial outcomes, one goal of effective, meaningful advance care planning is to increase concordance between the care provided at the end-of-life and patients' related values/preferences, and in the process decrease ethical distress for substitute decision-makers and clinicians. Achieving these outcomes appears to be linked more to patients having considered and discussed their values and preferences related to end-of-life care than to their having read or completed advance directive documents. If

such outcomes are worthy of pursuit, effort must be made to encourage patient/family-centred advance care planning that promotes consideration and discussion of end-of-life care goals between patients and their intimate others above all else. It seems that once these initial stages have occurred, they are more likely to go on to discuss these issues with their clinicians and in some cases to complete advance directives (Detering, et al., 2010; Garrett, et al., 2008; Rizzo, et al., 2010; Sudore & Fried, 2010; Westley & Briggs, 2004). The possibility that improved advance care planning may result in positive ethics- and resource-related outcomes further strengthen the case for increasing effort in this regard.

Study Limitations

A larger, more diverse sample would have strengthened the findings. While a 15-participant (eight families) sample was adequate in terms of this type of qualitative study, it is likely that the purposeful addition of more participants would have enriched the data. Adding more patients with fewer negative determinants of health, from other ethnic or cultural backgrounds, experiencing rancorous relationships with intimate others, with no intimate others, or whose intimate others were adult children, may have yielded additional findings to enrich the final analysis. Certainly it is impossible to say much about how the study approach might work in situations where a patient has no intimate others or is experiencing a rancorous relationship with her/his intimate others. However, the study was strengthened by the fact that the sample included good representation by sex, age, relationship of intimate other to patient, and urban versus rural settings. Also, the consistency of findings within and across the groups within this sample attests to the robustness and adequacy of the study sample. As well, the approach is strengthened by its patient/family-centredness, which enhances its capacity to be adapted to differing circumstances. Therefore it seems reasonable to think that the proposed approach has good potential for sensitivity and responsiveness to any demands introduced by cultural diversity as well as differing social determinants of health and relationships with intimate others.

The potential for role conflict between the facilitator and researcher roles, although addressed already, may have been an issue especially with respect to soliciting feedback from participants about their experience of the study sessions. They may have

been less likely/comfortable to give negative feedback or suggestions to me because we had developed a warm and trusting relationship as part of those sessions. However, the very fact that the relationship was strong is equally suggestive that they would be able to risk offering their true feelings about the experience. Another limitation associated with the evaluation phase was the lack of follow-up questions to better understand what contributed to participants' positive (and neutral) assessments. Although timing, concern for their comfort, and a desire to encourage further end-of-life reflections took the discussion in other directions, it would have strengthened the study to have pursued these responses more fully.

There were also a number of study limitations in terms of assessing advance care planning effectiveness. Engaging participants in advance care planning discussion in their homes was an important aspect of the study. While this was done intentionally to increase their comfort level and decrease formality, nothing can be said about the applicability of the study advance care planning approach to clinical settings such as hospital or an out-patient clinic. However, the gains resulting from the study venue included increased accessibility for participants, more equitable balancing of the power differential, and contextual insight for the facilitator. The focus of the study was on advance care planning for those living with advanced COPD and thus there was no exploration of how co-morbidities may have factored into participants' experience in the sessions. Co-morbidities are very common in COPD (Chatila, et al., 2008) and thus it seems reasonable to suggest that any approach to advance care planning should be responsive to concerns and needs beyond a single medical condition. The study made no provision for filtering out participants' concerns in terms of co-morbidities, but "being a resource" in the context of COPD and concomitant co-morbidities implies a need for additional targeted facilitator knowledge.

The study did not include follow-up after the two sessions were completed. Thus little is known about the approach's possible impact on outcomes such as: a) participants' revisiting the conversations (on their own, with clinicians, or by completing documents), b) clinicians' awareness/understanding of patients' goals of care and/or decision-making preferences/values or care consistent with these, c) level of satisfaction with care or decision-making in end-of-life crises, and d) concordance between the patient's actual

preferences/values and the substitute decision-makers' understanding of these, or confidence/stress level if required to make the decision.

Future Research

These limitations provide some possible directions for future research in this area. The usefulness of the study approach in more formal clinical settings and other chronic illness contexts is worthy of exploration. It will also be important to investigate the effectiveness (if any) of the advance care planning approach over time on: clinicians' follow-up with patients/intimate others, clinicians' awareness of patients' preferences/ values, patient/intimate other/substitute decision-maker satisfaction with decision-making and care outcomes, concordance between patients and substitute decision-makers, and substitute decision-makers' confidence in their role. Exploring ways to incorporate the approach into the regular care continuum could increase the consistency and use of advance care planning. Doing a cost/benefit analysis of the approach implemented in various venues and by a variety of clinicians is an important step for finding the most efficient as well as effective application. Repeating the study with a more ethnically, culturally diverse group could increase insight into whether a approach based on active listening enables sufficient cultural sensitivity. It will be important to find ways to ensure that other team members will be aware and respectful of patients' goals of care. Finally, in medicine the "randomized control trial (RCT)" is the gold standard for most clinical care guidelines. While an RCT is a logical step, it is ethically questionable given the positive results for study participants and those enrolled in the INSPIRED program.

Conclusions

The "collaborative care" approach, based on three elements of partnering, negotiating ambiguity, and being a resource, has potential for facilitating meaningful, effective advance care planning in the unique context of advanced COPD. Incapacitating dyspnea, increasing dependency, isolation-induced social death, perceived stigma, and profound uncertainty-related anxiety experienced by many of these patients and their intimate others indicate the need for advance care planning that focuses on *care*. This care is enhanced through attention to *engaging hope* and *reflective praxis*, a practice stance that seeks to understand and respond respectfully to patients'/families' evolving

care-related values and goals. A *reflective praxis* orientation requires that the facilitator continually monitor her/his own feelings/reactions as well as those of patients and their intimate others, to deepen understanding, enhance sensitivity, and adjust the discussion framework accordingly. Patient-centred advance care planning in COPD depends on identifying and addressing patients/intimate others' current concerns before encouraging them to consider future goals of care concerns. Attention to *contextual sensitivity* including meeting with patients in their homes and being sensitive to the effects of negative social determinants of health is also an important element of the "collaborative care" approach.

In terms of the facilitator role, the approach requires a clinician who is: a) skilled in relational communication, b) comfortable with emotionally intense interactions, c) experienced in providing psychosocial <u>and</u> spiritual support, and d) knowledgeable about COPD, end-of-life implications, life-sustaining treatments and ICU, and end-of-life decision-making ethics/legal considerations. Additionally, the study underscores the importance of the facilitator being a "reflective" practitioner, aware of personal motivators and able to monitor and make use of countertransference dynamics. Competence and experience are key; professional discipline less so. Although advance care planning has often been a responsibility of physicians, tasking other skilled healthcare professionals to facilitate these discussions may improve efficiency along with effectiveness. However, regardless of who facilitates the discussion, the final step of effective patient-centred advance care planning includes collaborating with physicians and other members of the patient's healthcare team. If clinicians responsible for end-of-life care are not made aware of patients' preferences, advance care planning cannot effectively impact decision-making or outcomes. As well, if other team members do not know that advance care planning has occurred, they do not know to revisit the discussion in the interests of keeping the patient's care plan current.

Meeting with patients and intimate others in the patient's home for advance care planning is consistent with a patient-centred care approach and relational care ethics. The Chronic Care Model (Wagner, 1998; Wagner, et al., 2005) advocates designing, coordinating, and delivering "care" desired by patients and their families in their communities. The study findings suggest the approach may be well suited to the

incorporation of advance care planning as an element of care in such a community-based approach. In the study and in "INSPIRED" (CDHA home-based pilot program for those living with advanced COPD), an important aspect is the inclusion of the patient's substitute decision-maker and/or other intimate others. Inviting these individuals into the discussion may increase their understanding of the patient's preferences/values along with their own confidence level, thus decreasing decision-making stress. It may also enhance concordance between decision-making and the patient's desired goals of care. This sort of outcome has major ethics implications related to informed choice and respect for autonomy.

Traditionally advance care planning has been envisioned in terms of completing advance directive documents as a way to support and protect patient autonomy for times of potential loss of decision-making capacity. This approach has been less than effective. In contrast, the study approach, like other patient-centred models in the literature, focuses on caring, relational discussions consistent with participants' perspectives, level of readiness and comfort, and information/resource needs relevant to COPD, end of life, and decision-making. This focus appeared to facilitate informed "choice" for study patients and their intimate others, even without documentation of related preferences. Ultimately the professional goal of patient-centred care that respects a patient's autonomy mandates informed choice as a central concern (Godolphin, 2009). To achieve this goal in the context of COPD, clinicians need to provide chances for patients/intimate others to explore COPD-related current and future uncertainties as manifested in their experiences, hopes, and fears. Developing an advance care planning framework that is individually responsive to these hopes and fears continues the effort to enhance informed choice. Currently this does not happen with any consistency for patients and families living with advanced COPD.

Barnard (2002) suggests that the traditional bioethics related basis for advance care planning is inadequate and inaccurate because this sort of advance care planning has focused on "getting it right."(Barnard, 2002) Such a view implies there is a "right" end-of-life care decision to be identified, a naïve notion that denies the profound uncertainty, complexity, and variability associated with such scenarios, particularly in the context of chronic illnesses like COPD. Just as there is seldom a pre-determined "right" decision to

be discovered, there is no one "right" clinician to do the "discovering." Although advance care planning has tended to fall to physicians, many do not have the requisite time, interest, communication, and/or self-reflective practice training/skills. Research is accumulating to suggest that other appropriately trained clinicians can take on this particular responsibility. Continuing with the traditional physician-centered, single session, crisis approach is likely to obscure other more fruitful understandings of advance care planning by keeping us focused too narrowly and potentially in the wrong direction.

Prognostic uncertainty, patients' and families' "natural aging" view of declining quality of life in advancing COPD (Pinnock, et al., 2011), and increasing institutional pressures (time, personnel, space) militate against continuing the current approach to advance care planning. It is time to revise advance care planning and models of care more generally, particularly in the case of chronic illness (Hickman, et al., 2005; Jordens, et al., 2005; Lynn & Goldstein, 2003; Pinnock, et al., 2011). This qualitative study employed one possible combination of facilitator and approach to achieve a positive advance care planning experience for the eight families who participated. Certainly there will be other ways to achieve similar results, just as there will always be patients and their intimate others who choose not to engage in such discussions under any circumstances. However, respecting their decision while sensitively providing opportunities for them to do so is the essence of patient-centred care. The important thing is to continue to improve approaches to advance care planning generally as part of revising models of care for patients and families living with advanced COPD. Anxiety about prognostic uncertainty and erosion of hope, rather than a justification for avoiding advance care planning with these patients is actually a reason to initiate the process, albeit with a different goal and format. The time has come to embrace advance care planning as a patient-centred, on-going process of adjusting goals of care that is much more than a means to an end. As an end in itself, it is about improving care throughout the illness trajectory, not just at end of life. Done well it may enhance end-of-life care decision-making, and just as importantly, may be experienced as a mode of care at a time and by a population that often seems neglected on both counts.

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Capital Health

CONSENT TO TAKE PART IN A RESEARCH STUDY
Participant Information

STUDY TITLE: **NEGOTIATING HOPE IN A CONTEXT OF UNCERTAINTY: Care Planning in Advanced Chronic Obstructive Pulmonary Disease (COPD): a Qualitative Study.**

PRINCIPAL OR QUALIFIED INVESTIGATOR
Catherine Simpson,
Interdisciplinary PhD candidate
Department of Graduate Studies
Dalhousie University
Rm 314, Henry Hicks Bldg
6299 South Street
Halifax, NS, B2H4H6
902 466-8508 (H); 902 483-9595 (cell)

PRINCIPAL OR QUALIFIED INVESTIGATOR
Dr. Deborah McLeod
Clinician Scientist
Psychosocial Oncology Team
Nova Scotia Cancer Centre
1st Floor Dickson
5280 University Avenue
Halifax, NS, B3H1V7
902 473-2964

ASSOCIATE INVESTIGATOR:
Dr. Graeme Rocker
Division of Respirology
Room 4457
Halifax Infirmary Hospital
1796 Summer Street

Halifax NS B3H 3A7
902 473-7059

STUDY SPONSOR:

PART A

Research Studies
General Information

1. INTRODUCTION

You have been invited to take part in a research study. Taking part in this study is voluntary. You can decide to be in the study or not. To help you decide, you need to understand why we are doing the study, and what the risks are as well the possible good it might bring. This form explains these things.

It tells you what will happen during the study, including possible inconvenience, discomfort, risk, and benefit. Please read the information carefully. Take as much time as you like. If you choose, you can take it home to think about it for a while. Make a note of anything you do not understand, or want more information about. After you have read it, please ask questions about anything that is not clear.

The researcher will:

- Discuss the study with you
- Answer your questions
- Work to keep confidential any information that could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in the study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. No matter what you decide about the study, you will get the best possible care.

If you decide not to take part or if you leave the study early, your health care and that of your loved ones will **not** be affected in any way.

PART B.

EXPLAINING THIS STUDY

2. WHY IS THIS STUDY BEING DONE?

The study is being done to try to improve care for patients and families living with advanced Chronic Obstructive Pulmonary Disease (COPD). The study is being done in the Capital Health care district where the staff is committed to patient-centred care. This

means we are trying to find ways to provide care that is practical and based as much as possible on expectations and values that matter most to patients and their loved ones. This means that along with studying diseases and treatments, we need to know about the expectations and values of the patients and families coming to us for care.

COPD is a common disease that gradually gets worse over time. It often leads to increasing shortness of breath, cough, and need for help from caregivers as well as decreasing ability to do day-to-day activities and quality of life. When you live with COPD you also live with uncertainty because no one, including your doctor, knows exactly how the disease will affect each person. Although your doctor has provided treatment to help with the symptoms, so far there is no cure for COPD.

Patients with advanced COPD are often treated in the Emergency Department or admitted to hospital because of episodes of extreme shortness of breath. Sometimes they are so sick they cannot speak for themselves during these episodes. In these cases a family member or friend (substitute decision-maker) is asked to make care decisions for them. Too often patients have not talked with their loved ones about the sort of choices they would make for themselves in these situations. Studies have shown this kind of decision-making in a crisis can be very stressful for those asked to make the care decisions. The process and end results are often unsatisfactory for all those involved. We are doing this study to try to change this and be able to plan care that is more satisfactory for those living with advanced COPD and other chronic illnesses. Our goal is to offer care based on what is important to those living with this illness.

COPD affects not only the person with the illness, but also their family members or other caregivers. Therefore, we think it is important to include at least one family member or caregiver in the study. We know that because COPD involves a lot of uncertainty, many folks would rather just focus on living each day as it comes and not think about future care planning at all. But research has shown patients and families are generally more happy with care when everyone concerned understands the wishes of the person who is sick. In this study we are inviting you to talk about your particular hopes, values and concerns to help us understand your priorities related to living and dying. This will help us to plan care based on your particular needs now and when the illness worsens. By inviting patients and families to talk about these things we hope to be able to plan care that will be what they would want. Talking with you will also help us to understand more about the hopes, fears, expectations, and decision-making priorities of those who live with advanced COPD.

3. WHY AM I BEING ASKED TO JOIN THIS STUDY?

You are being asked to join the study because you were identified by your doctor as having advanced Chronic Obstructive Pulmonary Disease (COPD) and you said you might be interested when your doctor told you about the study.

4. HOW LONG WILL I BE IN THE STUDY?

The study will take approximately one (1) hour of your time during each of three (3) visits, making 3 to 4 hours in total. Each of the visits will take place 4 to 6 days apart if this is convenient for you. Each visit will be done on a day and time best for you.

5. HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

We are planning for 8 -10 patients living with advanced COPD to take part in this study. For each patient who agrees to take part we will also be inviting one family member or friend (someone who has been helping regularly with the patient's care) to take part.This means a total of 16-20 people will be taking part.

6. HOW IS THIS STUDY BEING DONE?

If you agree to take part in the study, the researcher will meet with you in your home, unless you choose to meet at the clinic. She will meet with you three times, the first time to go over the study, have you sign the consent form if you choose to take part in the study, and fill in a form about some background information. You will then take part in the conversation of the first study visit unless you choose to postpone this to another day. During the next meeting you will be invited to continue the discussion of your experiences and care planning needs with respect to advanced COPD, and during the third meeting the researcher will interview you about what this conversation has been like for you. Each visit will be tape-recorded and later the tape of the third session will be transcribed verbatim (the questions and your responses will be written down as exactly as possible from the tape recording). The researcher who will be doing the visits may call you afterwards if she is not clear about something you said or wants to make sure that all the information she has is correct. There will be no other study visits to your home once the four study sessions are done.

In total the study will require 3 to 4 hours of your time, about 1 hour on each of three occasions. The first session may be longer than one hour if you agree to do the consent process, fill in the background form, and take part in the first study conversation at that meeting.

You are always free to withdraw from the study or stop a study visit **at any time**. You do not have to give any reason for doing so and your care and that of your loved ones will not be affected in any way.

7. WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

After you have had a chance to read over and think about the information in this form, the researcher will call you. If you agree to take part in the study, she will arrange to meet with you to answer any questions, make sure you have understood all the parts of this form, and then, if you still agree, she will ask you to sign it and initial each page. She will also ask you to fill in a short form about background information such as your age, sex, race, marital status, work situation, education and income level, and a bit about your COPD. You can leave out any questions you don't want to answer. If it is convenient for

you, she will then ask you to take part in the first of the three study visits. If you prefer, you can schedule this first study session for another day.

Each of the sessions will be a conversation that includes you, your caregiver, and the researcher, unless you would rather talk with the researcher alone. Each conversation includes a chance for you to talk with the researcher alone if there are things you want to add or explain. Otherwise, each session will be done with both you and your caregiver together. It will last about an hour and will take place in your home unless you would rather meet somewhere else such as the clinic. The first conversation will be based on questions about what it has been like for you both to live with COPD, especially how it has changed your life, what you hope for, how you cope, and what it is like when there are episodes of extreme shortness of breath. You can choose at any time not to talk about these or any other questions the researcher asks. It is always completely up to you.

The second session will be a conversation about your thoughts, hopes, worries, concerns, and fears for the future, especially as you consider severe episodes of breathlessness, and what it will be like as the COPD gets worse. It will include questions about what is most important when you think about being admitted to hospital with worsening COPD and the possibility of having someone else making the care decisions. The researcher will talk to you about advance care planning and explain the health district's patient and family information booklet about this. She will also go over the advance directive template provided with this booklet. It provides guidelines to follow when folks are thinking and talking about choices related to advance care planning or making an advance directive. She will leave these papers with you for you to think about and fill in if you choose.

The third session will be an interview to find out what it has been like for the two of you to take part in these conversations about your illness and future care planning. The researcher will ask you to comment on the topics covered in the first three sessions. She will ask you whether the length and number of the sessions was okay or not, and about what was helpful and what was not. She will also ask for your suggestions about what would have made the process better for you, and anything else you want to add about how we might plan care to better suit your needs. Any and all feedback you can give will be appreciated. No matter what you say to the researcher, your care will be the best the health district can offer. You do not have to answer any questions you find distressing and you are free to stop taking part in the study at any time. If you choose to stop, it will not affect the care you or your loved ones receive at Capital Health. You will not be named in any study reports. Once this third visit is complete you will have finished your part in the study.

The researcher will tape record each session so that she can review it more easily and follow-up on questions and concerns you raise during the conversation. The third session interview tape will be transcribed word-for-word to a written form to be analyzed. Your name and any other identifying information will not be used so that your identity and what you have said will be confidential. You can contact the researcher at any time during the study with questions or concerns. Her contact information is included in this consent form and you will be given a copy to keep. The study will take 8 to 10 months to finish completely.

8. ARE THERE RISKS TO THE STUDY?

It is possible you may find parts of the study interviews upsetting or distressing.

Talking about illness and your future care needs may be uncomfortable for you. You may find it harder to talk about these things in a joint conversation with loved ones. Or you may find it easier to have loved ones present. In any case, choosing to take part in any or all of the study discussions is completely up to you. As well, you are welcome to talk with the researcher alone in any of the sessions if you think this would be more comfortable for you.

We do not know if you will benefit from the study. Sometimes having a chance to talk about your concerns, hopes, and future care needs can make you feel better. Sometimes having someone else begin such discussions makes it easier to think and talk about these things with loved ones. We hope by doing this study we will learn something that will help other people in situations like yours, but we might not. It is hard to know ahead of time how the study will work out.

9. WHAT HAPPENS AT THE END OF THE STUDY?

When the third session interview is finished your part in the study will be done. The researcher may contact you to check on any questions she has from the fourth session. She will ask your permission before including details that might reveal your identity in any reports about the study. Otherwise you will not hear from the researcher again. Your doctor will continue with your usual care.

10. WHAT ARE MY RESPONSIBILITIES?

Your responsibilities as someone taking part in this study are to:
- Be available for four conversations that will be about an hour long
- Be willing to have these conversations audio-taped
- Be willing to complete a short questionnaire about your personal data (age, sex, race, marital status, family, education, income)
- Be willing to receive a follow-up telephone call if required.

11. CAN I BE TAKEN OUT OF THE STUDY WITHOUT MY CONSENT?

Yes. You can be taken out of the study at any time, if:

- You do not follow the directions of the study staff
- There is new information that shows that being in this study is not in your best interests
- The Capital Health Research Ethics Board, or the Principal Investigator decides to stop the study

You will be told about the reasons why you might need to come out of the study.

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12. WHAT ABOUT NEW INFORMATION?

It is possible that new information may become available while you are in the study, about some new treatment for advanced COPD. You will be told about any other new information that might affect your health, welfare, or willingness to stay in the study.

13. WILL IT COST ME ANYTHING?

You will not be paid to take part in this study.

By signing this consent form you are in no way waiving your legal rights or releasing the investigator and sponsor from their legal and professional responsibilities to you.

14. WHAT ABOUT MY RIGHT TO PRIVACY?

We will do everything possible to keep your personal information confidential. Your name will not be used at all in the study records. Instead, we will use special numbers (which may include your initials). If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. We will ask your permission if we want to present or publish anything that might reveal who you are.

Your records will be kept for 7 years in a secure area such as a locked file cabinet and office. Only the research staff will have access to them and know your name.

Access to records
Some people or groups may need to check or see your study records to make sure all the information is correct. All of these people have a professional responsibility to protect your privacy.

These groups are:

- Dr. Graeme Rocker (who is a Co-Investigator for the study) or his representative who may need to check the study documents
- Dr. Deborah McLeod (who is also a Co-Investigator)
- The Capital District Health Authority Research Ethics Board which is responsible for the protection of people taking part in research here
- Quality assurance staff including the auditors for the Capital Health Research Ethics Board, who ensure the study is being done properly.

The information they check may include clinical test results.

You may also be contacted personally by the Capital Health Research Auditors for quality assurance purposes.

Use of records.
The research team will collect and use only the information they need to complete the study. This information will only be used for the purposes of this study.

This information will include your:
- date of birth
- sex
- medical conditions
- the results of tests and procedures you had before and during the study
- information from study interviews and questionnaires

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team.

15. WHAT IF I WANT TO QUIT THE STUDY?

If you choose to participate and later decide to change your mind, you can say no and stop taking part in the study at any time. Your decision to stop being in the study will not affect your health care or that of your loved ones. If you decide to withdraw from the study, any information collected before the date you stopped taking part with be kept as part of the study unless you ask in writing for your study doctor to have it removed.

16. DECLARATION OF FINANCIAL INTEREST

The researcher is not gaining financially by conducting this research study.

17. WHAT ABOUT QUESTIONS OR PROBLEMS?

For further information about the study call **Dr. Graeme Rocker.** Dr. Rocker is in charge of this study at this institution (he is the "Principal Investigator" and the study supervisor). Dr. Rocker's work telephone number is (902) 473-7059. If you can't reach Dr. Rocker, please refer to the attached Research Team Contact Page for a full list of the people you can contact for further information about the study.

The Co-principal Investigators are:
> **Dr. Graeme Rocker**, telephone: (902) 473-7059
> **Dr. Deborah McLeod**, telephone: (902) 473-2964

Your Researcher is **Ms. Catherine Simpson**, telephone: (902) 466-8508.

18. WHAT ARE MY RIGHTS?

After you have signed this consent form you will be given a copy. You may change your mind and withdraw from the study at any time. This will not affect the care you or loved ones receive at Capital Health.

If you have any questions about your rights as a research participant, contact the **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is "yes", you will need to sign the form.

19. CONSENT FORM AND SIGNATURES

I have reviewed all of the information in this consent form related to the study called:

NEGOTIATING HOPE IN A CONTEXT OF UNCERTAINTY: Care Planning in Advanced Chronic Obstructive Pulmonary Disease (COPD): a Qualitative Study.

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction. _____

I agree to allow the people described in this consent form to have access to my health records. _____

My signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time. _____

_____	_____	____ / _____ / ___
Signature of Participant	Name (Printed)	Year Month Day*
_____	_____	____ / _____ / ___
Witness to Participant's Signature	Name (Printed)	Year Month Day*
_____	_____	____ / ____ / ____
Signature of Principal Investigator	Name (Printed)	Year Month Day*
_____	_____	____ / _____ / ____
Signature of Person Conducting Consent Discussion	Name (Printed)	Year Month Day*

Note: Please fill in the dates personally

I WILL BE GIVEN A SIGNED COPY OF THIS CONSENT FORM.

Thank you for your time and patience!

APPENDIX B. Conversation Guide

This is the conversation guide approved by the CDHA REB. I adapted it to the people and each unique situation as these presented themselves. I did not follow this guide as it is printed with any of the families I visited with.

I. First Session:

- What made you decide to take part in this study?

- So for you (answer from first question) is important? In what ways has living with COPD affected how you feel about that…?

- Tell me about living with COPD day-to day? Prompts:
  - coping
  - relationships
  - roles
  - identity, sense of independence, self-worth
  - finances
  - activities, social connections
  - work
  - co-morbidities, health generally
  - hospitalizations; encounters with healthcare system and personnel
  - biggest changes/most difficult aspects

- What gives quality (meaning?) to your life now? Is this different than before you were affected by COPD—can you tell me more about that?

- As you think about how things are going with the illness, what are you hoping for? What worries you most…your greatest fear? What helps with this worry and fear…how do you cope?

- Do you think much about the future? What worries you when you think about the future? What are your hopes for the future? When you think about death or dying, what bothers you most/what are you hoping for? Can you tell me more about these things?

- Anything else you would like to tell me about what it has been like to live with this illness?

II. Second Session:

- [in separate sessions if either or both participants choose this option – 10 minutes] Is there anything we talked about last time that you would like to go back to or add anything to from your point of view? e.g., illness experience, quality of life, exacerbations, what is hardest, coping, things that help. Are there particular things

that you prefer not to discuss with [name of carer]? Can you tell me more about your concerns?

- Last time we met you mentioned you were hoping that _____. And you also said you were worried that _____. When we talked about the future you said _____, and when you think about the possibility of dying, you hope that _____.

- Introduce the notion of advanced care planning. Explore understanding of and interest in this. Review Capital Health booklet.

- Explore more fully interest and thoughts re: advance care directives.

- Can you tell me what you have been thinking /talking about? What do you think about the hospital's idea of folks having an advance care directive? Prompts:
  - Tell me about what it is like for that you to talk about this topic?
  - Your thoughts/feelings about creating an advance care directive?
  - Previous experiences with discussing advance care directives?

- Thinking about the advance care directive, can you imagine how other family members might feel about or react to your thoughts/decisions in this area?

Follow-up Phase

Can you tell me about what it was like for you to take part in the conversations we had? What stands out for you? (Explore from each person's point of view)

Prompts:

- Impact of the conversations (self; other; relationship; thoughts about the future; communication with family members; note to ask each participant about how they think the conversations affected the *other* person *and* the accuracy of that perception)
- Content (topics; things discussed/not discussed)
- Process (conduct of the researcher; any changes; number or length of conversations)
- Is there anything else you would like me to know? (other thoughts or suggestions)

APPENDIX C. Advance Directive Information Booklet

What is advance care planning?

Advance care planning is making decisions about your future health care and treatment. It usually involves talking with your family or loved ones about your wishes. It may also include talking to your family doctor, others who provide your health care and your lawyer.

You may decide you want to write down your wishes and preferences about your health care and treatment. This written document is called an advance directive (AD) or "living will."

Capital Health supports the use of advance directives (that are consistent with professional standards-of-care, other Capital Health policies and the law) made by individuals who wish to express their wishes about their health care and treatment in the future if they are unable to make such decisions on their own. This is one important way that Capital Health supports open and honest communication between patients and the people who provide their health care.

Why should I consider making an advance directive?
- Some people wish to ensure that the right person makes decisions about their care and treatment when they are not able to make these decisions for themselves.
- Making an AD gives you the opportunity to talk about what kind of health care and treatment you want with people who are close to you (such as your partner and family or loved ones) and people who provide your health care (such as doctors and nurses).
- Having an AD helps ensure that your wishes about your health care and treatment are understood and respected.

What is found in this booklet? *[2]
- Helpful definitions
- What information is usually included in an AD?

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[2] This booklet was produced and is the property of Capital District Health Authority (CDHA), Halifax, NS, Canada

- How do I make an AD?
- Do I need a lawyer to create an AD?
- Will my AD be followed? When will it be used?
- Where do I keep my AD? Who should have a copy?
- What if I change my mind about my wishes?
- What if I have questions about ADs?
- What if I am concerned about my experience with an AD in Capital Health?
- Other sources of information about ADs
- A sample, blank advance directive form

Definitions

Advance Directive - a document in which a capable person (see definition of capacity) sets out what, how and/or by whom health care decisions are to be made in the event that he or she is not capable of making health care decisions on his or her own. The two types of advance directives are: proxy directives and instruction directives.

Proxy directive - an AD (sometimes referred to as an "enduring" or "durable" power of attorney) in which a person with capacity, who is 19 years or older, names a proxy (or substitute person) to make health care decisions for him or her when the person does not have the capacity to do so. A proxy directive must be in writing; must be signed by the person making the proxy directive; and must be witnessed by someone other than the proxy or the proxy's spouse. The named proxy must be 19 years or older.

Instruction directive - AD in which a person with capacity specifies what health care and treatment he or she wishes to receive or not receive. A substitute decision-maker is not named in an instruction directive.

Capacity - a person with capacity is able to understand:

- The medical condition for which the treatment is proposed, and
- The nature and purpose of the treatment, and
- The risks involved in undergoing the treatment, and
- The risks involved in not undergoing the treatment

A person is presumed to have capacity unless otherwise assessed as being incapable by an appropriate physician.

Family - persons who have a close, intimate relationship to the patient (who may or may not be related by blood) who may assume an advocacy role for the patient when necessary.[3]

Guardian - a person appointed by the Court to make decisions on behalf of a person without capacity.

Health care decision - a decision about the prevention, examination, diagnosis, or treatment of a medical condition.

Health care provider - a person who is licensed or registered in the province to provide health care (such as a family doctor, specialist, nurse).

Medical Consent Act - the Act that governs proxy directives in Nova Scotia.

Substitute decision-maker - a person who is authorized to make decisions on behalf of a person without capacity. Guardians and proxies are substitute decision makers.

Proxy - a person of age 19 years or older who is named in a proxy directive to make decisions for a person who does not have capacity.

Substituted judgment - a judgment made by a substitute decision-maker for a person without capacity based on the that person's previously expressed wishes or values.

What information is usually found in an AD?

Information in an AD may include:

- what kinds of health care and treatments you would choose or refuse
- the name and telephone number of your proxy decision-maker (in a proxy directive)
- a statement of personal goals or values you wish to guide decision-making

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[3] Taken from: Canadian Council on Health Services Accreditation, *Standard for Acute Care Organizations: A Client-centred Approach,*1995.

- any other information you wish those who provide your health care to have

How do I make my AD?

We encourage you to talk about your wishes to the people who you are close to and the people who provide your health care. It is important to ask questions, be informed, and understand your choices when you make your AD. Remember that the AD must be:

- easy to read
- signed and dated by you
- witnessed

You are welcome to use the sample, blank AD form attached to this booklet. It provides information to help you write your own AD. The use of this AD form is endorsed by Capital Health.

Do I need a lawyer to make my AD?

You do not need a lawyer to make an AD. However, it is a good idea to tell your lawyer as well as your substitute decision-maker, the people you are close to, and those who provide your health care about your AD. This will help ensure your wishes in the AD are known and respected.

When will my AD be used?

Your written AD will **only** be used when you are unable to make health care decisions on your own.

Where do I keep my AD? Who should have a copy?

Your original AD should be kept with other important documents in a safe place. Your family doctor should be given a copy of your AD. If a substitute decision-maker has been named, you should also give him or her a copy.

It is very important to remember to bring your advance directive, or a copy of it, to the hospital with you.

What if I change my mind about my wishes?

As long as you have capacity you can change or cancel your AD at anytime. Remember to tell the people who provide your health care and your substitute decision-maker about any changes you have made. You should consider reviewing and updating your AD each time you experience one of "the five Ds": a new *decade* of life; the *death* of a loved one; *divorce*; a bad *diagnosis*; and a *decline* in your health.

You may change your AD in one of two ways:

- write a new AD and sign and date it in the presence of a witness (the preferred way); or
- write the change on your AD and then, sign and date it in the presence of a witness

You may cancel your AD by:

- writing a new AD; or
- providing a written statement signed by you stating you want to cancel your AD; or
- destroying your AD or directing some other person in your presence to destroy your AD

What if I have questions about ADs?

If you are being treated at Capital Health, ask a doctor on your medical team.

What if I am concerned about my experience with an AD in Capital Health?

You may talk to a doctor on your medical team. You may also contact a patient representative (or site manger, if a patient representative is unavailable).

Other sources of information about ADs:

 "Let Me Decide: The Health and Personal Care Directive That Speaks for You When You Can't…" by William Malloy, MD and V. Mepham, RN

"My Plans for Me" produced by the Canadian Pensioners Concerned Inc. by Jane McNiven, MA. and Jeffrey P. Ludlow, LLB

"Handbook *for* Mortals: Guidance *for* People Facing Serious Illness" by Joanne Lynn and Joan Harrold – developed for American readership, but applicable to Canadian context for the most part; downloadable from the internet

"Preparing for an Expected Death at Home" developed by Home Care Nova Scotia – to request brochure and related Physician Do Not Resuscitate Order Form telephone 1-800-565-3611

Please feel free to use the blank, sample tear-off AD below. Remember that your AD must be signed, dated, and witnessed. Your statement of personal wishes may include:

- types of treatments/technology (machinery) you would choose or refuse;
- your priorities for your health care;
- cultural and religious beliefs; and
- any other goals or values you wish your substitute decision-maker and those who provide your health care to know about

Capital Health Advance Directive Template

ADVANCE DIRECTIVE OF _____

In this Advance Directive, I state my wishes and preferences for my health care and treatment should the time come when I am unable to make health care decisions on my own. In these circumstances, I wish for the content of this Advance Directive to be respected and followed by my family/substitute decision-maker and people that provide my health care.

In circumstances in which I am unable to make health care decisions on my own,

I request that the following deeply held personal values and beliefs be respected:

_____

_____

_____

_____

I wish the following goals and priorities to be followed in my care:

_____

_____

_____

_____

If possible, I wish to avoid the following:

_____

_____

_____

_____

If it is possible, I hope for the following location of my death:

_____

_____

_____

I am CERTAIN I do not wish, under ANY circumstances, that the following medical treatments and/or interventions be used in my care:

_____

_____

_____

_____

Other specific instructions or information (not covered above) that I wish my family/substitute decision-maker and people who provide my health care to be aware of:

_____

_____

_____

_____

_____

Complete the section if you wish this to be a proxy and instructional advance directive. If you do not name a proxy, this will be an instruction advance directive.

In circumstances in which I am unable to make health care decisions on my own, I hereby designate _____ (telephone number: _____),
who is 19 years of age or older, as my proxy (substitute) decision-maker under the Nova Scotia Medical Consent Act. I have discussed this with him/her and he/she has agreed to be my proxy decision-maker.

_____

Name of family doctor: _____ Telephone number: _____

Dated and signed this ___ day of _____200__

_____

Signature   Print name

_____

Witness signature   Print name

(if a proxy decision-maker is named above, the witness must not be the proxy or the proxy's spouse)

To request a copy of an electronic version of this sample advance directive form telephone: 902-473-1564

APPENDIX D: Copyright Release Letters

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Anna Catherine Simpson
ACSIMPSO@dal.ca

22nd June 2012

Dear Anna Catherine Simpson,

REF: Simpson, A Catherine, 'An opportunity to care? Preliminary insights from a qualitative study on advance care planning in advanced COPD', *Progress in Palliative Care,* **Volume 19, Number 5, September 2011, pp. 243-253(11)**

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Please do contact me here with any further requirements or requests that you may have with regard to this matter.

Yours sincerely

Becky Hill
Editorial Assistant
r.hill@maney.co.uk

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June 21st, 2012

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Anna Catherine Simpson

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Delme Stephenson

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