Title

Dying to Breathe: A Conversation at the Crossroads of Respiratory and Palliative Nursing Care – An Action Research Project

A thesis presented to the University of Dublin, Trinity College for the degree of
Doctor in Philosophy

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Declaration

This thesis has not been submitted as an exercise for a degree at any other university and the work herein represents the sole work of the author.

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Geralyn Hynes

Acknowledgements

Dedication

This work is dedicated to the memory of KR who was such a powerful presence in the inquiry process.

Summary

Background

Palliative care policy documents and reports have called for greater equity in palliative care delivery across malignant and life limiting non-malignant conditions. However, in the acute healthcare environment, advanced chronic obstructive pulmonary disease (COPD) is framed within a disease model in which the focus of research and care is on physical symptoms and bio-medical markers. This runs counter to the philosophy of palliative care with its focus on total pain and illness experience. The project sought to develop respiratory nursing practice through the idea of Bildung which centres on engagement with that which is *Other.* Bildung offered an approach that invited conversation between the competing philosophies of palliative and acute medical care through engagement with the local moral world of respiratory care in which a disease oriented care model conflicts with that associated with palliative care.

Research Question

The central question for this project was how might palliative COPD care be construed and addressed through developing respiratory nursing practice? In this question, I was acknowledging and seeking to engage with the challenges of integrating palliative care in non-malignancy including the conflict between competing narratives in acute medical care.

Aim

The aim of the project was to develop respiratory nursing practice to address palliative care needs of patients with advanced COPD. The objectives were to:
- Identify palliative care needs among patients attending hospital for COPD management in an Irish healthcare context;
- Develop an understanding of palliative COPD care in acute hospital context;
- Identify how unmet needs can be addressed in an acute hospital context.

Methodology

The inquiry was situated within an action research framework that was guided by the idea of Bildung. The project was two-phased in which phase one incorporated mixed methods to identify palliative care needs of patients with

advanced COPD who were receiving hospital-based care. The mixed methods included health status measures and qualitative data. The second phase was a cooperative inquiry involving palliative and respiratory clinical nurse specialists; ward based clinical nurse managers and a researcher. The inquiry met to make sense of respiratory nursing practice and with the findings from the first phase, to develop an understanding of palliative COPD care in a hospital environment.

Results

Integrated analysis of health status and qualitative themes pointed to the interplay of physical and emotional distress, and lifeworld and explanatory responses. For the patient participants, basic everyday activities were dominated and severely curtailed by breathlessness and overwhelming anxiety. This resulted in an ever contracting world and loss of personhood.

Patients experienced frequent admissions, sometimes for relatively long periods and were regular attendants to OPD. This translated into often long term relationships with the respiratory members of the CI group. The phase 1 findings grounded our cooperative inquiry in addressing System-wide silencing of illness experiences. Conflicting disease and illness oriented care narratives in which the former was dominant underscored the local moral world of nursing. Our inquiry centred on understanding our responsibility to illness oriented care and the tensions this brought to working within the hospital environment. Bildung gave meaning to engagement with both illness experiences and these tensions. Our inquiry led us to understanding palliative COPD care as one which engages with the interplay between severe breathlessness and illness meaning making.

Conclusions

Palliative care in COPD should seek to minimize breathlessness and other symptoms, and acknowledge and respond to the patients' suffering by recognizing the uniqueness of and responsibility to *Other*. The antithesis of this palliative care view is failure to minimize breathlessness by failing to acknowledge the interplay of breathlessness and suffering.

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Abbreviations

A/E	Accident and Emergency
BiPap	Bi-level Positive Airway Pressure
BODE	Index of body mass index, airflow obstruction, dyspnoea and exercise capacity
CI	Co-operative Inquiry
CNS	Clinical Nurse Specialist
COPD	Chronic obstructive pulmonary disease
CRQ	Chronic Respiratory Questionnaire
EQ-5D	Standardised instrument for measuring health outcome
DON	Director of Nursing
FEV_1	Forced Expiratory Volume in one second
GOLD	Global initiative for COPD
HADS	Hospital Anxiety and Depression Scale
HF	Heart failure
HIQA	Health Information and Quality Authority
HSE	Health Services Executive
HCP	Health Care Professional
HRQOL	Health Related Quality of Life
IQOL	Individual quality of life
MRC Dyspnoea Scale	Medical Research Council Dyspnoea Scale
NHP	Nottingham Health Profile questionnaire
NIV	Non-invasive ventilation
P-CNS	Palliative Care Clinical Nurse Specialist
R-CNS	Respiratory Clinical Nurse Specialist
QALYS	Quality Adjusted Life Years
QOL	Quality of Life
SEIQOL	Schedule for Evaluation of Individual Quality of Life
SES	Socioeconomic status
SF-6D	Health related quality of life instrument composed of six multi-level dimensions.
SGRQ	St George's Respiratory Questionnaire
WHO	World Health Organization

Glossary

Bildung	Process of self formation/cultivation
BiPap	Bi-level Positive Airway Pressure: a for of non-invasive ventilation used for treatment of respiratory failure
Heteroglossia	Existence of Conflicting Discourses
Heteroglot	Adjective of heteroglossia
Hypercapnic Exacerbations	Exacerbations related to too much carbon dioxide in blood
Pulmonary Rehabilitation	Structured rehabilitation programme for people with COPD
Re/presentation	Representing from another particular perspective

Chapter One The Lead Up

Introduction

Just over 5 years ago on one very stormy evening I was among a small group of healthcare professionals and academics who met to discuss the plight of patients with advanced chronic obstructive pulmonary disease (COPD) in need of palliative care. As a lecturer in nursing but with a background in COPD care at the level of primary care, my interest was two-fold. Before taking up an academic career, I had worked with patients who had advanced COPD and for whom treatment however helpful failed to ease a constant fear over several years of severe breathlessness. Their breathlessness seemed to haunt every moment and was accompanied by a sense of frustration and loss. These patients were deemed to have advanced chronic illness; that they were also dying usually over several years was not always acknowledged. Typically, they were on maximum medication for their COPD symptoms. Consultations could be frustrating and demoralizing for patients in need of relief from symptoms and for me because of a sense of failing them. Secondly, in my later academic career, I was responsible for a post graduate diploma in respiratory nursing practice. My students were experienced respiratory nurses and the classroom provided a rich shared learning environment grounded in clinical experience. Experiences were frequently aired about patients with advanced COPD who were dying in acute wards without the benefit of palliative care. There were accounts of frustration and sense of failing patients in OPD and in the wards similar to my own clinical experiences. We seemed to be locked in a system that was unable to address the illness experiences of these patients. Despite the significant advances being made in COPD symptom management, we seemed to unable to address patients' distress.

For those of us who met on that stormy night, the issue was not about gathering evidence to support a call for palliative care. The evidence was already overwhelming (Williams 1993; Gore *et al.* 2000; Edmonds *et al.* 2001; Elkington *et al.* 2004). Neither was the issue related to policy since this had also been addressed (Department of Health & Children 2001; National Institute for Clinical Excellence 2004). The issue seemed more related to how, at local level, we could address the factors that seemed to defy both the evidence of care needs and the policy to address care needs. The rich narrative accounts in the classroom illustrated a complex web of interlocking factors influencing the current impasse. There seemed uncertainty about how to proceed; reluctance among medical team

members to refer patients to palliative care teams; reluctance among palliative care nurses to become fully involved; and fear within the organization about increasing workload and services without added funding. These factors were complex and already articulated by others (Addington-Hall and Higginson 2001a). However much we talked about these, the fact remained for our small group that somehow, in our basic care of patients with advanced COPD, we were failing them and failing our own professional ideals.

Chandler and Torbert (2003) make the point that at one level, action research is part and parcel of life and human endeavour. We are continually identifying, addressing and evaluating problems. However, when we invoke action research as a method we are bringing a state of mindfulness to all aspects of the process. We are also making explicit a set of principles underpinning the process. Reason and Bradbury (2008a) link these principles to seeking a better world in ecological and human terms. To this end, my action research journey and understanding its principles could be described as a slow burning one. Not long after nursing and midwifery training, I joined *Concern*, a large international aid agency. I worked in Bangladesh alongside local staff managing health centres and feeding centres in large slums. Everyday problems included confronting the environmental, political, health and social circumstances in which we worked and people lived.

I was subsequently seconded to work for a local non-government organization (NGO) operating in a large rural region. This NGO was founded on and worked to the ideas of Paulo Freire (Freire and Ramos 1972) and specifically that of conscientization. My responsibility was to evaluate and develop the organization's health programme. The staff members were largely middle-class and Bangladeshi. Our action research approach to assessing healthcare needs while working with villagers as the target population and health workers, revealed challenges and problems of positionality and participation. Typically, the immediate and expressed needs of villagers with whom we spoke conflicted with the intended process of collaborative building and education by staff. A recent paper by Arieli *et al* (2009) illustrating the paradox of participation resonated with these early experiences in Bangladesh. In terms of positionality, as *the 'foreigner'*, my outsider position was explicit. For other team members, their outsider position was more complex. They were insiders relative to me but outsiders as middle class educated Bangladeshis seeking to work with the landless poor. My limits as outsider were apparent in terms of knowledge and understanding of culture and language not to mention the fact that I was a white

single woman moving about on a motorbike in a strongly Muslim community. I learned also that outsider status affords an outside-the-frame perspective that offers opportunities to look differently at ways of being or our everyday scripts (Goffman 1971). I was too young and inexperienced in action research to explore more fully how it was that village women sometimes brought me into their world to a greater and more intimate degree than they did my colleagues. However, it was clear to me that positionality was complex. In action research, recognising and engaging in participation that is both epistemological and political (Reason 2006) demands an examination of our everyday scripts that is at once challenging and unsettling (Friedman *et al.* 2004).

Since that formative early action research learning, subsequent research in Zambia and practice development in Dublin presented opportunities for exploring the ways we collaborate and attend to problems of practice. In particular the gaps between espoused values and ways of working; reluctance to engage with different ways of knowing; the hegemony of reductionist approaches to care delivery; and fear and uncertainty to look beyond our everyday scripts seemed to be recurring traits that characterise the way we work. It was against this background that I began to work on a research proposal to address palliative care needs of patients with advanced COPD. The respiratory consultant and respiratory clinical nurse specialist (R-CNS) from the hospital site in which this project was eventually based, were clear in their request for a research project that would make a meaningful difference to their patients. The 'fit' with an action research approach seemed to support a proposal that would focus on the messiness of addressing COPD palliative care at local level but which might also help us understand better the factors influencing how we care for patients with advanced COPD.

The first significant challenge then was not related to gaining access as might be expected in action research (Herr and Anderson 2005) but rather it was gaining ethical approval. Initially, I was seeking what Heron (1996) refers to as a counterpartal inquiry that is to say one in which those targeted in the inquiry, in this case patients, are themselves participating in it. My reasons were two-fold. My Bangladesh experience which had been repeated in different ways and different settings told me that patients had both a right to be involved and expertise in living with COPD not known to those providing nursing care. In short, my reasons were both political and epistemological. Secondly, I believed

that the bringing together of nurses and those living with and receiving care for COPD would provide the basis to challenge our assumptions about care delivery.

In the end, the Faculty's ethics committee did not agree on the basis that patient involvement to this degree would be overly burdensome on people who were by definition very ill. Our co-operative inquiry was ultimately made up of nurses only, albeit with one patient group meeting. As so often happens in life, the apparent blow presented opportunities. Firstly, I needed to revisit our plans for the first phase of the project namely to identify what are the palliative care needs of patients with COPD in an Irish context. I needed to do so in a way that would provide the hospital with the kind of data others could use to garner resources to support practice development towards addressing palliative care needs. This meant including health status measurement. However, I needed to also ensure that patients could speak about their illness as they wished and saw fit and in a way that would counter what Opie (1992b) refers to as appropriation in research such as approaches to health status measurement. This ultimately resulted in a journey into feminist writings and from there onto the work of literary theorist, Edward Said (2003). The first phase of this project benefited from this added reading and my developing confidence in interview approaches within an action research framework.

Secondly, in the early stages of the co-operative inquiry, a meeting became an unexpected focus for expressing grief following the death of a patient a few days earlier. It is unlikely that members would have felt able to express grief in this way at that stage in the inquiry had patients been present. Yet, there is no forum in place for nurses who have built up close relationships with patients over years to express grief at their passing. This meeting was a turning point in the inquiry as I discuss later. It opened up questions about disease versus illness oriented care, and about the close relationships built up with patients over time and the sense of loss at their passing. This thesis is dedicated to the memory of that patient, KR, who became such a presence in the project following her death.

I was very fortunate to have been awarded a fellowship to undertake this research based on the project proposal. However, one of the reviewers also made the point that a project on palliative care needs should include relatives. At the same time all reviewers were in agreement that the proposed research was already substantial. The reviewer in question had confirmed a niggling doubt in my own mind about the exclusion of relatives who are providing everyday care to

patients with advanced COPD. One of my supervisors and I developed a second proposal for a small study exploring the experiences of informal carers of patients with advanced COPD and were awarded funding enabling us to employ a research assistant. Though separate studies, most of the patients who participated in this project were anxious to highlight the work of and dependency on their informal carers. Several requested that their carers sit on interviews.

Along the way, the carer study and this project have taught me not just that carers are integral to advanced COPD care, palliative needs, and illness experience, but also the complexity of a counterpartal inquiry and participation in action research. Patients and carers alike experience loss and distress. Efforts to engage with and address illness suffering inevitably involved attention to patients and also their carers. Care delivery and decision-making impinged on carers and was often reliant on carers in relation to discharge planning and between hospital admissions. In short, had we received ethical approval for and proceeded with a counterpartal inquiry, we would likely have had to confront the possibility that our approach was less counterpartal than intended since carers were not included.

Action research, as a method, requires the continual testing of assumptions, beliefs and values including and perhaps especially those claiming to be informed by its principles. If there is one ultimate methodological lesson from this inquiry it is that one never arrives at a penultimate action research approach; the picture is always more complex and asks more questions. Action research must be continually action researched; its scripts questioned from within and without. In that sense, this project as presented here has barely begun.

Thesis Structure

Others have grappled with the challenge of structuring an action research thesis (Herr and Anderson 2005). Findings or emerging themes may give rise to revision and further development of methods that may in turn lead to new avenues to be explored in the literature. Thus, arguments raised in a literature review chapter may have emerged late in a project rather than as suggested using the standard logical format of a research thesis. This is how it was in our project. However, to tell the project story in such a fashion would render the thesis difficult to read. I have therefore opted to follow the standard format for a PhD thesis but without wishing to ignore the emergent nature of the inquiry.

In the following chapter, I present the context of COPD: how it is understood within healthcare and attempts to explore the experience of living with the condition and highlight unmet palliative care needs. COPD is a chronic condition and chapter 3 addresses chronicity in relation to how it is conceptualised within healthcare and medical sociological literature. In the final section, I discuss the idea of palliative care and questions arising in relation to chronicity. In chapter 4, I raise a number of methodological issues in terms of how COPD is conceptualised giving rise to different voices or languages in healthcare and beyond. I draw on the ideas of Mikhail Bakhtin to explore different and conflicting languages that characterise different voices. I address issues with COPD research methods specifically health status measurement and researching suffering. I finish with the inquiry question, aim and objectives.

The project was ultimately about how we, as nurses, might develop practice to address palliative care needs of patients with advanced COPD. In chapter 5, I begin with a discussion about practice development and situate this within the ideas of pragmatism and specifically inquiry as a continuing conversation with the world and remaking of ourselves. I draw on the German idea of Bildung to highlight self cultivation/development within this continuing conversation. This provides the backdrop to the justification for and understanding of action research as the framework for the inquiry. Action research has been called a family of inquiry approaches (Reason and Bradbury 2008a). In chapter 6, I detail the framework for this project, the setting, participants, inquiry methods, and quality and ethical issues.

The findings and emergent themes are presented across 4 chapters and focus on suffering and the significance of shifting to an illness oriented care approach as key to palliative COPD care. How palliative care might be construed is explored in chapter 11. The local moral world of nursing and conflicting languages in COPD acute care are presented as significant challenges to embedding palliative COPD in practice. In Chapter 12, I return to the value of Bildung and Bakhtin to this inquiry and their potential contribution to action research.

Chapter Two COPD

Introduction

COPD is an umbrella term for the conditions emphysema, chronic bronchitis and chronic asthma all of which share clinical markers and may evoke images of coughing and breathlessness. In this chapter, I set out the context of COPD as it is understood and presented within the world of healthcare. COPD is often discussed in terms of its burden on resources and health status against a backdrop of high prevalence, morbidity and mortality particularly in the advanced stages of illness. In sharp contrast, there is also a growing body of work that focuses on the lived experience and patients' sense making of their COPD. Thus, within the COPD healthcare literature there is what might be referred to as a disease/illness dichotomy. In this, disease refers to a focus on bio-medical markers or patho-physiology and reducing aspects of the condition to elements that can be measured and possibly controlled. Illness, on the other hand, addresses the physical, emotional, cultural and lifeworld experiences of living with the condition.

I first address the current definition for COPD and associated symptoms. I then address the epidemiology and disease progression with specific reference to hospitalization and end stage of the condition. In the final section I attend to the impact of COPD on the individual in terms of health status measurement and qualitative studies. The structure of the chapter reflects the weighting given to a disease focus in how COPD is understood in healthcare. Health status measurement instruments, though addressing burden on the individual, are also criticized for their reductionism a point I address in a later chapter. Illness oriented COPD research stems largely from the fields of healthcare sociology and nursing. The disease/illness dichotomy provides an important backdrop to the challenges in both construing and addressing palliative COPD care.

Defining COPD

Definitions for COPD have evolved over the past decade with that proposed by the GOLD project being the one most widely used in Ireland (Global Initiative for Chronic Obstructive Disease 2009). The GOLD project defines COPD as 'a disease characterised by airflow limitation that is not full reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases' (Global Initiative for Chronic Obstructive Disease 2009). Clinical syndromes associated with COPD include: chronic

bronchitis, emphysema and chronic asthma. These syndromes differ from each other anatomically and in their pathogenesis. However all are associated with airflow limitation and therefore come under the umbrella of COPD.

COPD is characterised by airflow limitation that is not fully reversible and may be irreversible. The condition may follow different patterns from person to person with some people experiencing a rapid progressive decline in lung function with increasing morbidity and early death. Others experience progressive decline in lung function that whilst more severe, nonetheless mimics the downward curve of lung function associated with aging. Symptoms can range from those who continue to experience a chronic and productive cough, to those who progress to severe and disabling dyspnoea on minimal exertion. COPD is associated with acute exacerbations and there is a positive correlation between the frequency of exacerbations and accelerated decline in lung function (Global Initiative for Chronic Obstructive Disease 2009). Frequency of acute exacerbations has been linked with progression towards end-stage disease and death. Assessment of airflow limitation underpins the diagnostic criteria for COPD. The GOLD project uses spirometric classification to diagnosis disease severity ranging from stage 1 with mild airflow obstruction and sometimes a chronic cough to stage 4 reflecting very severe airflow limitation and chronic respiratory failure. More recently a number of important markers have been identified for classification of disease severity. These include: body mass index (BMI), dyspnoea score, spirometry and a 6 minute walking distance (Celli *et al.* 2004; Celli *et al.* 2005; Franciosi *et al.* 2006; Casanova *et al.* 2008).

Common Symptoms

Cough and breathlessness are the most common symptoms of COPD. Breathlessness is associated with poorer prognosis, increasing disability and loss of lung function. In patient studies on quality of life and experience of living with COPD, breathlessness dominates activities of daily living (Williams and Bury 1989; Williams 1993; Jones *et al.* 2004; Fraser *et al.* 2006). In severe COPD, patients are usually breathless on minimal activity with factors such as weather, humidity, emotional state and anxiety often dictating the degree of day to day breathlessness.

Severe disease is associated with increasing reliance on accessory muscles for breathing. This, in turn, places an added burden on normal activities that would

call on these same muscles e.g. carrying a shopping bag. Measurement of respiratory function underpins diagnosis and assessment of disease severity. Other disease morbidity is associated with COPD including heart disease, depression, osteoporosis and diabetes (Calverley and Georgopoulos 2006; Sevenoaks and Stockley 2006). Anorexia and weight loss are associated with advanced disease, and body and fat-free mass indices are gaining importance as markers for poorer prognosis.

Epidemiology

Establishing Prevalence

The majority of patients presenting with COPD are >50yrs, have a history of cigarette smoking and report symptoms that may have first appeared some years earlier (Annesi-Maesano 2006; Celli 2008). Consequently establishing true prevalence of COPD is difficult. This is due to a range of methodological difficulties including under-presentation and under-diagnosis both of which are well recognised challenges in COPD prevalence studies (Dales *et al.* 2006; Gulsvik *et al.* 2006; Hoogendoorna *et al.* 2006; Manninoa and Holguinb 2006; Global Initiative for Chronic Obstructive Disease 2009). Population studies generally rely on the presence of symptoms and a history of cigarette smoking. The key symptoms, cough and breathlessness, are common to a range of conditions. The term 'COPD' is not widely used in the general population. Some prevalence studies are based upon eliciting symptoms with/without a diagnosis. Other studies focus on physician diagnosed COPD thus, estimating the prevalence of clinically significant COPD. However within these types of studies are two subsets: those that seek spirometric confirmation of diagnosis for inclusion criteria and those that include patients who are diagnosed on the basis of history alone. Of those using spirometry, unless this includes reversibility testing, which is not always the case, then their diagnostic accuracy is compromised. Moreover, establishing the exacerbation rates among patients with COPD as a marker for significant COPD, is challenged by under-reporting of episodes to physicians (Annesi-Maesano 2006).

Despite these methodological difficulties, prevalence of COPD is generally thought to range between 5 and 10% based on those population studies in Europe and the US (Halbert *et al.* 2003; Annesi-Maesano 2006; Manninoa and Holguinb 2006). However, data from prevalence studies that applied standardized methods including spirometry point to higher prevalence of up to 25% of adults

aged 40 and over (Global Initiative for Chronic Obstructive Disease 2009). Irish rates are not cited in Halbert's et al (2003) review of published prevalence studies. The European Community Respiratory Health Survey (ECRHS) provided data on chronic bronchitis in young adults (20-44yrs) from centres in 35 participating centres in 13 European and 3 non-European industrialized countries (Cerveri *et al.* 2001). The ECRHS study reported a prevalence of chronic bronchitis in Europe ranging from .07% to 9.7%; the median was 2.6%. Ireland, Spain and the US had the highest rates (Cerveri *et al.* 2001).

Mortality

International Trends

COPD is the 4th leading cause of mortality worldwide (Annesi-Maesano 2006) and is projected to be the 3rd leading cause of death worldwide by 2020 (Global Initiative for Chronic Obstructive Disease 2009). Further increases in mortality are predicted based on demographic changes, mortality trends from other diseases and current smoking prevalence. With the strong association between smoking and COPD, data on smoking prevalence among younger adults today can be extrapolated to predict COPD mortality rates in years to come. The rise in smoking prevalence among females accounts for much of the predicted rise in COPD rates in Western economies (Gulsvik *et al.* 2006). There have been notable difficulties in comparing mortality rates internationally. These are, in part, historically associated with terminology for COPD where chronic bronchitis and emphysema are used in conjunction with COPD. COPD is not a specific category in the International Classification of Diseases. Rather, COPD data is derived from subgroups encompassing chronic bronchitis and emphysema. The Ninth and Tenth Revisions of the ICD refer to COPD and allied conditions (ICD-9 codes 490-496 and ICD-10 codes J42-46). However there remain difficulties with differences in diagnostic criteria, recording of co-morbidity and certification in different countries. COPD may be cited as contributory cause of death and there is some indication that in elderly populations, COPD may be associated with misclassification of death certificate (Gulsvik *et al.* 2006; Manninoa and Holguinb 2006; Global Initiative for Chronic Obstructive Disease 2009). Moreover earlier research found that the reporting of COPD as a contributory cause of death was influenced by the underlying cause such that it was mentioned more often with ischemic heart disease than malignancy (Camilli *et al.* 1991; Andersson *et al.* 2006). Co-morbidity appears significant both in terms of number of conditions

(Lynn *et al.* 2000; Groenewegen *et al.* 2003) and their relationship with the COPD disease process (Huiart *et al.* 2005; Decramer *et al.* 2008; Wouters 2008).

Irish Trends

Respiratory disease accounts for one in five deaths in Ireland, the highest death rate from respiratory disease in Western Europe (Brennan and O'Connor 2003; Brennan *et al.* 2008). Age-standardised death rates per 100,000 population stand at 122 for Ireland compared with EU and European averages of 57 and 66 respectively. Deaths from respiratory disease in Ireland are similar to those from coronary heart disease. Differences in ICD coding over the past 30 years present challenges to establishing true trends in mortality in the Irish context. However there appears to be little change in respiratory disease death rate since 1987 (drop of 3%) compared with coronary heart disease (drop of 29%). COPD accounts for 26% of total respiratory mortality, second only to pneumonia as leading cause of respiratory death.

The inverse relationship between socio-economic groups and respiratory disease death rates is well documented (Institute of Public Health in Ireland 2001; Brennan *et al.* 2008; Global Initiative for Chronic Obstructive Disease 2009). Across the whole island of Ireland, deaths from respiratory disease are 20% higher in the lowest compared with the highest socio-economic group (Institute Public Health 2001). Internationally however, the role of SES as a predictor for death from COPD is more contentious. Studies examining mortality following hospitalization for COPD have not found SES to be an independent risk (Almargro *et al.* 2002; Groenewegen *et al.* 2003).

Addressing Mortality

The most important intervention for COPD is smoking cessation to arrest the accelerated decline in airflow limitation and reduce susceptibility to acute exacerbations thereby effecting mortality (Postma and Boezen 2006; Global Initiative for Chronic Obstructive Disease 2009). Apart from smoking cessation, the impact of all the current and different treatment interventions on COPD mortality is not readily known (Postma and Boezen 2006). Home oxygen (Cranston *et al.* 2005) has been found to be effective in increasing survival. Celli

et al (2005; 2008) from their work suggest a BODE index of 4 factors that predict the risk of death (Table 2.1)

Table 2.1 BODE Index	
Acronym	**Description**
B	Body mass index
O	Degree of airway obstruction
D	Degree of functional dyspnoea
E	Exercise capacity

Early indications suggest that patients with a higher BODE score have a higher risk of death (Celli *et al.* 2005; Celli 2008). Interestingly, in their research, Groenewegen et al (2003) found that BMI reached only borderline significance as an independent factor associated with mortality in contrast to findings elsewhere (Celli *et al.* 2004; Gudmundsson *et al.* 2006a).

Other studies have reported on factors that appear significantly associated with mortality: levels of activity (Oga *et al.* 2007), health status measured with SGRQ (Domingo-Salvany *et al.* 2002; Oga *et al.* 2007), dyspnoea (Garcia-Aymerich *et al.* 2003; Mannino and Buist 2007), old age (Almargo *et al.* 2002; Groenewegen *et al.* 2003; Mannino and Buist 2007) and poor lung function (Connors *et al.* 1996; Global Initiative for Chronic Obstructive Disease 2009). Hospitalization for treatment of acute exacerbation of COPD is also suggested as a predictor of risk of death (Lynn *et al.* 2000; Groenewegen *et al.* 2003; Andersson *et al.* 2006; Kinnunen *et al.* 2007). Drawing on centralised databases on all admissions and follow-up to hospitals in Finland over a 10 year period, Kinnunen et al (2007) report that nearly a quarter of patients who required hospitalization because of COPD, had died within one year. The mean survival time was 2.2 years for men and 2.4 years for women. Mortality within one year following hospitalization for acute exacerbation from COPD in studies in the Netherlands (Groenewegen *et al.* 2003) was 22%; in Spain it was 22% (Almargo *et al.* 2002) and in the US (Connors *et al.* 1996) it was 43%.

That, treatment days in hospital increase as the disease progresses is well known. However, in the Finish study, hospital use appeared U shaped with high use at earlier in addition to late stages of treatment. Those patients who died within the first year accounted for 40% of hospital treatment days recorded for COPD over

the study period (Kinnunen *et al.* 2007). In a Spanish study (Soler-Catuluna *et al.* 2005), the link was also made between hospitalizations for acute exacerbation of COPD and mortality. Mortality increased with the frequency of exacerbations. Andersson et al (2006) reviewed the Swedish Inpatient and Mortality registers for patients across Sweden who died in 2000 and in whom the underlying cause of death was COPD. Those patients who were admitted with COPD as an underlying reason had on average 5.8 COPD admissions and an average 8.4 days length of stay per admission. Of those patients with COPD, 19% had their first ever COPD related admission in the 6 month period before death while the median was 2.5 years. The research team found that there was an increase in the number of admissions before death and an increase in length of hospital stay in the 6-8 month period before death.

Morbidity

COPD morbidity is generally expressed as disease burden and in terms of consultations with physicians and GPs, hospital admissions, outpatients, and accident and emergency visits (Annesi-Maesano 2006; Global Initiative for Chronic Obstructive Disease 2009). COPD morbidity databases are less readily available or reliable (Global Initiative for Chronic Obstructive Disease 2009). As with mortality research, morbidity studies on COPD have methodological issues rendering difficult comparisons between data from different countries and within countries. Patients, for example, frequently under-report exacerbations (Annesi-Maesano 2006). A global estimate of respiratory disease accounting for 15% of all GP consultations is suggested in the INHALE study for Ireland (Brennan and O'Connor 2003). Significantly average lengths of stay in hospital for patients admitted with COPD in 1994 in the UK stand at 9.9 (Annesi-Maesano 2006) and more recently 8.4 in Sweden (Andersson *et al.* 2006) and 6.8 in Finland (Säynäjäkangas *et al.* 2004). In Ireland average length of stay (8 days) is reported as only slightly less than in the UK with COPD viewed as an important factor in hospital overcrowding (Costello *et al.* 2003; Brennan *et al.* 2008).

Disease progression

Hospitalization

A range factors are increasingly acknowledged as important in COPD diagnosis. These include exercise capacity, functional status, depression, fat-free body mass, the presence of co-morbidity such as depression, cardio-vascular disease

and diabetes (Gulsvik *et al.* 2006; Janson *et al.* 2006; Mannino *et al.* 2009). Since moderate to severe COPD is more common in older people, the presence of cardio-vascular disease and diabetes is not surprising. However, progressive COPD and associated co-morbid conditions in older patients results in significant disease burden on individual sufferers and hospital services (Mapel *et al.* 2000; Gulsvik *et al.* 2006; Hoogendoorna *et al.* 2006; Janson *et al.* 2006; Global Initiative for Chronic Obstructive Disease 2009).

There is evidence that patients who are either admitted or attend outpatients for treatment of COPD have twice the prevalence of congestive heart disease, gastritis, depression and localised cancer compared with matched age adjusted and gender adjusted controls who do not have COPD (Mapel *et al.* 2000). Thus patients who attend hospitals for treatment of COPD have more hospitalization and outpatient visits than matched controls and experience greater overall morbidity (Mapel *et al.* 2000; Loddenhemper 2003; Gulsvik *et al.* 2006). Patients with COPD and cardiovascular disease have also been found to be more prone to severe exacerbations than those with COPD only (Kinnunen *et al.* 2007). As one might expect, patients nearing death from COPD accounted for a substantial proportion of all COPD admissions and were likely to remain in hospital for longer periods particularly in the presence of co-morbidity. Moreover those patients who were >65 had longer stays in hospital (Kinnunen *et al.* 2007). Lynn et al (2000) found that those patients who die from COPD spend one fifth of their final 6 months of life in hospital.

Acute exacerbation

The recent focus on burden of COPD in the context of health services utilization as above reflects the importance of moderate and severe stages of the disease for resource planning and evaluation. Acute exacerbations are most frequent among patients with moderate to severe COPD and can also be the point at which patients are diagnosed with COPD (Zoia *et al.* 2005). Exacerbations among patients with moderate to severe COPD are associated with burden on healthcare delivery (Oostenbrink and Rutten-van Mölkena 2004; Emtner *et al.* 2007), deterioration in health status (Donaldson *et al.* 2002; Andenaes *et al.* 2004; Jones 2009), and increased risk of both mortality and readmission (Garcia-Aymerich *et al.* 2003; Gudmundsson *et al.* 2006b; Aimonino *et al.* 2007).

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Spencer and Jones (2003) found that after a single exacerbation, recovery takes >3 months. A prospective study involving 519 patients with COPD in the Netherlands and Belgium, tracked the duration of exacerbations, associated risk factors and hospital burden (Oostenbrink and Rutten-van Mölkena 2004). This study is interesting in that it established the total duration of exacerbations rather than simply the length of hospital stay. All patients were receiving treatment for COPD on recruitment to the study. Of the 40% of patients who experienced exacerbations, the mean duration of attacks was 16 days. Some 10% of exacerbations were severe and in this group the mean duration of exacerbation was 25 days. About 16% of exacerbations required hospital admission. Among those with severe exacerbations, 78% were admitted to hospital compared with 16% and 5% of those with moderate and mild exacerbations respectively. Low body mass index (BMI), high numbers of respiratory medications, co-morbidity, poor health status and a poor dyspnoea score as distinct from FEV_1 were associated with increased risk of hospitalization.

The most important of these risks were more than two concomitant diseases and a BMI of less that 18.5 (Oostenbrink and Rutten-van Mölkena 2004). These findings confirm the importance of low BMI found elsewhere (Franciosi *et al.* 2006; Hallin *et al.* 2006). In another prospective study, across 5 Nordic countries, Gudmundsson et al (2006a) analysed re-hospitalization among patients with COPD. In their study patients re-admission was associated with poor health status, anxiety and low activity. In short, important indicators for COPD severity and risk of exacerbations requiring hospitalization can be gleaned from assessment of health status, dyspnoea score and BMI (Oostenbrink and Rutten-van Mölkena 2004; Gudmundsson *et al.* 2006a).

Patient outcomes following acute exacerbations that require hospital admission are associated with increased risk of mortality within two years (Almargro *et al.* 2002; Groenewegen *et al.* 2003; Soler-Cataluña *et al.* 2005). Increased risk is associated with health status, depression, marital status, co-morbidity and prior hospital admission. More recently the use of non-invasive ventilation has improved mortality following acute severe exacerbation. However, patients experience increased loss of function following an exacerbation compared with health status prior to their attack (Lynn and Adamson 2003) Thus, a pattern emerges: with each exacerbation there is loss of health status, and an increased in-hospital and post discharge risk of mortality. For those patients with severe COPD and who experience acute exacerbations requiring hospital admission, it is

difficult to predict which attack will result in death. In a prospective study, Gudmundson et al (2006b) analysed mortality in COPD patients after hospitalization and associated risk factors across the 5 Nordic countries. Some 416 patients who were admitted with acute exacerbations of COPD over a one year period were recruited and data was collected up to two years later. Some 29% of this group died within the two year follow up. Those who died were older, had poorer health status, co-morbidity and a history of previous hospitalizations. Significantly this research found diabetes to be a risk factor for mortality (Gudmundsson *et al.* 2006b). Health status was measured using the St George's Respiratory Questionnaire

End stage COPD

The term 'end-stage COPD' is frequently used interchangeably with severe or very severe COPD though this is challenged by those drawing a distinction between active therapeutic and palliative management (Kimathianaki *et al.* 2006). However, there are as yet no formalized definitions for end-stage COPD within respiratory medicine. In the US, the National Hospice Organization developed a set of criteria for end-stage pulmonary disease (Abrahm and Hansen-Flaschen 2002). These criteria have been challenged for their accuracy and purpose, which is to define eligibility for hospice care (Kimathianaki *et al.* 2006). A counter definition has been proposed:

> End-stage COPD may be defined as very severe (forced expiratory volume in one second (FEV_1) <30% predicted) COPD accompanied by severely limited and declining performance status, plus at least one of the following criteria: 1) advanced age; 2) presence of multiple morbidities; and 3) severe systemic manifestations/complications of COPD (Kimathianaki *et al.* 2006:430).

This definition addresses the importance of co-morbidities and draws a distinction between severe COPD, as defined in classification and management guidelines, and end-stage COPD requiring a move to palliative care. Nevertheless it remains the case that predicting death or estimating prognosis in COPD is notoriously difficult (Lynn *et al.* 2000; Domingo-Salvany *et al.* 2002; Nishimura *et al.* 2002; Celli *et al.* 2005; Kimathianaki *et al.* 2006). There are several factors at play here. Lyn and Adamson (2003) describe a gradual deterioration punctuated by acute exacerbations any one of which may result in death. It is difficult to

identify which exacerbation will prove fatal. Consequently, there is considerable uncertainty surrounding disease trajectory even in advanced disease making it difficult for physicians and patients to broach the topic of death. Patient studies have pointed to the consequences of uncertainty concerning their illness and prognosis; namely patients feel more isolated from their physicians and experienced communication difficulties and unmet information needs (Williams 1993; Skilbeck *et al.* 1998; Curtis *et al.* 2002; Jones *et al.* 2004).

In their interviews with carers of recently deceased individuals from COPD, Elkington et al (2005) found that some 40% of carers were unaware that the deceased were likely to die. There are growing debates in the medical literature on themes such as advanced directives and end of life discussions with patients (Ahmedzai and Muers 2005; Hyland and Sodergren 2005), advances in treatment of very ill patients and 'treatment ceilings' of very ill patients (Kimathianaki *et al.* 2006), and use of opioids for relief of dyspnoea (Jennings *et al.* 2001). The growing use of non-invasive ventilation (NIV) in advanced disease places a burden of responsibility on physicians to explore advanced directives. These debates serve to highlight the challenge facing physicians in defining and estimating the prognosis in end-stage COPD. Research has shown that prognosis is particularly poor for those patients who are treated with NIV for acute hypercapnic exacerbations of COPD (Chu *et al.* 2004). However, it is likely that such patients will have already lived with uncertainty and severe symptoms for some time during which end of life discussions might have been aired. Moreover, if applied, advanced directives for this group of patients should be considered before or at the onset of NIV management.

In a study examining treatment preferences among patients with limited life expectancy including those with COPD, participants balanced burden of treatment against likelihood of treatment outcome (Fried *et al.* 2002). If the likely outcome was severe impairment, then the majority of participants indicated they would not want even low-burden treatment. However, it must also be said that given the uncertain COPD disease trajectory even at advanced stage, it is difficult for individuals to express preferences in 'what if' scenarios. More recent research suggests that barriers to end of life discussions between oxygen dependent patients and their physicians are multi-layered and extend well beyond time pressures. Patients may want to focus on living, while physicians may want to focus on fostering hope (Knauft *et al.* 2005). On the other hand, end of life discussions provide scope to address complex care needs ranging from symptom

burden to much needed support for carers who, themselves, are likely to be elderly (Simonds 2006). Among the less contentious elements of severe and end-stage COPD management is that of pulmonary rehabilitation, which appears to improve exercise capacity even among very ill patients provides a forum for introducing topics on advanced directives and end of life.

Pulmonary Rehabilitation

Pulmonary rehabilitation has been defined as 'an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities' (Troosters *et al.* 2006). Pulmonary rehabilitation seeks to optimise functional status, reduce symptoms and reduce hospital costs through addressing symptoms and disease state. A noteworthy point in the definition and aims is the emphasis on symptoms and disease impact on everyday life rather than simply focussing on lung function. Key components of pulmonary rehabilitation include patient education including smoking cessation, psychosocial support, physiotherapy, exercise and muscle training, and nutritional support. A central tenet of patient education is the development of self management skills. These, for example, include managing increased sense of breathlessness or a coughing fit. The prevalence of depression and anxiety among patients with COPD is well rehearsed in the literature. Pulmonary rehabilitation programmes increasingly have a psychologist or psychotherapist on their teams to address psychosocial support needs of patients. Though, generally those patients who are recruited onto pulmonary rehabilitation programmes have moderate to very severe COPD, there is a dearth of literature on talking with participants about death and dying. Chest physiotherapy, exercise and muscle training, and nutritional support all seek to address specific markers associated with poor prognosis including inability to cough effectively, poor exercise capacity and low body and fat-free mass indices.

Pulmonary rehabilitation programmes that are both hospital and home-based have become an integral feature of moderate and severe COPD care particularly following an acute exacerbation. A worrying feature of evaluative studies and systematic reviews is the growing debate as to the most suitable patients for pulmonary rehabilitation. This debate juxtaposes tensions between cost benefit analysis using economic markers on the one hand, and quality of life markers supported by qualitative research on the other. There are some suggestions that patients who are socially isolated are more likely to drop out, those with very

severe COPD are less likely to improve based on disease markers and those who are confirmed smokers are less likely to benefit (Troosters *et al.* 2006). In cost benefit terms this would suggest targeting those most likely to complete the programme. The exclusion of some patients may mean that they never gain access to psychosocial, nutritional and physiotherapy support while they face death since these support systems do not extend beyond the pulmonary rehabilitation programmes in hospitals.

Smoking

The single most effective intervention for COPD has repeatedly been shown to be smoking cessation (Global Initiative for Chronic Obstructive Disease 2009) given the association of exposure to tobacco smoke with progressive decline in expiratory flow rate. While many people who smoke do not develop disabling symptoms of COPD, the more pack years people achieve the more likely they are to fulfil diagnostic criteria for COPD[1]. Reaching those individuals with mild disease is therefore difficult but urgent in terms of reducing mortality (Dales *et al.* 2006; Rennard and Vestbo 2006). In short, patients who present with moderate to severe COPD might have benefited from earlier diagnosis and help with smoking cessation. There is evidence that sustained quitters experience a mean FEV_1 decline of less that 27mL per year compared with 60mL per year for continuing smokers (Anthonisen *et al.* 1994). The implications for all people with COPD including those at end stage are that smoking cessation remains the key intervention for disease management. This point has consequences for the nurse/patient and physician/patient relationship throughout the disease process.

Burden of COPD on the individual

While COPD is characterised by increasing airflow limitation, loss of lung function frequently correlates poorly with changes in quality of life, health status, functionality, dyspnoea and depression. In short, patients can experience significant deteriorations in health status and quality of life with less dramatic changes in FEV_1. Thus patient reported outcomes are likely to differ from physiological measures used to mark the disease status (Spencer *et al.* 2001a; Andenaes *et al.* 2004; Oga *et al.* 2007). The core symptoms of COPD: cough,

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[1] A pack year is defined as 20 cigarettes smoked every day for 1 year. Pack years are calculated by multiplying the number of packs of cigarettes smoked per day by the number of years an individual smoked.

walking distance ability, disability, anxiety and wheeze account for only 50% of variance in quality of life scores (Jones and Wijkstra 2006). A 5 year longitudinal study in Japan that followed patients with moderate to severe COPD found significant deteriorations in: health status using the St George's Respiratory Questionnaire (SGRQ) and Chronic Respiratory Questionnaire (CRQ); depression using the Hospital Anxiety and Depression scale (HADS) and dyspnoea using the Medical Research Council scale (MRC). In all but the HADS depression score, there was only a weak correlation with FEV_1 changes (Oga *et al.* 2007). In HADS depression score, there was no significant correlation with FEV_1.

The association between depression and anxiety, and COPD is well documented (van Ede *et al.* 1999; Crockett *et al.* 2002; van Manen *et al.* 2002) despite concerns about the sample sizes (van Ede *et al.* 1999). Di Marco et al (2006) studied the prevalence of anxiety and depression among all patients who attended a respiratory unit for treatment of COPD. Those who were dependent on long term oxygen or suffering from a severe non-pulmonary disease were excluded from the study. The study included a control population. Prevalence of anxiety and depression were 28.2% and 18.8% respectively among COPD patients. These findings were significantly higher than those found in the control group. The findings also suggest higher rates of anxiety and depression than those found in similar studies involving cancer patients (Di Marco *et al.* 2006). There were no statistically significant differences among the rates of anxiety and depression according to classification of severity of COPD. This may have been in part due to small numbers of patients with mild COPD (13%) compared with moderate (43%) and, severe and very severe (44%) COPD respectively. Patients with high levels of anxiety and/or depression had worse health status as measured with SGRQ while depression correlated positively with dyspnoea. Women had higher rates than men for anxiety, depression, poor health status and dyspnoea despite differences in lung function (Di Marco *et al.* 2006).

At the level of individual patients' care, understanding both their perceived existing quality of life and their desired quality of life is an integral part of optimum care (Hyland and Sodergren 2005). Jones and Wijkstra (2006) question the practice of using the terms quality of life and health status interchangeably. Specifically quality of life focuses on the balance between one's desired life and that which one has achieved. This view of quality of life is considered too broad to be meaningful in any attempt to measure the effects of disease across a patient population (Jones and Wijkstra 2006). In the majority of studies

reviewed here, health status is the term used when referring to general health or disease specific tools. Measurement of health status is problematic (Jones and Wijkstra 2006) both in terms of comparing studies that use different instruments and the potential at the level of the individual for fluidity in one's concept of health related quality of life and health status. Of the general health and disease specific questionnaires for COPD, the Chronic Respiratory Questionnaire (CRQ) and the St George's Respiratory Questionnaire (SGRQ) are the most frequently used and of these the SGRQ is the more widely used. The SGRQ appears capable of predicting mortality independently of age, lung function and BMI. The Medical Research Council dyspnoea scale (MRC scale) is used as a measure of disability that stems from breathlessness. More recent instruments, Baseline Dyspnoea Index (BDI) and Trans Dyspnoea Index (TDI) appear to be potentially more sensitive that the MRC scale (Jones *et al.* 2005). However the MRC scale remains the most widely used.

The COPD experience

Early work on the experiences of people with COPD highlighted the continual presence of fear, tiredness and lethargy associated with breathlessness such that these governed daily life (Williams 1989; Williams 1993). An attack of breathlessness was associated with a battle for life itself (Williams 1993). In a series of qualitative interviews involving 24 people with COPD, Williams (1993) found a sense of bodily betrayal or Cartesian dualism associated with tiredness and lethargy. Respondents referred to the gap between a willing mind and a weak body on a day to day basis as a source of distress and depression. The need for constant vigilance against an infection and exacerbation of COPD, attention to weather forecast and even very minor changes in the weather, and social withdrawal to avoid panicky situations were examples of how basic elements of daily life had become part of the emotional straightjacket within which sufferers lived.

The forced social withdrawal was associated with both fear and embarrassment of a coughing or breathlessness attack in the presence of others and in some cases, others referred to immediate family. Social withdrawal was also associated with poverty arising from long term disability and inability to work. Thus, Williams (1993) reports a total dependency among his interview subjects on the spouse for care and company. Fears concerning further dependency and uncertain future were voiced. Strategies for adjusting to their illness included limiting

expectations and learning to appreciate the accomplishment of what were previously mundane daily tasks. A trip to the local shop or hospital outpatients department required minute planning to minimize exertion and exposure to triggers for breathlessness and coughing.

More recent studies report similar findings suggesting that despite advances in symptom management through medication and rehabilitation, there has been little real impact on the COPD experience for many sufferers particularly those with moderate to severe stages of illness (Lynn *et al.* 2000; Jones *et al.* 2004; Seamark *et al.* 2004). The more recent studies focus on patients with marked symptoms including those in their last year of life (Skilbeck *et al.* 1998; Elkington *et al.* 2004; Elkington *et al.* 2005) and palliative care needs (Guthrie *et al.* 2001b; Seamark *et al.* 2004). While Williams (1993) undertook his research before the first published classification of COPD (The COPD Guidelines Group of the Standards of Care Committee of the BTS 1997), the fact that the patients in his study were under the care of hospital physicians would suggest that his study group were similar to those in later studies. Moreover, the patient experiences reported by Williams (1993) were those of patients with at least moderate COPD.

In an interpretative phenomenological study involving 10 patients with severe COPD, Seamark et al (2004) found loss as a major theme where loss was associated with social withdrawal and included breathlessness, loss of personal liberty, loss of relationships and ability to step outside. Relationships with healthcare professionals included positive and negative sub-themes. The positives related to a trusting relationship with the doctor, usually the GP; the negatives related to misgivings about hospital visits, the effort required, the role of clinics and of specialist respiratory nurses. This study was based in one general practice setting and that 3 of the 4 authors were from the practice might have some bearing on the findings here. In another community based study, Jones et al (2004) interviewed 16 patients from 7 practices. Among the key themes identified in their study were: breathlessness, information needs, and limited social contact. Interestingly in this study, half of the 16 patients interviewed did not want further information about their illness.

Skilbeck et al (1998) interviewed 63 people with COPD about their experiences of living with the disease and the services utilized by them. Breathlessness was again a key issue but the study reported on a high symptom load greater than that of published studies on lung cancer. Social isolation and loss of functionality

were again, major themes where people reported a continual loss over time. Similar themes were reported by Elkington et al (2004) who interviewed carers of patients with COPD who had died in the preceding 3-10 months. Fraser et al (2006) reported on a hermeneutic phenomenological study involving 10 adults with COPD. Knowing what works for them, loss and vacillating between losing and regaining control were the major themes in her work. The overlapping themes from these qualitative studies namely loss, uncertainty, isolation, dependency, physical symptoms and deterioration and loss of function have resonance with debates in sociology of health and illness literature regarding chronicity (Lawton 2003). It is to these debates that I turn in the next chapter.

Conclusion

COPD is a complex disease and a major cause of mortality and unmet patient need in advanced disease. Patients who progress to advanced stages of disease stages of disease experience acute exacerbations that further compromise health status and a range of variables associated with increased risk of mortality. The high use of health services by these patients has resulted in an emphasis on measurement of and addressing the burden of disease but with an eye principally to health economics and policy development.

While pulmonary rehabilitation seeks to minimise the impact of disease on exercise tolerance and activities of daily living, there is considerable debate as to the long term effectiveness of such interventions. The controversy may, in part, be related to tensions surrounding the purpose of pulmonary rehabilitation from the perspective of health economists, health service managers, clinicians and patients. Moreover, among clinicians there may be tensions between those who view the purpose of rehabilitation as targeting specific variables associated with risk of poorer health status, further exacerbations and mortality, and those who have a broader of purpose to include the experience of illness and addressing unmet needs.

Those patients experiencing very severe exacerbation and/or co-morbidity are most likely to be admitted to hospital, have unmet palliative care needs and to die within a two year period. In qualitative studies on experience of living with advanced COPD, the overlapping themes: loss, uncertainty, isolation, dependency, physical symptoms, and deterioration and loss of function resonate with debates in sociology of health and illness literature regarding chronicity.

Chapter Three Chronicity

Introduction

The Chronic nature of COPD might be viewed at different levels. Firstly, COPD may typically appear as a morning cough or annual chest infection either or both of which worsen over years. Secondly, those for whom their condition moves into advanced stages may live with COPD as a life threatening illness over many years. Recent interventions including medications, home oxygen and non-invasive ventilation mean that patients live longer but with advanced disease and increased risk of co-morbidity. Thus, chronicity that is to say the experience of living with an illness with all its physical, emotional, lifeworld, cultural, political and economic connotations provides an important framework for exploring further the COPD experience, and meanings and explanations ascribed to it. Others have long distinguished disease from illness perspectives and meaning making (Kleinman 1988; Cassell 1991; Martin and Peterson 2009). By disease I am inferring a worldview that focuses on the bio-medical, reducible or measurable aspects of a condition in contra-distinction to illness that embraces the experience of living with, in this case, COPD.

In this chapter, I explore chronicity and palliative care. My purpose is to situate palliative care within a chronic illness framework to explore possible factors related to continuing concerns about unmet palliative care needs in COPD. In section one, I present an overview of how chronic illness is conceptualised within the healthcare and sociology and more recently in medical anthropology literature. Section two focuses on negotiation with healthcare with particular reference to the work of Sally Thorne (Thorne 1993; Thorne and Paterson 1998; Thorne *et al.* 2003). The discussion will then move on to suffering in the context of chronicity in section 3. The final section will address debates in palliative care in relation to its philosophy and chronic illness. In particular, I question the idea of transposing a palliative care model from cancer care to COPD.

Simon Williams (1993) reported on people's adjustment to living with COPD that evolved over many years. Where initially, people sought to adjust to and accommodate the growing impact of symptoms on work, later adjustment focused on changes in community and family roles, and relationships. Finally, in advanced disease, people became fully dependent and unable to engage in

routine family activities. Similar findings have since been reported by a number of authors (Jones *et al.* 2004; Seamark *et al.* 2004; Fraser *et al.* 2006; Ek and Ternestedt 2008). The significance of this to patients with advanced COPD is that they will have had a history of adjustment to their condition and its consequences on physicality and interaction with the world, lay knowledge, self management and relationship with healthcare professionals.

The impact of a protracted chronic illness that is associated with different stages representing deterioration and increasing dependency is multi-layered as evidenced in sociological and healthcare research. Sufferers experience uncertainty about their illness and prognosis (Williams 1993); frequent changes of healthcare professionals in medical teams (Jones *et al.* 2004; Seamark *et al.* 2004); disillusionment with and shifts in relationships with healthcare professionals (Thorne 1993); conflict between lay and professional expert knowledge (Thorne 1993; Paterson 2001; Williams and Popay 2001) and loss (Charmaz 1983; Williams 1993; Fraser *et al.* 2006). In short, the unmet palliative care needs identified in COPD research (Gore *et al.* 2000) seem inextricably linked with issues related to chronicity.

Healthcare Sociological Conceptualization

In sociological terms, chronic illness has been defined as 'those forms of long-term health disorders that interfere with social interaction and role performance' (Gabe et al. 2004:77). Three central frameworks for conceptualizing chronic illness provide the basis for current health sociological literature: the notion of loss (Charmaz 1983); biographical disruption (Bury 1982) and narrative reconstruction (Williams 1984).

Notion of Loss

Kathy Charmaz (1983:169) offers a bleak view of the 'spiralling consequences of advanced chronic illness' in which there are loss of productivity, financial resources and previous relationships within the family, stigma and what she referred to as 'restricted existence'. Life is restricted by being increasingly housebound as a consequence of illness, a recurrent feature of people interviewed by Williams (1993) in his COPD research. For Charmaz (1983), the result is a 'diminished self' with social isolation and of increased burden on others. Illness

becomes all consuming in this restricted life wherein illness shapes one's world and self.

Charmaz situates her conceptualization of chronic illness in the context of what she refers to as the American tradition of autonomy, independence and privacy, and the protestant ethic of individual responsibility and hard work. While the System supports these values and tradition, the consequences for the family unit are a heavy burden of care. Against this background 'illness as an experience shapes situations in which the person learns new definitions of self and often relinquishes old ones' (Charmaz 1983:170).

Charmaz brings to light the pervasive nature of the impact of serious chronic illness that extends to family and others. The impact is felt in different but overlapping ways such that, for example, social isolation compounds sense of self-worth. Social isolation may logically follow being housebound as a result of illness.

> Their illnesses become the focus of their lives as treatment regimens, periods of discomfort, medical appointments and the problematics of mundane activities structure and fill their days (Charmaz 1983:172).

More recently, in his linking of poor health with low social capital, Robert Putnam (2001) argued that social isolation precedes illness. While he draws on large studies that suggest low social capital as being a significant risk factor even surpassing smoking in illness, Charmaz's work highlights the impact of social isolation as a consequence of illness. In reality, it is likely that if low social capital precedes chronic illness, this is significantly aggravated by the effects of self imposed isolation that Charmaz found as a result of fear and uncertainty that accompany symptoms. Illness is seen in terms of good days and bad days disrupting life as it was experienced hither to fore. While patients aim to protect their lives through self-imposed isolation 'they do so at great costs to their self-images' (Charmaz 1983:174). This self-imposed isolation as a consequence of restricted lives removes opportunities for participation in social networks and consequently for reciprocity fuelling Putnam's relationship between poor health and low social capital.

Discrediting definitions of self emerge in chronic illness as a consequence of interaction experiences with and expectations of others. Typically, in the former

instance, interaction experiences may relate to visible impairments in COPD such as slowness, use of portable oxygen and extreme breathlessness. These disease labels can attract unwelcome comments and labelling. Expectations of others may emerge from poor understanding of symptom impact. Decreasing physical activity and engagement with family and social roles and activities may, for example, be construed by others as reflecting poor motivation and self efficacy. In this way the *person* with a chronic illness becomes *the problem*. This process of invalidation can result in the person no longer participating in decision-making since s/he is now the problem thus fuelling spiralling invalidation and diminished self.

Biographical Disruption

Bury's (1982) conceptualization of chronic illness as 'biographical disruption' remains the most frequently cited reference point in medical sociology (Lawton 2003). Persistent illness and its impact on every-day living results in a 'disruption' to taken for granted assumptions, and 'a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others' (Bury 1982:169). Disruption or 'tear in the fabric of one's life' (Radley 1994:145) forces a readjustment to bodily capacity, sense of self and identity (Bury 1982; Charmaz 1983; Bury 2001). Disruption can occur at different levels such as disruption to the normal 'unconsciousness' of the working body and working with new awareness of physicality as a result of physical symptoms. There may be disruption to one's biography with a new awareness of mortality and anticipated future.

The experience of chronic illness can lead to a rethinking of one's biography and self concept. There is a new awareness of one's body, life trajectory and meanings in respect of relationships. The consequences of disease result in a breaching of norms of reciprocity within social relationships and mutual dependency (Bury 1982; Bury 1991). This breach in reciprocity norms corresponds in part with that suggested by Charmaz (1983) in the context of restricted lives. Re-constructed illness narratives repair disruption or tears through re-interpreting biography so that the inter-relationships of body, self and identity are re-aligned (Scambler 2002). The nature of reinterpretation of biography is contingent on ability to enlist support from significant others.

Bury (1991) subsequently elaborated on the coping strategies of a chronic illness sufferer to maintain a sense of self worth. Strategies, in this case, refer to actions and processes required for the management of the condition including mobilization of resources and balancing demands on others in order to maintain independence. Coping strategies involved the adoption of a lifestyle that determined interaction with others, public identity and normalization.

More recently, Williams (2000) took issue with the assumptions underpinning biographical disruption. A particular point of contention is the notion that biographical disruption implies the appearance of illness in a life hither to fore untouched by any similar distressing event. He argues the importance of the contextual nature of disruption and, in particular, the relevance of class, age, gender and ethnicity to the experience of disruption. People coming from poorer backgrounds and who have struggled through life express a stoicism, and greater acceptance of and tolerance to illness.

Lives that have experienced hardship in youth and middle-age may result in lower expectations for health and a certain degree of expectation of illness in old age (Pound *et al.* 1998; Williams 2000; Lawton 2003). Where Bury's (1982) framework stems from his work with young adults experiencing rheumatoid arthritis, the degree of disruption to biography and sense of self may be different in the case of chronic illness in older age groups. Thus, for Williams (2000), the concept of biographical disruption may be more aptly described as biographical anticipation.

However, even allowing for Williams' review of biographical disruption, the gradual onset of COPD symptoms allows sufferers to ignore or at least delay acknowledgement of disease progression. This delayed acknowledgement is inferred in COPD prevalence studies (Global Initiative for Chronic Obstructive Disease 2004; Dales *et al.* 2006; Gulsvik *et al.* 2006; Hoogendoorna *et al.* 2006; Manninoa and Holguinb 2006). In biographical disruption terms, this delayed or ignored response to symptoms seems to further muddy the waters. People may attribute the onset of disease to a critical event such as hospital admission signifying worsening symptoms and disease status as reported by Williams (1993). Thus, biographical disruption may occur well into the disease trajectory and may even herald the move from mild/moderate to moderate/advanced stages of disease. Such disruption may be anticipated and therefore minimised because of the 'conditioning' effects of early symptoms and life experience.

For Williams (2000), a feature of living in late modernity is constant reappraisal of self identity and biography. We live in a risk society, with all its constituents of health promotion, screening and surveillance, of self appraisal, information and lay expertise. The notion of biographical disruption in an erstwhile constant taken for granted state is no longer tenable. Rather, illness takes place within this maelstrom of reappraisals and contingency in which what might be a disruptive state for one person is simply part of normal life for another. Moreover, biographical disruption can lead to reinforcement that is to say drawing one's own biography or group identity to situate illness experiences (Carricaburu and Pierret 1995).

Meaning, context, timing, purpose and expectation can determine the degree of biographical disruption or anticipation. For older persons experiencing strokes, the significant impact on their lives may be mitigated by how they viewed this event in the context of their advancing years, familiarity with pain and infirmity from other illnesses, and awareness of mortality (Pound et al. 1998). Put another way, an examination of chronic illnesses such as COPD, necessitates looking at whole biographies of those affected (Lawton 2003). The issue is more likely not whether individuals' advanced disease should be regarded as disruptive; rather it is that these people have arrived at a point when they are facing serious impairment, increased dependency and their own mortality. The journey they have made to this point is an integral part of their current experience and illness management.

Nonetheless, the core principles of biographical disruption: the disruption of previously taken-for-granted assumptions about continuity of life, remain relevant to an attempt at conceptualizing the needs of those affected by advanced COPD. The importance of acknowledging whole biographies: disease, social and life experiences; age and gender are all integral features to understanding the illness experience (Carricaburu and Pierret 1995; Williams 2000). Advanced COPD is associated with reduced capacity in abilities of daily living and that reduction increases with each exacerbation (Lynn and Adamson 2003; Oostenbrink and Rutten-van Mölkena 2004) and poor health status (Jones and Wijkstra 2006). Thus, each exacerbation represents a disruption to the previous state.

However, biographical disruption and its strands of anticipation and reinforcement need also to be considered in the context of advancing technologies in disease

management. The impact of increasingly invasive long term treatments on the illness experience is not explored in detail by those who have developed the ideas of Charmaz and Bury. This is understandable given the pace of advancement in treatments. Nonetheless, while anticipation may well be a strong influencing factor in the illness experience as described through theory of loss or biographical disruption, the role played by technology in anticipation is less clear. In COPD, for example, the interplay between anticipation and loss/disruption might be considered in the context of recent COPD treatment interventions such as home oxygen, non-invasive ventilation and more recently ventilation via tracheostomy. In short, patients live for longer but in chronic respiratory failure. The impact of this on self concept, life experience, suffering and confronting death invites a further review of chronicity.

Narrative Reconstruction

Charmaz (1983) and Bury (1982) both develop their theories from people's illness narratives. In this sense, narrative's underpinning principles include our awareness of our existence through time or understanding the present in the context of past recollections and future aspirations, and our ongoing process of making sense of our experience (Scambler 2002; Charon 2006). Williams (1984) explored the ways that people suffering from rheumatoid arthritis find legitimacy and meaning in their lives by through what he refers to as 'narrative reconstruction'. In this, people find ways of explaining their illness in a way that 're-situates' them in their worlds. This may take the form of attributing the cause to a significant life event such as a death or exploitative work practices.

Illness narratives demonstrate differences in meaning in cultural and existential terms. People may attribute the cause of their individual illnesses to oppression such as poor working or living conditions. They may view a specific illness as having a religious meaning and purpose. Thus, at the level of the individual, illness is characterized in different ways that may have moral, political, cultural and gender-specific undertones. Characterization is complex but serves to somehow stabilize the inter-relationships among self, identity and society. Through this narrative reconstruction, it becomes possible to adapt to living with illness, manage that illness.

Narratives are contingent; they respond to the moment and are therefore dynamic, shifting from 'heroic to tragic; ironic to comic' at any given moment

(Scambler 2002:115). Drawing on Habermas's idea of speech acts, Scambler (2002) argues that narratives may be performative. In this sense, narratives can serve as a way of coping, as an expression of the moment or as a strategic act to serve a purpose e.g. normalising the self 'designed to square self with audience, context and the prevailing (sub)cultural norms' (Scambler 2002:115). Narratives can also reflect dynamism between those of self and of others. This has particular relevance in the dialectic between lay and professional expertise. In this dialectic, 'the composition of both narratives for self and narratives for others reflects an ongoing dialectic between lay 'experiential' narratives of illness and professional 'expert narratives of disease' (Scambler 2002:115). In essence, medical scientific knowledge, however hegemonic, is but one resource for local or experiential knowledge development.

Illness Narratives: Medical-anthropological Perspective

The contingency of illness narratives is stressed by Bury (1988) in his writing on the emergence of illness meaning. However, the relationship between illness narratives and everyday life appears a complex one (Robinson 1990). In short, when illness appears and becomes established, it does so in an already negotiated life in which our meaning making stems from the past and into the future. However, our personal meanings are also inter-dependent on our everyday experiences not least those influenced by the changing course of advanced illness (Robinson 1990). Thus, personal accounts, rather than being definitive are important interpretations and contribution to our knowledge about illness. For Kleinman (1988), illness is polysemic wherein the chronic illness trajectory is assimilated into the one's life such that the illness becomes fused with one's life history. Illness is a uniquely personal experience that a person has and makes sense of in terms of what is happening to him/her. In the polysemic sense, illness has different meanings that may be related to symptom, culture, and lifeworld with explanatory and emotional meanings. Symptom as meaning reflects the significance of symptoms and the disability and distress arising from them. How an individual understands her body in relation to self and world are constituents of symptom as meaning.

Cultural meaning reflects the cultural symbolism attached to an illness including chronicity and, for example, association with cultural values such as those relating to smoking. Kleinman (1988), argues that in different societies and at different times, symptoms and diseases have particular meanings. These can

bring particularly powerful cultural significance with them 'often of a stigmatising kind' (Kleinman 1988:18). Lifeworld as meaning reflects the merging of illness and sense of self such that '[a]cting like a sponge, illness soaks up personal and social significance from the world of the sick person' (Kleinman 1988:31). Explanation and emotion as meaning reflect ways of questioning, explaining and responding to illness. *What is happening to me; why me; why now*- typically address this explanatory illness meaning making.

Kleinman's anthropological worldview to understanding chronic illness accommodates the idea of biographical disruption and loss while positioning the illness experience as dynamic in the context of one's life, past and anticipated future; and roles and identity. His shorthand phrase of '*one darned thing after another*' (Kleinman 1988:44) summarises the continual assault of chronic illness on one's hold in life and, significantly, one long story in counter distinction to the medicalized or technical view of illness as a series of acute phases. While Bury's (1982) biographical disruption and Charmaz's (1983) focus on loss continue to inform chronic illness writing especially within medical sociology, Kleinman has arguably informed a current focus on narrative illness accounts and methods (Bury 2001). Frank (1997, 2002a, 2004) and Charon (2001, 2006) have drawn on Kleinman's work to inform their narrative work. While the theoretical perspectives reviewed here have all in common a focus on illness experience, for Kleinman, Frank and Charon, this has extended into frameworks for application to practice and professional education. Their different approaches stress ways of working with patients drawing on ethnography (Kleinman 1988), dialogism (Frank 2004) and literary theory (Charon 2006).

Chronic illness and Health Care

Engaging with Healthcare

Bringing the chronic illness experience into the context of healthcare and specifically, relationships with healthcare professionals, Sally Thorne (1993) drew on 3 inter-related levels: the individual, the social and the structural. While chronic illness is typically viewed as vacillating between relatively stable periods and acute episodes, a more complex trajectory is suggested of a life 'complicated by medical regimes, time management, and negotiating with health services' (Thorne 1993:54). Moreover, acute episodes in chronicity reflect struggles for control between the healthcare professionals and patients. In sharp contrast,

David Rier (2000) a sociologist, experienced life threatening acute respiratory and renal failure and consequent 3 week stay in intensive care life during which he was content to submit to medical staff, even to the extent that he was 'spared' the details during the critical stage of his illness.

Working from the basis that the quality of health care is a central feature in the experience of living with chronic illness, the relationships with healthcare professionals are brought to the fore. Thorne's participants described their relationships with healthcare professionals as dynamic and evolving through 3 stages: naïve trust, disenchantment and guarded alliance. Naïve trust placed healthcare professionals on a pedestal in a kind of hero worship with patients passively submitting to advice. There was an expectation that healthcare professionals would understand the individual patient's problems and experience, and provide solutions.

Disenchantment followed when naïve trust was shattered and no longer tenable. Disenchantment could be triggered by a single event or a series of insights over time and often related to withheld information or an awareness of a career rather than a care focus on the part of healthcare professionals. Guarded alliance emerged from awareness of healthcare professionals being part of a larger system and the individual's own capacity to and responsibility for managing illness. Guarded alliance involved a reconstructed or selective trust that could involve trusting a single or specific healthcare professionals and only to a certain level. However this reconstructed trust took one of several forms often chosen very deliberately including hero worship, resignation, consumerism, and team playing. These different forms each had recognized strengths and limitations such as precarious dependency in a hero worship form of alliance; sense of defeat in resignation; manipulative and defensive strategies in consumerism. The mutual trust that defined the team player alliance was offset against the difficulties in finding healthcare professionals who would engage in and accept conflict as part of that relationship.

Even after finding the 'right' healthcare professionals and developing a mutual trusting relationship, there remained considerable difficulties in negotiating through services. Healthcare professionals move on and the process of finding begins again. Thorne's participants described falling through the cracks; being a guinea pig, suffering incompetence and human error, and getting caught in red tape. Confrontations with the system were also manifest in socio-cultural issues

such as attitudes towards those on welfare, power struggles between patients and healthcare professionals, and dehumanizing experiences. Thorne's findings underscore the healthcare professional/patient relationship in the struggle between the voice of the lifeworld and that of institution.

An inherent feature of this struggle is the 'objectification' of the patient in the healthcare professional/patient relationship that is to say the focus on disease rather than illness experience. Experiential knowing and everyday decision-making is subservient to if not silenced by authoritative (scientific) knowledge (Paterson 2001; Thorne *et al.* 2003). Thorne (1993) makes clear in her work, that this objectification is not so much a medicine-specific issue. Rather, her participants recognized that doctors and other healthcare professionals are cogs in a large objectifying system. This is not to underplay the serious and avoidable effects of bad encounters with doctors and care practices of healthcare professionals in general. On the contrary, Thorne's account implies the profoundly alienating impact of the twin effects of objectification by healthcare professionals and the system. Medical encounters highlighted doctors as both persons exemplifying the gamut of communication and empathic skills, and institutional actors (Monks 2000).

This resonates to some degree with the illness accounts of Arthur Frank (2002a), Reynolds Price (2003), and Carolyn Ellis (1995). However, these accounts also highlight other factors such as context, temporality and vulnerability in serious and advanced illness relationships with healthcare professionals. In his illness account, having already 'learned how to respond' to questions in medical (including nursing) encounters, Frank (2002a) consciously moves from his prior guarded relationship with healthcare professionals. His account suggests twin relationships working in tandem: one related to each individual healthcare professional encountered and the experience of that encounter. The other related to his journeying through a system in which the healthcare professionals sought to engage or not with the patients' journeys. Rather than move in any linear fashion through these stages, he was plunged into disenchantment or guarded alliance in any given encounter. In contrast, Rier (2000) describes full and naïve trust in his medical team to reverse his acute life threatening illness.

In other words and similar to Frank's account (2002a), the dynamic nature of serious chronic illness and illness meaning making (Kleinman 1988) is likely to influence a to-ing and fro-ing through Thorne's passages of negotiation.

Sociologist, Carolyn Ellis (1995) wrote a socio narrative of her nine-year relationship with Gene Weinstein, a sociologist and her teacher, who was ill with emphysema. Her work traces their changing relationship as his caring needs increased and the resultant tensions; his changing world and response to that as his disability increased; and finally the end stage of his illness. Their experience of negotiation with healthcare services and primary physician was to a large extent determined by the interacting dynamics of what was happening between Ellis and Weinstein at a given moment and Weinstein's own illness meaning making in terms of his lifeworld and symptoms. Perhaps because of the experience built up from living for years with emphysema, Ellis and Weinstein exerted greater covert control over negotiations with healthcare professionals. Typically, his oxygen use was informed by an increasingly conflicting mix of their instinctive or experiential knowledge and advice from their physician. For Ellis and Weinstein, and Frank negotiation with healthcare professionals was one aspect of drawing meaning from illness experience and loss. Put another way, issues relating to negotiation with healthcare are perhaps better explored with temporality and context in mind.

Suffering

Defining Illness Related Suffering

To a large degree, the focus on illness experiences from whichever of the above theoretical frameworks centres on loss of or change in sense of self and relationship between self and world. Eric Cassell (1991) defined suffering as the state of severe distress associated with events that threaten the intactness of the person. From his vantage point, a person has a past with memories, built up truths, life experiences, family, relationships, cultural background, roles and a relationship with self. All aspects of personhood are susceptible to damage and loss. A feature of Cassell's understanding of suffering is the notion of conflict with self wherein, for example, the body may prove untrustworthy or linked with social failure, or there is conflict between will to live and will to die. Cassell (1991) argues that since suffering extends well beyond the physical to mind, spirit and the subjective, it is the exorcising of the person or personhood from the clinical encounter that actively contributes to the patient's suffering. In other words, personhood is associated with mind, body, spirit and the subjective.

Any threat to the integrity or intactness of personhood results in the distress associated with suffering. People may report suffering in the absence of apparent

severe pain while others may deny suffering even in extreme pain. In addition, in cancer, suffering may alleviated by demonstrating that pain can be controlled. In other words, there is a temporality to suffering wherein the anticipation of pain and the associated fear or terror, in these instances, contributes to suffering. Fear always involves the future. For Cassell (1991), this suffering can be relieved by relinquishing one's sense of the future.

Suffering and Chronic Illness

Disease knowledge and management are not sufficient to predict suffering in chronic illness. The threat to intactness and distress are longstanding and feed into the distress and fear. Drawing sharp distinctions among physical, psychological, and social factors prevents understanding of the illness experience. For Cassell, all social behaviours involve body movement; all body actions have social meaning and all function impairment have psychological consequences. Symptom avoidance and compensatory mechanisms frequently aggravate the illness and produce further losses e.g. reducing physical activity leads to reduced muscle mass and this in turn further limits activity. Chronic illness results in a changed world perception: a diagnosis may result in the person perceiving herself as disabled or as self in the light of her diagnosis.

With medicine's focus on body, personhood and all its other dimensions that cannot be readily objectified are assigned to the mind leaving a mind body split. Drawing on Cassell's understanding, Sacks and Nelson (2007) explored the non physical suffering experiences of 18 patients with chronic illness and found inner trust or losing trust in self to be a central theme. The conflict with self or losing trust in self reflects a profound loss that permeates through identity, cultural self and relationships. Similarly, Rehnsfeldt and Eriksson (2004:264), explain suffering in terms of 'not being able to hold oneself together as a whole' and is unbearable when it is hidden and silent.

For Katie Eriksson and her colleagues, patient dignity is readily violated because of the ease in which the patient is not believed or dismissed (Fagerström *et al.* 1998; Arman *et al.* 2004; Rehnsfeldt and Eriksson 2004). This can be understood as human suffering (Arman et al. 2004) with caring needs closely connected to the experience of suffering and health (Fagerström et al. 1998). In her focus on medical encounters, Judith Monks (2000) refers to sufferance as a state of unwilling tolerance and endurance with reference to the anxiety and anguish that

surfaces in the medical encounter as a result of inequity in the relationship and objectification. Medical encounters were adversely experienced more as a result of denial of different ways of making meaning than people's voices being silenced:

> To be diagnosed with serious disease may be to experience the sufferance of patienthood at its most acute (Monks 2000:32).

In her research involving people with multiple sclerosis, medical encounters formed illness narratives that told a moral story about suffering and culture. For her and others coming from a more medical anthropological perspective illness narratives and related suffering emerge from the culture and structures to which they belong (Skultans 2000). Thus 'the terms social suffering offers a shorthand way of referring to this relationship of a medical biography whose existence and direction are overdetermined[sic] by political forces over which the individual has no control' (Skultans 2000:11). Thus, social suffering as that associated with life conditions shaped by powerful social forces (Kleinman *et al.* 1997) is integral to illness related suffering.

Palliative Care

Cicely Saunders' idea of total pain and as suffering encompassing physical, psycho-social and spiritual distress or struggles (Richmond 2005) highlights a close proximity with the distress recalled in chronic illness experiences (Kleinman 1988; Frank 2004; Charon 2006). Put simply, the idea of total pain in palliative care philosophy seems equally relevant to a philosophy of care for the chronically ill. Indeed, it is the denial by modern acute healthcare services and professionals of total pain in the clinical encounter that lies at the heart of the illness narratives in nursing (Fagerström *et al.* 1999; Arman *et al.* 2004) and broader healthcare literature (Kleinman 1988; Kleinman *et al.* 1997; Morris 1997; Monks 2000; Charon 2001; Frank 2004; Charon 2006). Not surprisingly, for these authors, disease focused care that denies illness experiences increases suffering.

'Total care' is a central constituent of palliative care (Clark and Seymour 1999) and implicit in the current definition:

> Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness,

through the prevention and relief of suffering. Palliative Care focuses on the treatment of pain and other problems, integrating the physical, psychosocial and spiritual aspects of care. Palliative Care offers a support system to help patients live as actively as possible and also offers a support system to help the family cope during the patient's illness[2].

Table 3.1 Levels of Palliative Care

Levels	Palliative Care Approach	Description
1	Basic	Palliative care principles should be appropriately applied by all health care professionals.
2	General/intermediate	a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care
3	Specialist	Specialist palliative care in which core activity is limited to the provision of palliative care.

Department of Health & Children (2001) *Report of the National Advisory Committee on Palliative Care*. Stationery Office, Dublin.

There is increasingly widespread acceptance in principle that palliative care should be extended beyond incurable cancer care with which it has become associated, to include all patients who are dying. Moreover, within the palliative care literature distinctions are made between a palliative care approach and specialist palliative care (table 3.1).

The idea of a palliative approach to care 'aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles' (Department of Health & Children 2001:20). Specialist palliative care, on the other hand is care provided by an inter-disciplinary team with palliative care as their core specialism under the direction of a consultant physician in palliative medicine. Thus, addressing suffering as total pain is fundamental to the idea of palliative care which is, in turn, a fundamental part of

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[2] www.cancer**care**.on.ca/pdf/GTA2014Chapter12.pdf Accessed 16th September 2008

care delivery irrespective of the conditions being treated. This understanding of palliative care takes issue with any conflation of the terms palliative and terminal care. Terminal care has been defined as 'care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less' (Department of Health & Children 2001). Clearly, palliative care as it is described encompasses but goes well beyond terminal or end of life care. Where the terms palliative and terminal care are conflated in practice, patients are denied appropriate palliative care (Clark and Seymour 1999).

Challenges to Integrating Palliative Care in Non-Cancer

Despite the widespread acceptance for over a decade in policy and clinical research, integrating palliative care into chronic illness care including COPD remains challenging (Addington-Hall and Higginson 2001b; Health Service Executive and Irish Hospice Foundation 2008b; Health Service Executive 2009a). For COPD specifically, reports of unmet palliative care needs span 20 years (Williams 1993; Gore *et al.* 2000; Elkington *et al.* 2005; Spence *et al.* 2008). Yet, there is a recognition that where patient needs can be addressed by palliative care specialists, this is a basic human right (Ahmedzai *et al.* 2004). The barriers to integrating palliative care into chronic illness generally and COPD specifically appear to be clinically, organizationally and professionally related. Additionally there is some debate concerning tensions between the current philosophy of palliative care and assessment methods and specialist knowledge claims.

Clinically Related Barriers

Lynn and Adamson (2003) contrasted a cancer disease trajectory from those of chronic illnesses and dementia. This highlighted the difficulties in transposing a palliative care model of care that has historically developed from cancer care to one for chronic illnesses such as COPD. Where acute exacerbations/attacks in advanced illness may occur repeatedly over months or years, any one episode may prove fatal. Prognostic predictions are inherently difficult and error prone with consequences for referral patterns to specialist palliative care (Traue and Ross 2005) Thus, there are no clear markers by which clinicians, patients and their carers might judge a new illness phase. Kleinman's (1988:44) summation of chronic illness as 'one darned thing after another' means it is difficult for patients and their carers to locate palliative care needs in their illness trajectory (Elkington *et al.* 2005; McIlfatrick 2007).

Similarly, a continuing tendency for healthcare professionals to conflate palliative with terminal care (Clark and Seymour 1999; Dunlop 2001; McIlfatrick 2007) limits scope to consider palliative care in chronicity. Moreover, there also appears to be evidence of resistance among physicians and healthcare professionals who have built up long term relationships with their patients to what might be perceived as handing over patients to palliative care specialists at a time when patients are especially vulnerable (Ahmed *et al.* 2004; Kaasalainen *et al.* 2007). However, while the uncertain disease trajectory is widely cited as a barrier to palliative care provision for patients with chronic illness, there is also evidence that delayed referral is a problem in cancer care (Dunlop 2001). Moreover, this focus on the semantics of palliation as care for the dying overlooks the idea of palliative approach to care and recognition of palliative care needs prior to end of life. In their systematic review of problems and issues accessing palliative care, Ahmed et al (2004) found lack of knowledge and education among healthcare professionals as a major barrier to delivering palliative care as either an overall approach to care or specialist referral.

The disease management focus of clinical guidelines and related protocols positions acute exacerbations as medical emergencies. This fosters a foregrounding of a bio-medical care model that silences other symptoms or a total pain view of care. Active treatment protocols 'protect physicians from a sense of therapeutic nihilism' (Dunlop 2001:193) that prevents them from recognizing suffering. Ahmedzai et al (2004) argue this is not just an issue in chronicity but rather as a consequence of new cancer treatment therapies, people are living longer including older patients with cancer and co-morbidity. Thus, the cure/care divide has become overstated, a point also argued by Selman et al (2009). In a debate about palliative care and heart failure (HF), they characterise specialist palliative care as focusing 'very much on living with HF, not just dying' (Selman *et al.* 2009:156). In other words the place of palliative care is alongside curative care as illustrated in recent heart failure research (Daley *et al.* 2006). While this includes specialist palliative care, Ahmedzai et al (2004) stress the importance of integrating a palliative care approach across disciplines and services. Put simply integrating a basic palliative approach to care sensitizes healthcare professionals to Saunders' concept of total pain (Richmond 2005) or suffering. This should in turn facilitate appropriate and timely referral to specialist palliative care as the need arises irrespective of location along any particular illness journey.

Professionally and Organizationally Related Challenges

Needs rather than diagnosis-based palliative care provision has become enshrined in healthcare policy (Department of Health 2000; Department of Health & Children 2001; Health Service Executive 2009a). However, at professional and organizational levels, uncertainty continues as to how best to respond (Addington-Hall and Higginson 2001a; Ahmed *et al.* 2004; O'Leary and Tiernan 2008). Lack of evidence of the effectiveness of palliative care in non-malignancy appears to be a considerable impediment to driving a palliative care agenda and securing funding (Ahmed *et al.* 2004; O'Leary and Tiernan 2008). In Ireland, non-cancer patients account for just 10% of the specialist palliative care workload rather than an expected 25% (Igoe *et al.* 1997; Marymount Hospice and The Atlantic Philanthropies 2006; O'Leary and Tiernan 2008). Developing criteria for referral to specialist palliative care is a recognized barrier compounded by reported fears among palliative care team members of being swamped (Ahmed *et al.* 2004; O'Leary and Tiernan 2008). However, these fears are also refuted by many within palliative care and more recent research on heart failure (Davidson *et al.* 2004; Johnson and Houghton 2006).

In their assessment of the gaps between policy and practice, Chattoo and Atkin (2009a) suggest that there are professional boundaries of expertise and claims to specialist knowledge that support the continued association between palliative and cancer. They argue that a focus on different disease trajectories underplays the significance of negotiations between disciplinary boundaries that are required at local level. The notions of open awareness and good death that are core to specialist palliative care challenge the nature of heart failure and risk of sudden death (Chattoo and Atkin 2009a). In short, the cancer palliative care script with which healthcare professionals and patients alike can identify is different to what which the authors see as the script of heart failure. The issue here is not to negate the importance of palliative care in heart failure in this instance, but rather it is to highlight difficulties at local level that may contribute to the current gap between policy and practice.

While their paper gave rise to some debate in the context of palliative care in heart failure (Chattoo and Atkin 2009a, 2009b; Selman *et al.* 2009), the core issue would seem pertinent to the wider palliative care in non-malignancy debate. A multi-disciplinary approach to palliative care involving specialist palliative care

and disease-specific care teams will require complex negotiations across disciplinary and practice boundaries. Tensions are inevitable between acute care and palliative care approaches. Recent research points to these tensions manifesting in specialist palliative care clinicians being called upon to provide basic psychological support while also finding their advice ignored by those referring in some instances (Ewing *et al.* 2009). Moreover, these negotiations and tensions are taking place against a background of lack of research evidence on the views, preferences and needs of patients with advanced chronic illnesses in respect of models for palliative care (Wilkinson *et al.* 1999).

Issues Relating to Defining Palliative Care

The noteworthy elements of the most recent WHO definition for palliative care (Sepúlveda *et al.* 2002) include its reference to life limiting illnesses and thus moving away from a cancer focus; and its emphasis on early introduction of palliative care. This reflects the responsiveness and shifting perspectives of the world of palliative care to current epidemiological trends and treatment changes across the globe. In short, life limiting or chronic illnesses particularly in old age have become important targets for palliative care while treatment interventions in cancer and other conditions are likely to result in patients living longer with disease. Active treatment by way of disease-specific interventions and palliative anti-cancer medication frequently continue through to end of life blurring the curative/palliative divide (Ahmedzai *et al.* 2004). Typically, in end-stage COPD, treatment interventions are not just continued but rather may be increased and intensified such as the introduction of non-invasive ventilation. Thus, palliative care is increasingly complex in terms of working alongside medical teams and deciphering how best to ensure patients receive optimum palliative care over the course of their illness trajectory.

Other definitions are suggested in response to these challenges including:

> Palliative care is the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends (Ahmedzai *et al.* 2004:2194).

This definition emerged from the European School of Oncology Working Group who went on describe basic palliative care as that which should be provided by all healthcare professionals, in primary or secondary care, within their duties to

patients with life-limiting disease. Specialist palliative care was described as that provided at an expert level by a trained multi-professional team, 'who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialist members of the primary or secondary care teams' (Ahmedzai *et al.* 2004:2194). The group further distinguished end of life care as that involving the specific application of palliative care interventions and services in the final hours, days or weeks of life.

In formulating this broad view of palliative care the group was specifically addressing the need for palliative care to work alongside other specialist medical teams. For end of life care, the group recognized the difficulties in gauging a patient's deteriorating condition and drew attention to acknowledging the patient's own changing attitude towards the illness. Thus, end of life care involves discussion with the patient and family to inform 'a conscious decision by the healthcare team' (Ahmedzai *et al.* 2004:2195) to stop pursuing curative or life-prolonging treatments. As with palliative care, the group distinguished basic from specialist end of life care wherein every healthcare professional should be competent in providing the former.

Critiquing Palliative Care

While various definitions are proposed as means of addressing changes in care requirements, all have in common a response to total pain or suffering. For Randall and Downie (2006) there is increasing conflict between the espoused philosophy of palliative care and practice. Their critique begins with the assumptions, values and beliefs upon which the WHO definition (2002) is based and stated as a given without reasoned justification. This gives rise to a series of paradoxes in palliative care. Firstly, Saunders' response to total pain (Richmond 2005) has given way to a series of assessment tools as templates that reflect a more reductionist approach and based on the values and assumptions of the healthcare professionals. Moreover, these tools are perceived as interventions in their own right. Secondly, Randall and Downie (2006) contend that the emphasis on psychosocial and spiritual needs may result in paternalism since patients who do not wish to co-operative with these needs assessment may be viewed as in denial. Felicia Ackerman (2003) raises similar issues in her critique of hospice care that, in her view: claims to improve quality of life but adverse to prolonging it.

Thirdly, the positioning of relatives alongside patients in palliative care philosophy neglects the potential conflicting interests between patients and their relatives. Fourthly, the assumption that a palliative care approach across all disciplines and specialities is not just feasible but actively promoted brings into question whether or not palliative care itself should be a specialism. Fifthly, for Randall and Downie (2006) simultaneously providing curative and palliative care is a contradiction in terms. Sixthly, the definition's assertion that palliative care seeks neither to hasten nor prolong death is meaningless since death occurs in an instance. Rather, the issue is whether or not palliative care prolongs or hastens dying. Lastly, the emphasis on patient autonomy and choice sits alongside opposition to patients' wishing for the right to end their own lives or hasten their dying.

Randall and Downie's counter definition for palliative care is

> ..the care of patients whose disease is incurable and is expected to cause death within the foreseeable future. The aims of treatment are to minimize pain and other symptoms, and to prolong life, but with a minimum of burdens and risks as assessed by individual patients and professionals working together (Randall and Downie 2006:224).

Their definition and critique was, not surprisingly questioned as relegating palliative care specialists to symptomatologists (Jeffrey 2006). Nonetheless, they foreground tensions and conflicts within palliative care that in turn warrant attention when forging a greater palliative approach in chronic illness.

Research Focus

Specifically, how palliative care is construed in advanced COPD would seem an important early focus in addressing care needs. Questions remain concerning healthcare professionals' unquestioning assumptions and values about palliative care (Randall and Downie 2006). Others are also calling for debate about what they see as a dominant ideology (Ackerman 2003). Ackerman argues that debate is necessary so that patients be allowed 'to consider each life prolonging medical treatment individually to decide for himself whether the possible discomfort is worth the prolonged life' (Ackerman 2003:34). Her argument seems pertinent to chronicity in a palliative care context and specifically in COPD. Patients who have experienced advanced COPD over many years have already travelled a long

illness journey. Despite this and as reflected in chapter two, the dominant COPD worldview remains a disease oriented one with health status measurement the primary mode of needs assessment. Interventions such as non-invasive ventilation, made in crisis situations during an acute exacerbation often become part of symptom management from thereon. Were such interventions made in a palliative care approach with the concept of total pain as its focus, this would signal a shift in decision-making with greater emphasis on patients' illness meaning making.

The point here is not to question the need for or importance of palliative care in chronicity and specifically in COPD. Rather, the point is to confront the potential tensions and conflicts inherent in transposing a palliative care approach to acute medical care including COPD with the attendant conflicting disease/illness narratives. In short, we need to understand patients' unmet needs, how we make sense of our practice in terms of conflicting care narratives and how we might address palliative care against the backdrop of such conflicts. In an acute care context, it seems important to approach such an inquiry by seeking to engage with different and potentially conflicting narratives.

Any notion of developing respiratory nursing practice to address palliative care needs demands an exploration of the conflicting care narratives and specifically how COPD is framed in an acute care context. The knowledge generated from a particular framing, the different voices that are heard and how they are heard seem important methodological issues to an inquiry that seeks to confront conflicting care narratives. In short, the research methods that are applied in COPD need to be critiqued in terms of the perspectives they represent and those that are silenced as a result. It is to these issues that I turn in the next chapter.

Summary

In summary, differing ways of understanding chronicity have in common a view of advanced chronic illness as permeating all aspects of life for an individual. Living with advanced chronic illness incurs loss that can be understood as suffering or total pain. Disease oriented care fails to address the broader interdependency between physical symptoms and living with illness and in so doing, denies and thereby further contributes to illness suffering. The evidence supporting palliative care in chronicity is overwhelming. Palliative care with its focus on total pain brings to the fore the need to address illness suffering. However, despite widespread promotion of palliative care for people with

advanced chronic illness at policy level and in professional journals, this has not translated into practice at local level. Possible reasons for this are complex and include tensions and conflicts within palliative care. Greater understanding is needed of how these factors are understood and might be addressed or negotiated at local level.

Chapter Four Methodological Issues

Introduction

The COPD literature is extensive. Despite this, advances in COPD understanding follow separatist lines of inquiry according to how the illness is framed within different disciplines and discourses. There is, for instance, little cross fertilisation between debates on the nature of COPD and illness experience on the one hand, and research into disease markers and treatment interventions on the other hand. Thus, the concept of health need in the context of COPD is determined by the particular perspectives that feature in the different worlds of medicine, nursing, and healthcare sociology respectively. Moreover, there is no consensus about the concept of need in health or indeed in sociology and political literature (Asadi-Lari *et al.* 2004). In advanced chronic illnesses where needs and health related quality of life extend towards the social and seem interconnected with social capital, meeting social needs may have a significant impact on health status (Putnam 2001).

The purpose of this chapter is to explore the impact of different and separatist lines of inquiry and lead-up to formulating the project question and aim. Specifically, the methodological issues and challenges for research on palliative care needs in COPD point to the fundamental question concerning what purpose lies behind the re/presentation of patients' experiences and needs in any inquiry. Arising from that, a further question is posed as to how we can engage with the suffering of another. The chapter considers voices in healthcare; language and heterglossia; the framing of COPD; knowledge development and power in COPD; representation and power; inquiry lens and local moral world of practice.

Identifying Issues of Voice and Framing

Health related quality of life (HRQoL) remains the dominant means of assessment of patient-needs and evaluative research in COPD. Disease-specific instruments such as the St George's Respiratory Questionnaire (SGRQ) are well validated thus contributing to their application in COPD research which further adds to the weight of evidence supporting their reliability and validity. This, in turn, further contributes to the application of the instruments and perpetuates the view that HRQoL can effectively assess patients' needs. Emphasis among medical and health policy researchers rests on large population studies and international

comparisons. Thus, only that part of the illness experience that is deemed to be measurable is captured and informs subsequent debate on patient needs, and treatment or care interventions. Small qualitative studies point to the limitations of HRQoL studies in assessing the whole illness experience.

In service delivery discourse, advanced COPD is framed in terms of acute and stable periods (Lynn and Adamson 2003). In other words, the management and organization of care revolves around service utilization and efforts to minimize this. This depiction of COPD as divided between stable and acute periods belies the complexity of illness management and everyday burden that is evident in illness studies (Bailey 2004; Bailey *et al.* 2004; Elkington *et al.* 2005; Fraser *et al.* 2006). Advanced COPD is all consuming with everyday activities dominated by fear of breathlessness. Thus, what constitutes a 'stable period' in the context of health policy and management research (Lynn and Adamson 2003) may be experienced as a chaotic moment to moment lurch from tolerable to frightening levels of breathlessness (Ellis 1995). Everyday management demands significant family support (Bergs 2002; Jones *et al.* 2004; Hynes *et al.* 2008) pointing to the contingency of a 'stable period'. Acute episodes are not discrete events but rather dominate day to day living in terms of avoiding triggers for exacerbations and the every day risks of severe breathlessness attacks. As David Morris, writer and scholar, puts it:

> Within biomedicine, by contrast, there is not even an agreed vocabulary with which to define suffering or to frame the questions it raises (Morris 1998:193).

In short, the acute/stable framing of COPD by policy makers and HCPs focuses on disease rather than the whole illness burden and trajectory, and thus, provides, at best, a partial picture of care needs in advanced illness.

Several authors interrogating how chronic illness is framed bring to the fore questions regarding representation (and power) (Kleinman 1988; Thorne and Paterson 1998; Frank 2001, 2002a; Bailey 2004; Bailey *et al.* 2004; Frank 2004; Charon 2006; Kleinman 2008). These authors have in common a focus on the silencing effect of current biomedicine-centred healthcare practice on the illness and suffering experience of patients. The various theories relating to chronicity explored in the previous chapter challenge the fracturing of the illness experience by a biomedical focus. Loss, illness trajectory and biographical disruption

highlight the narrow restrictive parameters within which a bio-medical model is located. These works raise issues regarding how the voice of the patient is heard and re/presented in terms of eliciting care needs both in terms of past and planned research efforts. Again to draw on David Morris:

> Contemporary theory has forced us to ask hard questions about the nature of interpretation and about the relations between text and world….. What narrative turns out to tell us about suffering, in short, depends on basic decisions about what counts as narrative, how to interpret it, and whose suffering matters (Morris 1998:194).

How the voice is represented also asks how the voice is *not* represented (Frank 2004). Suffering resists any biomedical labelling or diagnostic tool and is consequently largely absent from the biomedical narrative (Cassell 1991; Morris 1998; Frank 2004). The challenge for any research seeking to identify and address care needs, in a way that is meaningful to people's suffering and illness experience, begins with questions about representation and absence (Frank 2001, 2004). By this Frank implies that the means by which people's illness is represented such as through a biomedical perspective is to limit the experience through that particular lens and so rendering other 'views' absent from that which is held.

This brings to the fore, questions about representation and power within the research design, issues of context, values, organization of care and decision-making. There are two aspects to representation that seem pertinent to exploring care needs. Firstly, healthcare may be viewed as a melting pot of different voices from those of different disciplines to different narratives such as evidence-based practice, quality improvement, case mix, specialist practice, health status etc (Charon 2006). Secondly, representation also refers to how a voice, for example that of the patient, is represented. In healthcare, the voice is usually represented in terms of measurable symptoms associated with the pathophysiological understanding of a specific condition such as COPD. This in turn results in an absence of the whole illness experience and engagement with the patient's suffering. Representation seems therefore, a platform for exploring research challenges to identifying and addressing care needs.

Voices in Healthcare

Language in Healthcare

A feature of the research reviewed earlier is the correlation between research methods and disciplinary voices. Illness experiences are prominent in nursing research; HRQL dominates medical research. The resulting narratives from research reports may point to disciplinary-based re/presentation of accounts. Thus, 'there are always other accounts which, as a result of emphasizing constituent factors differently, make for alternative interpretations' (Opie 1997:261). For Opie, the marker for interdisciplinary team working is the development of a shared linguistic practice that would presumably be reflected in research accounts and commentaries. The point here is less the significance of power struggles, tensions and shared decision-making in multidisciplinary teams notwithstanding their importance. Rather the point is more that a shared linguistic practice should, logically, allow greater questioning of how patients are represented in individual disciplines and research approaches such as that reported by Crepeau (2000:766-767):

> ..stories told by health care providers facilitate a particular kind of clinical reasoning. This reasoning connects the impact of illness on the lives of patients, shapes intervention, and, in some cases, creates a future story toward which the patient and practitioner can work.

In the absence of a shared linguistic practice, the voices of nursing, medicine, management and other disciplines continue to follow their related but distinctive reasoning without compulsion to seek alternative interpretations.

For Opie (1997) and more recently Arber (2008), multidisciplinary team members in their meetings, focus on making things happen and not 'rock the interprofessional boat' rather than working jointly through different disciplinary accounts. In other words, the multidisciplinary team does not engage with different accounts. Thus, while disciplines operate within their own discourse, which is nurtured by discipline-preferred research methods that support a particular re/presentation, any joint engagement in exploring different disciplinary re/presentations seem limited despite the rhetoric of inter and multi-disciplinary healthcare team working.

For the different discourses producing their respective re/presentation, those that are dominant will define reality through them (Opie 1997). In other words, within the institution of healthcare, however different some nursing research methods might be, it is the dominance of a reductionist representation or medical model that defines illness and patients' needs. By medical model, I mean the means by which patients are defined by their illness condition and those by which care approaches involve the management and regulation of diagnosis and access to supports and treatment. This reductionist representation applies to the organization of healthcare wherein control rests with the system and healthcare professionals. Clinical reasoning stems from this:

> ..more often physicians are understood as fronting a bureaucratic administrative system that colonizes the body by making it into its "case". People feel victimized when decisions about them are made by strangers. The sick role is no longer understood as a release from normal obligations; instead it becomes a vulnerability to extended institutional colonization (Frank 1997:172).

In nursing, there is evidence of reductionist representation in documentation (Hyde *et al.* 2005) and in care (Bailey *et al.* 2004). Patients' illness accounts point to an over-arching reductionist approach implicating different disciplines including nursing (Thorne 1993; Frank 1997, 2002a). For Frank (1997, 2004) and Kleinman (1988), the reductionism that reigns over the voices of patients is institution-wide and all enveloping. Resistance to this on the part of individual healthcare professionals whether they are nurses or doctors generates struggle and even isolation as illustrated by Arthur Frank in the stories of a nurse (2004) and doctor (1997). In these stories, healthcare professionals become members of or challenge the dominant profession and system oriented ways of working and expression. The choices rest with how patients' are heard and engaged in conversation about their illness.

Language as Shaping Meaning

Similar to Said's re/presentation, for Bakhtin, discourse expresses a particular view of the world (Bakhtin *et al.* 1994); language is ideological. Bakhtin's philosophy of language extends beyond linguistics and literary theory to the concerns of everyday life in which the 'social dynamics of observable language practice as the specifying force that structures interpersonal relations' (Clark and

Holquist 1984:9). His focus is on the speakers of language rather than language in an abstracted sense. An utterance as the basic unit of language is value driven, historically centred and future oriented. In other words, every utterance reflects a separating out of a value, comes from the past and is directed towards the future. Every utterance responds to that which was uttered previously and 'shapes itself in anticipation of an addressee's response' (Bakhtin *et al.* 1994:61). In this way, it is language that shapes and gives meaning to the way we live: 'my words come already wrapped in contextual layers sedimented by the many intralanguages and various social patois the sum of which constitutes 'the' language of my cultural system' (Clark and Holquist 1984:13).

Language is therefore multi-layered and never neutral. Rather, it is effervescent, made up of different dialects and genres and sociolects (Vice 1997) that is to say determined by factors such as age, gender, socio-economic groupings and professional groups. An important concept in Bakhtin's philosophy of language is heteroglossia meaning 'different speech-ness'. Heteroglossia refers to different languages that occur in everyday life each with their everyday particular associations. These different languages are neither neutral nor equal but rather conflict with each other. It is conflict and inequity that distinguish the idea of the heteroglot from that of polyphony. The latter simply refers to multiple voices that are present and on an equal footing with one another. In the heteroglot, there is a dialogic interaction in which the dominant languages higher in the hierarchy will try to maintain their position while those lower down the hierarchical chain will try to negotiate around or avoid the control of the other. Bakhtin refers to those forces that gravitate towards the dominant language and status quo as centripetal while forces that pull away are centrifugal (Bakhtin *et al.* 1994). Thus, tension is the central characteristic of the heteroglot.

Conflicting Narratives

Thus, illness, disease and managerial narratives are positioned in the heteroglot of COPD care. These narratives within the world or sphere of acute care are in continuous conflict. The conflict is between centripetal or official and centrifugal or unofficial discourses within a national language (Bakhtin *et al.* 1994). For Bakhtin, dominant or official narratives seek not to destroy or prevent other narratives but rather to dominate or monologise them. Languages are, in this way, central to social conflicts taking 'the form not of a struggle between languages which are developing over time, but of a struggle over the context,

narrative or otherwise, which will embody the development of some languages at the expense of others' (Hirschkop 1999:266). At issue here is what narratives will emerge and how will they emerge in terms of hierarchy. In the heteroglot, every narrative and every utterance contains traces of previous narratives and utterances in the past and future sense. Narratives are therefore continually becoming: disease focused and protocol driven COPD management is challenged by a palliative care narrative. To silence or absorb a narrative is to finalise or monologise it (Bakhtin *et al.* 1994; Vice 1997). To spoil 'the patient's narrating by forcing it into medicine's preferred outline and sequence….streamlining the process of telling of symptoms' as Charon (2006:99) puts it is to deny the patient's own personal illness story. In Bakhtinian terms, this is to monologise the account through avoiding all but one language, that of bio-medicine. To reduce the chorus of voices that might potentially occupy an individual patient's chart to one voice is to finalize all to one

Narrative accounts in medicine are associated with dissonance between the "science" of objective measurement and the "art" of clinical proficiency and judgment (Greenhalgh 1999:323). In short, such narrative accounts recognise the heteroglot of medicine. Narratives in healthcare might be understood in terms of the accounts or stories behind everyday actions so that evidence-based practice, quality improvement, risk management, diagnostic criteria, clinical guidelines, documentation procedures can all be viewed as having their own respective narratives (Charon 2006). Put another way, the story of disease can be told in a bio-medical manner as it can in through the lens of organization of care. The story reflects our meaning-making of illness; 'illness is polysemic or multivocal' (Kleinman 1988:8).

Framing of COPD

The clinical management and organization of COPD care is almost entirely biomedical and system oriented in approach. Outpatients' appointments focus on pulmonary function tests, oxygen saturation, and monitoring use of various technologies such as home oxygen and non-invasive ventilation. Increasingly, outpatient care is assessed by key performance indicators including throughput of patients, and new/follow-up patient ratio (Health Service Executive 2009b) with little if any scope for extending beyond this focus. Moreover, proposals for and evaluation of new services are based on similar performance indicators thus closing down alternative views of service development and assessment.

Outpatients appointments are administered in a manner that ignores the unpredictable nature of chronic illnesses such as COPD (Thorne 1993; Williams 1993) and the felt needs of patients (Paterson 2001). Barbara Paterson (2001) illustrates, in what she refers to as the myth of empowerment, healthcare professionals working in a manner that complements the instrumentality of the health system. Sally Thorne's (1993) work reviewed earlier, further illustrates the symbiotic relationship of healthcare professionals and system supporting one another in their interaction with patients.

The problem of patient empowerment is explored further by Julienne Cheek (2003) in her differentiation between the rhetoric and reality of practice. The therapeutic relationship is one of power (Traynor 2003). Empowerment is controlled by the healthcare professional with the patient as passive recipient while the very notion of empowerment is multi-dimensional. A nurse may have control over a patient but has little if any control over the system within which she works. For Michael Traynor, in his historical and philosophical overview of empowerment:

> ..there is an inevitable tension between our humanistic valuing of the individual and his or her optimum experience and the utilitarian and bureaucratic basis of state health care provision (Traynor 2003:131).

At the heart of Traynor's (2003) and Cheek's (2003) concerns lie the contradictions inherent in the idea of patient empowerment and system control:

> no matter how sincere the individual health worker may be, because he or she is already implicated in a project which is about encouraging individuals to fit into patterns of behaviour in which the state and capitalism have a strong interest (Traynor 2003:135).

Typically, nurses write of empowering patients to change behaviour, adhere with medication regimes and self manage their condition. This serves to both impart responsibility for illness on to the patient while also ignore or sidestep the other factors known to strongly influence health and illness such as health and social capital (Putnam 2001; Blaxter 2003). Thus, engaging with the idea of empowerment in healthcare necessitates greater focus on the institutional factors influencing healthcare professional and patient status and behaviour.

COPD Knowledge Development and Power

The framing of COPD within a management discourse and medical model with its causation/remediation world view, and patient empowerment towards self management and efficacy, reflects the wider debates about knowledge and power within and beyond critical theory. Habermas's theory of communicative action has informed accounts of lifeworld narratives and expert cultures in healthcare (Scambler 2001, 2002; Thiede 2005); communicative and strategic action in primary healthcare consultations (Barry *et al.* 2001; Greenhalgh *et al.* 2006); colonization of lifeworld during hospitalization; obstetric and midwifery relationship (Hyde and Roche-Reid 2004). At the core of these works, expert knowledge dominates the patient lifeworld. Put another way, the voice of medicine 'can entirely dominate the voice of the lifeworld, in a manner suggestive of colonization' (Scambler and Britten 2001:57). Barry et al (2001) found 4 different communicative patterns in general practice-based case studies. These were: strictly medicine, mutual lifeworld, lifeworld ignored and lifeworld blocked. Of chronic illness related consultations, the authors noted:

> The real problems seem to lie in the consultations where patients were consulting about chronic physical problems. To patients these conditions were a lifeworld issue. However, the doctors seemed to see them as a physical issue requiring the voice of medicine, and the blocking or ignoring of the voice of the lifeworld as a nuisance or an inconvenience (Barry *et al.* 2001: 504).

Conscious deception or strategic action may seem obvious such as the use by healthcare professionals of technical jargon to influence or browbeat patients. However, unconscious deception or systematically distorted communication is more invidious since neither the healthcare professional nor the patient involved may be aware of it but instead, believe they are operating in communicative action (Scambler 2002). Significantly for Barry et al (2001) and Greenhalgh et al (2006) the dominance of the voice of medicine was not always a conscious act on the part of the doctors resulting in 'instances of strategic action in the form of unconscious deception or systematically distorted communication' (Greenhalgh *et al.* 2006:1184). In these instances there appeared to be an unspoken belief in the authority of the voice of medicine.

Representation and power

Drawing on Habermas's Theory of Communicative Action, these studies demonstrate that knowledge generated from within the system not only distorts communication in lifeworld, but also informs the flow and direction of the system. In Habermassian terms, this perpetuates the system's colonization of the lifeworld. Others in healthcare have drawn on Foucault's interconnection of knowledge, power and self to gain insight into how practice might be understood in terms of informal care (Heaton 1999); contested disease (Clarke and James 2003); practice (Irving 2002); home care (Ceci 2004); nursing knowledge (Ceci 2003); mental health (Roberts 2005) and policy (Light 2001). From within the Foucauldian horizon, we are invited to problematize COPD care, that is to say, to begin by questioning how we, in COPD healthcare, come to know or understand COPD and care delivery, evidence-base and policy formulation. For Foucault, the question is how knowledge evolves and is transformed at points that are less related to shifts in truths. Rather:

> ..it is a question of what *governs* statements, and the way in which they *govern* each other so as to constitute a set of propositions which are scientifically acceptable, and hence capable of being verified or falsified by scientific procedures. In short there is a problem of the regime, the politics of the scientific statement (Rabinow 1984:54) (Italics in original).

Foucault asks us to look for divergence of scientific discourses and the rules of a period that define and limit forms of knowledge. Thus, we come to know subjects as patients objectified or formalised through prescribed modes of documentation, categorisation and data accumulation.

Framing of COPD sets a boundary around a given or normalised perspective. Representations offer a version of knowledge only.

> In fact power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production (Foucault 1979:194).

Power and knowledge are conjoined so, our questions themselves must be interrogated in terms of the discourses within which they are embedded. Exploring or interrogating our nursing practice demands that we 'ask not only what constitutes the systems of meaning in which nurses are immersed but also

how the hardening of such meanings is achieved to give the appearance and effect of reality' (Ceci 2003:71). Where respiratory nurses can and do offer specialist COPD support, questions might be asked about how they arrive at understanding this role and relationships with patients with COPD while also questioning how we have come to understand and frame the COPD disease/illness experience. Significantly, from a Foucauldian perspective, the very inquiry frameworks that are applied in COPD research may simply reinforce current accepted wisdom in relation to COPD while ignoring or, at least, failing to question theories underpinning inquiry.

Issues with COPD Research Methods

Health Status Measurement

Health status measurement remains the dominant method in health research for establishing symptom impact and health related quality of life, and accessing patients' illness accounts. This reflects the import given to patients' accounts in treatment intervention research (Jones *et al.* 1991a; Spilker 1996). Measurement of health status using disease specific instruments has become routine in mapping needs, patient outcomes and intervention research in COPD. However, the use of health status measurement instruments might be explored further from 3 fronts namely: a) the conceptual journey travelled from the notion of quality of life to health status measurement; b) the generalizability and particularity of tensions arising from that journey, and c) instrument evaluation in terms of validity, reliability, appropriateness, feasibility including interpretability and acceptability, and evaluative, discriminative and predictive properties.

Conceptual Journey

The absence of any agreed definition for quality of life (QoL) seems well accepted (Bowling 2005) leading Randall and Downie (2006:29) to go so far as to conclude 'that data encompassing it cannot be collected, processed or communicated'. Nevertheless, quality of life, however vague and ill defined a term, is part of our daily lexicon inferring the balance between that which we desire in life and that which is achievable (Bowling 2005; Jones and Wijkstra 2006). Even this broad understanding is opaque since our desires and perceptions about what is achievable may be limited to experience or expectations that may in turn be governed by a multitude of other variables. As Carr et all (2001:1241) state, 'measures of quality of life do not account for expectations of health: they do not

incorporate the boundaries within which levels of expectation and experience are measured'.

Despite the absence of an accepted and clear definition, QoL research has derived much of its theoretical models from theories of human needs, personality, subjective wellbeing, social expectations and phenomenology (Bowling 2005). From these models a large range of variables claim to measure QoL (Hickey *et al.* 2005). The breadth of any notion of QoL in global terms places health as just one constituent among others such as wealth, safety, housing, social interaction etc. Moreover, the inter-relationship between disease and social inequality (Balanda *et al.* 2001, 2003) further complicates efforts to take health or any other possible constituent as a distinct and definable idea. For some, QoL relates to measures outside the medical sphere and reflect the extent to which hopes and ambitions are matched by experience. For Randal and Downie (2006), there are no clear boundaries between health-related and non-health related quality of life. QoL, health-related quality of life (HRQoL) and health status are used interchangeably in some healthcare literature[3]. Others distinguish the 3 ideas from one another (Patrick and Erickson 1993; Bowling 2005; Jones and Wijkstra 2006).

HRQoL has been defined as

> The value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy (Patrick and Erickson 1993).

This definition understands impairments arising from disease or injury to be influenced by the environment and prognosis giving rise to physical, psycho-social functioning domains. In a similar vein, another definition refers to 'the degree to which a patient's health status affects their self-determined evaluation of satisfaction, or quality of life' (Curtis and Patrick 2003). HRQoL has also been defined as 'the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient' thus stressing the centrality of the individual respondent's perception. Bowling (2005) claims that HRQoL has two parts

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[3] See, for example, Carr A.J. and Higginson I.J. (2001) Measuring Quality of Life: Are Quality of Life Measures Patient Centred? *BMJ* **322**(7298), 1357-1360.
Hopkins R.O., Weaver L.K., Orme J.F. and Chan K.J. (2005) Two-Year Cognitive, Emotional, and Quality-of-Life Outcomes in Acute Respiratory Distress Syndrome. *American Journal of Respiratory and Critical Care Medicine* **172**(6), 786-787.

namely functional ability and positive health. For Randall and Downie (2006), this typically infers a categorical mistake in philosophical terms with value judgements being made about factual qualities since positive health is a value judgement.

Health outcomes research with its focus on the efficacy and effectiveness of interventions and disease outcomes includes measurements of health status as one of a number of categories of measurement. The others include: health utilities, patient satisfaction and treatment adherence. In cost-utility analysis, states of health can be converted into 'healthy years' allowing the cost of an intervention be measured against the number of years lived in full health (QALYs). This also allows comparisons between different types of healthcare, different groups and conditions. The EQ-5D addresses 5 dimensions, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The SF-6D addresses 6 dimensions, including mental, pain, physical, social, role, and vitality. Comparisons across conditions point to the heterogeneity of domain specific scoring suggesting that different chronic conditions impact in different ways (Schlenk *et al.* 1997; Stavem *et al.* 2000; Saarni *et al.* 2006). Two generic health utility measures, the EQ-5D and the SF-6D have been employed in COPD research but, together, have failed to yield consistent values particularly in mild COPD (Szende *et al.* 2009)

In patient satisfaction research, similar conceptual problems arise to those for quality of life. There is no agreed definition of or theoretical underpinning for satisfaction (Hall *et al.* 1993a; Hall *et al.* 1993b; Hall *et al.* 1994; Sitzia and Wood 1997). This has not diminished interest in patient/user satisfaction research and the development of models or groups of factors that determine levels of satisfaction (Bikker and Thompson 2006). Patient satisfaction remains a key determinant of patient related outcome research. There may be a host of factors including expectations and values that influence satisfaction (Mead *et al.* 2002). Satisfaction may be conceptualised differently across different communities and individuals. Several studies have found factors such as gender influence satisfaction (Hall *et al.* 1994; Nguyen Thi *et al.* 2002; Christen *et al.* 2008). Gender-associated communication skills appear also to influence satisfaction (Christen *et al.* 2008). Patient age, health status on admission, seriousness of condition, length of hospital stay, accommodation and choice of hospital have also been found to influence satisfaction (Nguyen Thi *et al.* 2002). Jackson et al (2001) found patient satisfaction to be strongly influenced by the time interval

between care experience and interview. Moreover, the importance to satisfaction of different factors such as information varied across time periods following the experiences. In particular, such approaches are embedded in dominant views of the world and therefore possibly silence the vulnerable. Through her feminist lens, Turris (2005) offers alternative questions to typical criteria such as waiting times for measurement of satisfaction. Instead, researchers might 'consider the context of people's lives and they would be forced to ask the question: "What does the waiting time mean for this person?"' (Turris 2005:296).

Jones and Wijkstra (2006) differentiate health status measurement from QoL or HEQoL. They describe health status measurement as simply measurement of disease effects using questionnaires for patient populations. Standardized method of comparison is core to health status measurement in this sense. Health status is also viewed as the impact of health/illness on a person's ability to engage with activities of daily living (Curtis and Patrick 2003; Bowling 2005). In chronic illnesses such as COPD where there is no hope of cure, improving functional areas of daily living become the central goals of treatment interventions.

Generic Health Status Measurement

Where generic health status measurement allows for comparisons to be made across different patient population groups, disease specific health status measures are shown to be more responsive and sensitive to the conditions in question (Bowling 2001, 2005). There is also evidence that generic measures can bring to light diverse and unexpected disease effects not addressed in disease specific instruments (Engström *et al.* 2001; Curtis and Patrick 2003). For Engström et al (2001), the use of generic and disease specific instruments in COPD provide insight into the disease burden on everyday functioning and emotional wellbeing. The most widely used generic instruments in COPD include the Sickness Impact Profile, the Medical Outcome Trust (more commonly referred to as the SF-36) and the Nottingham Health Profile. Though not strictly speaking a generic HRQoL instrument, the Hospital Anxiety and Depression Scale (HADS) is increasingly important in COPD research given the strong association between anxiety and depression with COPD.

The Sickness Impact Profile (SIP) is well represented in COPD research and validity was demonstrated (Bergner *et al.* 1981; Guyatt *et al.* 1987; de Bruin *et*

al. 1997; Engström *et al.* 2001) though with varying reports on the discriminative powers of the instrument (Jones 1995; Bowers *et al.* 2009). The SF-36 is considered the most widely accepted and used generic questionnaire in recent years (Bowling 2005; Ståhl 2008). It is well represented in COPD research correlating with dyspnoea (Mahler and Mackowiak 1995) and has demonstrated responsiveness to changes disease severity over time (Jones and Bosh 1997; Spencer *et al.* 2001b) The SF-36 has performed less well than disease specific tools (Kaplan and Ries 2008) except in the area of healthcare utilization (Desikan *et al.* 2002). The NHP (Hunt *et al.* 1986) was developed with a focus on lay rather than professional definitions of health. Though not originally intended as a HRQoL instrument (Hunt 1999), the NHP is widely referred to as measuring HRQoL Though used in COPD research (Monso *et al.* 1998), the instrument demonstrated poor sensitivity in some research (van Schayck *et al.* 1995).

Hospital Anxiety and Depression Scale (HADS)

There is ample evidence of the importance and high levels of anxiety and depression among patients with COPD (Mikkelsen *et al.* 2004). The HADS (Appendix 1) is a well established and validated instrument of 14 questions for assessing anxiety and depression (Zigmond and Snaith 1983; Snaith and Zigmond 1994; Mykletun *et al.* 2001). It is widely available[4] and used across disease groups but is intended as a screening rather than a diagnostic tool (Snaith 2003). It assesses anxiety and depression in separate sub-scales and a total of 14 items. Participants rate each item on a four-point scale. Though its title infers a hospital only use, HADS has been well validated in community and primary care settings (Snaith 2003). HADS measures anhedonic depression as the indicator of choice for hypomelancholia that is affected by physical illness (Bowling 2005). Depression scores of 11+ suggest definite cases; scores of 8-10 are suggestive while scores of $\leq$7 are considered non-cases.

The validity of the HADS is well established across various conditions (Snaith 2003; Bowling 2005) and specifically as complementary scale with the St George's Respiratory Questionnaire (Jones and Wijkstra 2006). Recent research has suggested a link between poor HADS scores and exacerbation frequency in COPD (Quint *et al.* 2008). Interpretability, acceptability and feasibility have all been demonstrated across several studies (Bowling 2005).

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[4] See for example http://www.patient.co.uk/showdoc/40002439/

Disease-specific instruments

The St George's Respiratory Questionnaire (SGRQ) and Chronic Respiratory Questionnaire (CRQ) are the most widely used disease-specific instruments for COPD. Since the SGRQ does not measure anxiety, the HADS is generally used alongside. Additionally, the MRC dyspnoea scale is used extensively as a quick and simple measure to assess breathlessness.

The CRQ

The CRQ was the first questionnaire to be developed for COPD specifically and was developed as an interviewer-administered instrument (Guyatt *et al.* 1987; Guyatt 1993). More recently there have been attempts to develop a self-administered version of the instrument (Williams *et al.* 2001; Schünemann *et al.* 2004). The CRQ has 20 items across 4 domains: dyspnoea, fatigue, emotion and mastery. The dyspnoea domain is individualised; respondents choose 5 activities during which they experience shortness of breath. The respondents identify those activities that are important in their daily lives. From the 5 most important activities identified, respondents then rate each activity on a 7 point scale. The other 3 domains are in the traditional fixed format. The individualised component is informed by a view of the potential of individualised questionnaires to be particularly useful when respondents may be at opposite ends of a disease spectrum and are experiencing very different limitations (Lacasse *et al.* 1999).

The CRQ is well validated and widely used in COPD research (Lacasse *et al.* 1999; Kinnunen *et al.* 2007; Güell *et al.* 2008). A large scale study highlighted better responsiveness of the CRQ when compared with generic instruments while matching that of the SGRQ (Kinnunen *et al.* 2007). Longitudinal construct validity has been demonstrated by showing correlation of change comparable with other measures (Lacasse *et al.* 1999). The individualised component optimises responsiveness of the instrument because it taps the important areas related to perceived changes in health status (high content validity) and therefore improves discriminative power (Lacasse *et al.* 1999). In other words, the instrument has proven responsiveness detecting changes in health status over time and has been employed in respiratory rehabilitation trials (Lacasse *et al.* 1999; Güell *et al.* 2008). However, there can be a trade off relationship between responsiveness and reliability wherein an instrument may be responsive but not reliable, or reliable but not responsive. Despite the obvious appeal of the individualised dyspnoea domain for assessing health status in COPD where breathlessness is

progressive, difficulties have arisen in relation to internal consistency (Wijkstra *et al.* 1994). Low internal consistency was found in a Dutch translation of the CRQ possibly related to people adapting to dyspnoea over time by limiting activities and thereby becoming less breathless (Wijkstra *et al.* 1994; Jones and Wijkstra 2006).

The SGRQ-C

The SGRQ-C (Appendix 2) is specifically for COPD and is a validated shortened version (40 items) of the St George's Respiratory Questionnaire (SGRQ) (50 items) (Jones and Wijkstra 2006; Meguro *et al.* 2007). The parent SGRQ was developed as a disease specific self-administered measure of impaired health of people with COPD and asthma and remains the most widely used instrument in COPD research. The SGRQ and SGRQ-C are self-administered and take about ten minutes to complete. The SGRQ-C addresses 3 domains:

1. symptoms: frequency of cough, sputum production, wheeze and breathlessness, and the duration and frequency of attacks;
2. activities: disturbances of activity;
3. impact: overall impact on daily life and wellbeing, including being in control, panic and stigma

The impact component does not include anxiety and depression; a supplementary instrument (most frequently HADS) is needed to address this gap. The items vary between polytomous (likert scale) and dichotomous (true/false). Each item has an empirically derived weight based on earlier studies (Meguro *et al.* 2007). The weighting estimates the degree of distress with the items. The weights have been shown to be independent of age, sex, and disease duration and severity (Jones and Wijkstra 2006). Each of the 3 sections is scored separately. Scores range between 0 (no impairment) and 100 (worst possible health), thus the higher the score the poorer is the health status. A total score of all the items is also calculated.

The published literature on the SGRQ is substantial and is primarily focused on clinical trials and interventions (Jones *et al.* 1991b; Jones *et al.* 1992; Mahler *et al.* 1995; Jones 2001b; Lacasse *et al.* 2002; Jones *et al.* 2003a; Jones *et al.* 2005). The shortened version of the SGRQ was developed and validated specifically for COPD (SGRQ-C) (Jones and Wijkstra 2006; Meguro *et al.* 2007). A number of small revisions were made in the development and validation process

and this, it is claimed, has strengthened the instrument (Meguro et al. 2007). The revisions involved removal of items from the original SGRQ that were found to have weaker measurement properties and then testing the effect of their removal on the overall performance of in the instrument (Meguro et al. 2007). No additions were made to the instrument. The developers of the SGRQ-C were also responding to the history of the SGRQ application in that though the instrument was designed for asthma and COPD, it was used almost entirely among COPD populations (Jones and Wijkstra 2006). While the validity of the SGRQ-C seems well supported (Jones and Wijkstra 2006), larger population studies are need to further validate the newer SGRQ-C (Meguro *et al.* 2007).

Nevertheless, it would appear that the SGRQ-C and its SGRQ parent broadly meet the 9 dimensions of health status that appear as patient-based assessment outcome measures (Fitzpatrick *et al.* 1998). The validity, reliability and reproducibility (Fitzpatrick *et al.* 1998) of the SGRQ-C are not in question here albeit with the caveat regarding the SGRQ-C as above (Meguro *et al.* 2007). However, other criteria for assessing the suitability of the instrument may warrant closer examination. These include appropriateness, and interpretability, acceptability and feasibility (Fitzpatrick *et al.* 1998).

By appropriateness, I am referring to fitness for purpose. The SGRQ is employed in research examining the health status of patients with end stage COPD and interventions in their care though this research is also fraught with methodological difficulties (Hill and Muers 2000). Typically, these patients may not meet inclusion criteria for research because of frailty or co-morbidity. It is possible that for this subgroup of patients, the relevance of anxiety and depression, loss, uncertainty, grief and awareness of 'reaching the end of the road' may have a particular bearing on their health status and so separate them from the wider COPD population. The validity of the SGRQ was established primarily in clinical trials as with other disease-specific health status measures. Studies evaluating interventions, particularly those that are pharmacological, normally exclude those patients who are very ill or dying unless the intervention is specifically aimed at them. This possibly raises some question about the validity findings from earlier research for people in the latter stages of end-stage COPD.

Interpretability, acceptability and feasibility

The SGRQ is a self-administered instrument with proven interpretability (Jones and Wijkstra 2006; Ståhl 2008). Patients may be given assistance if they require it but extreme care is needed not to deviate from the precise wording of the questions (personal communication with the SGRQ research administrator). Patients with end-stage COPD are by definition extremely frail and ill, and this may impact on response rates of self administered questionnaires. Moreover, those with very advanced disease are likely to be older and may have visual and/or dexterity impairment. Interestingly, most of the studies reviewed do not specify if questionnaires were completed under supervision. It is likely, despite advice to the contrary, that carers will assist those who are frail in completion of questionnaires. Therefore, the questionnaires should be completed ideally under supervision particularly when the focus is on advanced COPD. In a Swedish feasibility review of 4 instruments including the SF-36 and SGRQ, age correlated significantly with perceived ease of completion (Ståhl 2008). Gender, socioeconomic status and disease severity did not appear to influence completion. However, the authors make two cautionary points in relation to this. Firstly, the respondents were possibly already familiar with the SF-36 and SGRQ. Secondly, this was a Swedish study and factors such as literacy, socioeconomic status and motivation to complete the questionnaires may have less significance than in other countries in which there are greater health inequalities and literacy problems in older age groups.

MRC Dyspnoea Scale

The MRC dyspnoea scale (Appendix 3) measures a level of perceived disability in patients with COPD and specifically the effect of dyspnoea on daily activities. Thus, it is a useful measure in studies that address care needs and illness experience. Research supports the validity of the MRC dyspnoea scale in categorising patients with COPD in terms of their perceived disability (Bestall *et al.* 1999).

Individualised Quality of life

Among the problems associated with measurement of HRQL using standard questionnaires however well validated, is that what is measured is pre-determined and therefore may not represent individuals. The domains may generate a normative definition that has little relevance for many (Hickey *et al.*

1999; Waldron and O'Boyle 1999). Scoring techniques assume a commonality of importance for different aspects of life irrespective of whether these scores are weighted or assigned equal weighting. There is evidence that such commonality is not evident towards end of life (Waldron and O'Boyle 1999). A striking feature of the most widely used health status instruments is their validation in many countries across continents and in countries with very different cultures, healthcare services and GDP. Joyce et al (2003) question the apparent similarity in the components of QoL in different cultures. The predetermined questions, scoring system and standardisation are thus challenged:

> If the individual's perspective on quality of life is to be validly captured, he must be permitted to influence each step of the assessment. The issues addressed should be those the individual holds to be important to the quality of his life and he should then be able to assess the level of functioning or satisfaction in each of these self nominated areas (Hickey *et al.* 1999:120).

Individualised quality of life includes the individual responder's views about the content and importance of the domains being measured. Previously well cited attempts have been made to measure individual quality of life (IQoL) most notably by Joyce et al (2003), and specifically in COPD by Guyatt et al (1987) as discussed above. The most widely cited of IQoL instruments is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (Hickey *et al.* 1999; Joyce *et al.* 2003). The SEIQoL is built on a view of quality of life that is defined as what the individual determines it to be (Hickey *et al.* 1999). The SEIQoL is well published and has demonstrated its ability to represent the dynamic influences on QoL. In a study using SEIQoL in palliative care, despite the advanced stages of illness and impending death, health was not always the principal concern for participants. Rather, other cues including family were of greater importance to QoL (Waldron and O'Boyle 1999).

SEIQoL has obvious advantages for establishing individual patients' concerns and needs in advanced COPD where symptoms permeate activities of daily living and relationships bringing to the fore different factors that, at least compete with health in terms of impact on QoL. However, the drivers for the development of health status instruments in COPD remain evaluative for intervention research. To this end, individual quality of life measurement is problematic and 'too insensitive to consistently detect clinically worthwhile responses to specific

treatment for COPD' (Jones and Wijkstra 2006:379). The instruments of choice therefore, are the disease specific supported by generic instruments that are self completed and so draw on fewer resources to collect.

Issues with HRQoL and Health Status Measurement

Despite agreed lack of clarity regarding what constitutes QoL and HRQoL, and the vociferous arguments of scholars such as Randall and Downie (2006) against attempts to define let alone measure HRQoL, measurement of the effect of disease is now embedded in health research. Their contention is that, firstly, QoL is not definable and therefore attempts to draw up a complete list of meaningful qualities for every individual are simply not feasible. Secondly and drawing on theories of measurement, subjecting ordinal data typically featured in QoL instruments, to statistical analysis is inherently flawed. QoL factors are often qualitative and turning these into ordinal scales is therefore questionable. The use and summation of Likert scales for example, implies an equal distance between items grouped into subsets. Thus, a score of 4 as 'very much' infers two times worse effect than a score of 2 as 'somewhat'.

> The obvious problem for quality of life tools is that the entities being measured, such as physical performance, role performance, mood, and social support can be represented on an ordinal scale but cannot be represented on an interval scale, since it cannot be said that a constant unit of measurement separates each point on the scale (Randall and Downie 2006:38).

The weighting of scores such as that applied in the SGRQ, is also problematic (Randall and Downie 2006). By applying a weighting the researcher assumes the individual's value system. The weighting given to different domains is more likely to differ across individuals. Though not acknowledged by many researchers, there is a distinction between the idea of HRQoL as unique to the individual, and efforts to measure disease and treatment effects across patient populations. In health status as distinct from the idea of HRQoL, all items are reduced to being measurable, and potentially applicable to every patient. In short, questionnaires items 'represent a lowest common denominator of areas of impaired health that may be experienced by all people with the disease; this is not measurement of quality of life…each patient is being measured as if they were a typical member of the population of patients with that disease' (Jones and Wijkstra 2006:378).

Researching Suffering

Examples of interpretative research reviewed earlier offer different and expanded insights to the COPD and chronic illness experience. However, interpretative research is also found wanting in its capacity to silence and re/present patients' experiences. Drawing on Dorothy Smith's notion of ruling relations, Frank (2001) highlights the taking or abstraction of people's actual experiences of suffering from local settings and organizing them into official accounts. He illustrates this through an account of a woman who had participated in research and articulated

> ..how disrespected she felt when she read the research reports that included her responses to an interview study concerning her particular illness. What insulted her was the fragmentation of her story (Frank 2001:356).

A gap exists between the local everyday account and the ruling relations. Ruling relations oversee the development and sustenance of written texts, of guidelines, protocols, and services, of care planning and review such that they pervade healthcare. Researchers abstract the local voice and respondents' 'approval of scripts is little more than resigned acceptance of what they already knew social science does: organize their local experience into extra-local categories in which their lives and their suffering effectively disappear' (Frank 2001:358). Although qualitative researchers may verify their interpretation with their participants, this process is already restricted by the authority of the ruling relations.

For Frank (2001) ruling relations in healthcare dictate the labelling and resolution of problems in an objectifying and compartmental manner. In contrast to this, suffering cannot be objectified. Suffering is an embodied reality; it is an integral part of one's reality. We cannot know another's suffering. Rather, the issue is how we encounter suffering. Drawing on the philosopher, Emmanuel Levinas, Frank argues that once we label or claim to know the other's suffering, we commit a form of symbolic violence against the other. In his account of his own experience of suffering, he was mourning the losses facing him in the event of a return of his cancer and the prospect of submitting himself to the task oriented medical team. Crucially, his suffering lay beyond the biomedical frame and cannot be articulated within it a point developed by David Morris with reference to Munch's painting *The Scream*:

Paradoxically, the scream might serve as a portent image for the metaphorical silence at the heart of suffering……. The impossible project of giving "speech" to silence is important especially as it exposes how we simplify and betray suffering whenever we ignore its power to elude every linguistic and conceptual tool that humans can marshal to understand it (Morris 1997:27).

How then, from this perspective do we engage with patients in attempting to understand patients' chronic illness experience? Frank sees little point in the continuing illness research that seeks to explain behaviour typically in terms of coping, support, adherence etc. Rather we need to 'amplify the voices of the ill themselves, offering them previously unrecognized connections and a sense of community' (Frank 2001:360). The responsibility of the researcher is to encounter suffering and ensure that this encounter remains central to her project.

How we might respond to patients' illness experiences has been articulated in differing ways such as Asklepian attention (Randall and Downie 2006), generosity between hosts (HCPs) and guests (patients) (Frank 2001, 2004), ethnographic engagement (Kleinman 1988), narrative care (Charon 2006), and establishing trustworthiness (Sacks and Nelson 2007). All have in common the idea of bearing witness to the suffering of and recognizing the face of the *Other* in the Levinas meaning that is to say recognising face as reflecting *Other,* and *Other's* invitation to respond to his/her needs as a symbol of human connectedness (Frank 2004; Lâevinas *et al.* 2006). All make explicit the importance of maintaining the integrity of the other through recognizing the uniqueness of each individual illness as distinct from disease experience. Of asklepian attention, Randall and Downie (2006) note: 'the gaze corresponds to the doctor's attention to the patient as a unique and important person in the context of our knowledge of our humanity (:8)…the attending physician or nurse directs their gaze towards the patient, and is totally receptive to what the patient is communicating' (:202). Given the emphasis on the suffering of patients with advanced COPD in interpretative inquiries, the idea of bearing witness to and recognising *Other* seems central to any palliative COPD endeavour. In short, responding to *Other* implies bearing witness to an individual patient's unique suffering experience.

Entering the Local Moral World of Practice

Arthur Frank's (2001) questioning of the need for continuing illness research and the issues raised by Kleinman and Charon above (see page 50) seem to have in common, an urgency in tackling how we might bring the face of the *Other* into a disease-focused and the System oriented acute care environment. In short, how do we open a conversation between disease focused care and the idea of *Other*? Such a question invites further questioning about the gap between our idealised nursing selves and the harsh reality of acute care in the current Irish healthcare environment of recognized bed shortages, overcrowding in A/E and limited primary/secondary interface (Wren 2003; Tussing and Wren 2006). Despite policy to the contrary (Department of Health & Children 2001) and supporting evidence spanning over 20 years, we seem unable to address unmet palliative care needs in acute care. The palliative care needs of patients with advanced COPD have been raised in research findings spanning over 20 years.

Kleinman (2006) offers an insight into the gap between our idealised selves and the reality of what he refers to our local moral world. Moral in this sense includes two dimensions. The first dimension refers to values in a broad sense. Life is essentially moral because life is about the things that matter to us. We negotiate relationships and engage in activities that are important to us; we live in communities with whom we share interests. The meaning of moral here should be distinguished from that which is ethical. The moral experience that people might share may be malign and their values may be evil in the eyes of an outsider. For this reason, Kleinman argues that the notion of moral needs to be understood as that which is local. The second dimension views the more focused idea of moral referring to our sense of right and wrong. We see a right way of conducting our lives that embodies our moral commitments e.g. in our responsibility towards others and responding to those in trouble. We may hold that others living in different communities might also view these acts as moral. We can feel ashamed if we act in a way that goes against the belief in doing the right thing

The moral life is closely connected to the idea of ethics that is to say we aspire to values that 'transcend the local and that guide us in living a life'. Divided world reflects a gap between the world of actual moral experience and that of idealized ethical reflection. The world of actual moral experience includes that which we are capable of doing while idealized ethical reflection includes that which we are socialized to aspire to or not to do.

> [In] the space of ethical deliberation, we address justice, for example, while operating in an unjust world, and in the latter, the space of everyday moral experience, we go about doing what we have to do to get on with the practical tasks of living, and in so doing end up practicing injustice. Danger, fear and power characterize actual moral experience (Kleinman 2006:219).

The divided self reflects the division between the reasoned reflective self and the passion-laden practical self. The reflective self offers reasoned justification for actions. The reflective self thus stands back from the unthinking reaction that is the natural response of the passion-laden self. However, the boundaries between reflective and passion-laden selves are frequently opaque such that actions may be plausibly justified by an uncritical reasoning or privately held assumptions:

> Those actions – what we actually do in living – are as much based in passion and wilfulness as in reasoned choice. The thoughtful justifications are often excuses, made up after the fact for things that we do (Kleinman 2006:219).

Thus our reasoned or thoughtful justifications for action (or non-action) frequently hide our unthinking reactive selves in action. Put another way, as Charon (2006) indicates in how ethicality features in narrative medicine, a particular challenge in life is how to judge things.

Those who seek to do the right thing may find that things are wrong in their moral (moral in the first sense) environment. They may protest, criticise or go against the tide and seek to do the right thing even against adversity and where there are negative consequences for themselves. Others may prefer not to rock the boat and so 'their interior moral life will reflect the problems with moral experiences surrounding them' (Kleinman 2006:3). Thus they collaborate publically with the practice of the day while holding deep reservations about this such that later they may experience guilt, misplaced loyalty or remain in denial for a lifetime. It is this scenario that reflects the state of divided world and divided self.

> We can protest and resist a dangerous moral ethos in our families, workplaces and communities, and even if we are unsuccessful at changing

our local worlds, which is not unlikely, we can keep our moral practices in line with our sense of what is right (Kleinman 2006:24).

The challenge that faces us in the everyday is our work to bridge the divides of world and self. The questions that Kleinman asks concern living in a way that goes against the grain in the moral environment in which we find ourselves; also the kinds of decisions we make when there is real uncertainty about what to do. Critical self examination and responsible action are the means towards building this bridge.

Kleinman's local moral world illustrates a possible conflict between responding to the *Other* or suffering and working in an environment that is System oriented and dominated by medical reductionism. For Frank and Charon, the face of the *Other* is about engaging with unique illness experiences of individual patients. However, both authors recognize the more dominant disease focused approach of the acute care environment with its attendant bio-medical markers, routines and pressures. Thus idealised practice that centres on *Other* gives way to a local moral world

Developing the Research Question

Patients with advanced COPD, have regular contact with acute care in which the environment might be understood in terms of heteroglossia (Bakhtin *et al.* 1994). Engaging with illness experiences seems the basis for understanding palliative needs of these patients. The importance of chronicity in COPD in terms of patients' illness experiences and trajectory pointed to the importance of understanding their palliative care needs. However, understanding these needs and how they might be addressed demanded an engagement also with the local moral world of respiratory care and heteroglossia therein. In other words, the central question that emerged was how might palliative COPD care be understood and addressed through developing respiratory nursing practice? In this question, I was acknowledging and seeking to engage with the challenges of integrating palliative care in non-malignancy including the conflict between competing narratives in acute medical care. This inquiry was less about transposing palliative care from cancer to acute medical care and more about how we might construe palliative COPD care.

The aim of the project was to develop respiratory nursing practice to address palliative care needs of patients with advanced COPD. The objectives were to:

- Identify palliative care needs among patients attending hospital for COPD management in an Irish healthcare context;
- Develop and understanding of palliative COPD care in acute hospital context;
- Identify how unmet needs can be addressed in an acute hospital context.

Engagement with patients' illness experiences and conflicting narratives in the acute care context was explicit in the project question and aim. Thus, the project was ultimately a practice development one within an action research framework. In the following chapter, I detail the theory underpinning my practice development and action research approach.

In summary, different ways of examining advanced COPD shape a particular purpose of re/presentation of patients' care needs and health status. The knowledge generated from a given re/presentation can silence other ways of viewing the COPD illness trajectory. The dominance of the bio-medical approach to care delivery and knowledge development in acute medical care has resulted in a focus on health status measurement. The theory underpinning health status measurement is questioned in terms of its rationale and re/presentation. However, interpretative research that seeks to counter issues of power and re/presentation is also open to question. Questions arise as to how we engage with the suffering of others or how we respond to the *Other.* A way forward is suggested that focuses on engagement with *Other* while acknowledging issues of re/presentation and engaging with the heteroglot of the local moral world of practice. This route brings to the fore a focus on how we respond to the *Other*.

Chapter Five Inquiry Orientation

Introduction

In planning this project, I was conscious of the implicit challenge of ultimately seeking to develop respiratory nursing practice but doing so in a way that would allow knowledge to emerge regarding the palliative care needs of patients with advanced COPD and how we might construe palliative respiratory care within the maelstrom of different care narratives within the acute care environment. In other words, this was a practice development project but within a framework of action research that could bring to the fore the ideas of knowledge development, context specificity, different voices and problem focus. The first objective: to identify palliative care needs among patients invited attention to how COPD and by implication, care needs are framed in the inquiry. The second and third objectives: to develop an understanding of palliative COPD care and how unmet needs might be addressed in the acute setting invited an exploration into our own nursing approach, engagement with disease/illness narratives and relationship with patients. In other words, this included attention to self as nurse interacting with the individual patient and practice in addition to a shared understanding of practice.

Action research falls within the family of practices of living inquiry that is action research (Reason and Bradbury 2008a). Action research is described by Reason and Bradbury (2008a:1) as 'not so much a methodology as an *orientation to inquiry* that seeks to create participative communities of inquiry in which qualities of engagement, curiosity and question posing are brought to bear on significant practical issues' (italics in original). The authenticity of an action research inquiry is founded on a clear account of the theoretical principles underpinning it and which guide the project to its conclusion. In this chapter, I will explore the idea of practice development in nursing and its relationship with action research. I will frame this relationship within pragmatism as a philosophy of practice and specifically the arguments of Richard Rorty (1980, 1999). I will also introduce the idea of Bildung that, though has its origins in ancient Greek, has been given a modern interpretation by Gadamer (2003) and, in turn, by Rorty (1980). Though Bildung has not previously been linked with action research, I will argue that doing so enriches what is known as 'an attitude of inquiry' (Marshall and Reason 2007) and brings an important dimension to this inquiry into nursing practice and

attending to self and *Other* where *Other* reflects different worldviews and narratives therein. This added dimension is based on the view that, as practitioners, our assumptions about our practice are always culturally and historically embedded and as such 'they can only be tested through a form of research concerned to promote historical consciousness' (Carr 2006:433).

Practice Development

The broad aim of my research: the process of identifying and responding to patients' unmet care needs, reflected the core constituents of practice development as it is represented within the nursing literature (Clarke 2004; McCormack *et al.* 2006). A number of approaches to practice development have emerged reflecting differences in emphasis e.g. practice-based knowledge development interacting with policy (Clarke and Wilcockson 2001; McCormack *et al.* 2006), an emancipatory ideal (Garbett and McCormack 2002), innovative practice (Eve 2004), and healthcare governance (McSherry 2004). Their central themes include quality improvement, clinical effectiveness and recognition of cultural influences, reflecting the trends in discourses that inform policy development and implementation. The bulk of publications on practice development themes appearing in nursing journals fall within the 3 approaches named above and more commonly report on initiatives at ward or unit level.

Three concept analyses of practice development have appeared in nursing journals (Unsworth 2000; Garbett and McCormack 2002; Hanrahan 2004). The findings from these papers had in common 3 core attributes namely patient centeredness, continuous quality improvement and change in nursing practice all of which appear to underpin the vast number of published accounts that report on a raft of practice development initiatives. The differences among these papers lie not in the core attributes per se but rather in the implied weighting given to and interpretation of any given attribute. Patient centeredness is rarely defined or explored as a concept in itself in the current debates on the nature of practice development. Yet there are clear differences between a view of practice development that seeks to assert influence on the System (Clarke and Wilcockson 2001; Garbett and McCormack 2002) and one looking to respond to the system such as need for information booklets as presented in Unsworth's (2000) model case. In the former instance, nurses might engage in pushing the boundaries of practice that reflect their challenging the System to provide care that better reflects their patients' needs. In the latter instance, nurses may seek to meet

with criteria set by the System in policy implementation e.g. provide patient information on an aspect of care or service delivery.

The point here is not to diminish the value in either case, rather it is to question the explicit intended meaning of the term patient centeredness, the philosophy underpinning it and basis for driving practice development. In all cases patients may be at the centre but the method and purpose of patient involvement is less clear. Claiming patient centeredness may confer legitimacy on a practice by symbolising conformity with current norms and standards relating to patient care. In this way, legitimacy might be considered as related 'not to actual efficiency or effectiveness but to the ability to *symbolize* efficiency or adherence to other social norms' (Lotia and Hardy 2008:370). This highlights the importance of rendering visible the nature of patient centeredness in a given practice development project.

Closely associated with the idea of patient centeredness and practice development is the idea of empowerment wherein through patient centeredness, patients are empowered to achieve greater participation in their care and decision-making. As Hardy and Leiba-O'Sullivan (1998) illustrate however, the link between power and empowerment needs to be explored more fully and with reference to different power perspectives. In the functionalist view, power is a benign force used to achieve intended outcomes. The potential negative aspects of power are ignored. A critical perspective focuses on the political dimensions of power, its hidden aspects and asymmetrical power relations in terms of control and exploitation. The Foucauldian perspective looks more closely at power as embedded in social structures: conversations and action. Involving or collaborating with patients in care and decision-making thus presents power as something that is fluid and includes different tensions in relationships

In short, the means by which patients become and remain involved in practice development, the patients' power within that involvement and their ownership of decisions emanating from their involvement are all contingent on the particular interpretation of patient centeredness at a given time. This is illustrated in Barbara Paterson's (2001) study of patient empowerment whereby patient participants identified covert and subtle ways that practitioners contradicted their stated goal of empowerment and working with patients as equal partners. Moreover, as Sally Thorne (1993) found, the factors driving and restraining collaboration extend beyond the nurse/patient relationship to include patients'

experiences over a long period of troubled relationships with the healthcare system and its elements. In summary, the idea of patient centeredness is complex and capable of being interpreted differently by those involved. Since patient centeredness lies at the heart of practice development literature, it follows that greater focus is needed on the what, why and how of patient centred approach in any practice development venture and the theory underpinning it.

Similarly, there is much emphasis in the practice development literature of nurses becoming empowered to question routine practice. However, practice development may simply be a mechanism to engage nurses in changing practice according to a particular discourse or agenda of the system and/or organization. While the nursing practice development literature describes individual initiatives, there is little attention given to the power/empowerment relationship and the often complex process of questioning the assumptions underpinning initiatives. This may partly be explained by the challenges in engaging patients or service users in the practice development process. Some notable exceptions focus on the assumptions underpinning a practice initiative and specifically the political and participative dimensions in, for example, palliative care (Hockley and Froggatt 2006) and mental health (Tee *et al.* 2007).

In a further and more recent attempt to establish an understanding of practice development and specifically the evidence concerning it, McCormack et al (2006) reported on their realist synthesis of practice development evidence. Drawing heavily on the realist evaluation and synthesis work of Pawson et al (2004), McCormack et al (2006) designed a two-phased process with several stages in each phase. Broadly, phase one involved a) a consensus on the focus of the review; b) the identification of contributory theories to practice development to guide the review process and c) the development of review criteria and undertaking a systematic review of the literature to address the identified criteria. Phase 2 followed on with a review of the grey literature on practice development and later a round of telephone interviews with key informants internationally. This approach seems complex in the first instance and this reflects an acknowledgement of the complexities of social interventions that underpins realist synthesis (Pawson *et al.* 2004, 2005).

In broad summary, they found that while there appears to be much emphasis in practice development on stakeholder involvement, evidence of how this is achieved in individual projects, and what model(s) is used is less clear. There is

little reported emphasis on the importance of and attention to scale of projects and decision-making processes that span planning, scoping, implementation, and the roles and positions of practice developers. Approaches to developing practice range from participatory and action research to pedagogical models. Drivers for practice development range from educational and credential to policy and practice issues. However, the report delineates educational programmes in practice development from professional development. In the case of the latter, '*the development of practice is an indirect consequence rather than a specific intent*' (McCormack *et al.* 2006:71). Practice development activity spans facilitation of change, implementation of evidence-based practice, responding to external drivers, education, practice-based inquiry, and audit and quality. The importance of stakeholder consensus to ensuring agreed outcomes is highlighted. Any measurement of practice development outcomes was made difficult by the range of change strategies reported and the lack of emphasis given to approaches and evaluation strategies. Reports of practice development frequently fail to articulate the evidence underpinning the various initiatives, their processes and developments. In short, despite a large body of related work now published in the nursing and grey literature, the term practice development appears to reflect a medium for reporting on practice activity aimed at quality improvement with limited if any attention to the principles underpinning the processes involved.

The approach taken by McCormack et al (2006) enabled a wide review of practice development related publications while also containing the search strategy to more manageable levels. The markers used to frame the synthesis, and the contributory theories to practice development to guide the review process, were informed by the particular school of thought that has emerged from a core group of practice development authors (Garbett and McCormack 2002; Rycroft-Malone *et al.* 2002; Manley and McCormack 2004; McCormack *et al.* 2004). In nursing literature, the term 'practice development' is most associated with this group of authors. Papers that reported on change or development initiatives but which did not use the term 'practice development', were not included in the synthesis. This would have excluded many possible practice development style initiatives that were undertaken in countries such as the US where the term is not adopted.

Problematising the notion of practice development in nursing

In simplest terms, the practice of nursing in the modern sense has, of course, been developing since the 19th century and will continue to develop and evolve.

The drivers and historic-politico-social contexts for the development of nursing practice over the past 200 years provide sources for rich discussion in the body of nursing literature and beyond. The specific phrase 'practice development' in nursing emerged in the 1980s and has become associated with a particular 'school' of thinking within nursing. That the term 'practice development' is not so widely used in the US, many European, African and Asian nursing communities seems to emphasise the point that the use of the term is currently, at least, limited to relatively few countries. Thus, the commentary on practice development implies something different to the wider nursing corpus that examines various aspects of the development of nursing as it is embedded within the technical, social, political and cultural contexts of our World. Practice development is promoted as being focused on clinical practice with its 3 core constituents namely person centeredness, change and quality (Unsworth 2000; Garbett and McCormack 2002).

The focus on these core constituents is neither unique to those countries associated with the term 'practice development' nor is it unique to the discipline of nursing. See, for example: (Baker *et al.* 2007; Eriksen *et al.* 2008; Lamiani *et al.* 2008; Lee 2008; Poochikian-Sarkissian *et al.* 2008). Rita Charon's (2006) seminal work on narrative medicine is underpinned by person centeredness centring as it does on the healthcare professional 'bearing witness' to the person's illness experience along her life journey. Similarly, particular questions about patient centeredness in relation to healthcare have been aired by commentators who are closer to medicine and psychiatry (Kleinman 1988) and the lived patient experience (Frank 1997, 2002a). The focus on the core constituents in what is referred to as practice development appears to signify a challenge to practice from becoming routine wherein clinically-based nurses question their practice and its relationship with their view of person centeredness and quality. Practice development seeks to foster and frame the '*why-don't-we-try-this*' kind of questioning in practice. In this way, practice development might be understood as a conscious mindfulness and creativity in addressing everyday problems of practice. Practice development's rootedness in quality ensures an evidence-based mindfulness and creativity while identifying and addressing everyday problems of clinical practice. However, there is less debate within the practice development literature as to how problems are defined, who defines them and why at this particular point in time they are defined in this particular way.

Garbet and McCormack's (2002) definition of practice development is the departure point for McCormack's et al (2006) realist synthesis and positions the review within a particular view of practice development.

> Practice development is a continuous process of improvement towards increased effectiveness in person-centred care. This is brought about by helping healthcare teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to a systematic, rigorous and continuous process of emancipatory change that reflects the perspectives of service users (Garbett and McCormack 2002:88).

Differences between espoused values and values-in-practice such as illustrated by Argyris (2006) result in confused or conflicting elements of organizational culture and sub-cultures within an organization. Addressing gaps between espoused and practiced values and beliefs such as within healthcare teams underpins the focus on changing culture (Manley and McCormack 2003; Manley 2004) or transformational change. The contextual focus examines organizational structures and factors that influence change including internal politics, expertise, inter-professional relationships, hierarchies and decision-making processes and devolution. For Manley and McCormack (2003:24) 'the development and empowerment of staff is deliberate and inter-related with creating a specific type of culture, termed a *transformational* culture'. They describe transformational culture as one where 'quality becomes everyone's business; positive change becomes a way of life; everyone's leadership potential is developed; and, where there is a shared vision, investment in and valuing of staff' (Manley and McCormack 2003:24).

This particular construct of practice development is not without critics in the nursing literature (Thompson *et al.* 2008; Walker 2009). Walker (2009:158) questions the 'loosely configured principles' of the definition. Both he and Thompson et al (2008) argue that the concept is poorly defined and given limited scrutiny by the practice development advocates. This lack of scrutiny appears to stem, in part at least, from two factors. Firstly, Garbett and McCormack's definition is strongly connected with the RCN[5] and a relatively small group of

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[5] See, for example, http://www.rcn.org.uk/development/researchanddevelopment/practice_developm ent

authors and researchers. Secondly, despite the flourishing practice development movement and publications, as McCormack et al (2006) rightly point out, there is little debate or exploration of the theoretical principles underpinning much of the published accounts of practice development in the nursing literature. Most of the accounts are simply descriptions of practice initiatives. Rather, what theoretical exploration there is, comes almost entirely from members of the small group associated with the RCN.

The practice development literature is notable for arguments developed from and supported by citations from within this small group of co-authors. That, in and of itself, is arguably, simply an indication of the early development of an idea or field of interest. However, notwithstanding a few recent comments (Thompson *et al.* 2008; Walker 2009), there has been little debate or questioning from the wider nursing community over the past 10-20 years leading up to the current body of nursing practice development literature. Thus, the RCN group are left to advance their arguments with little engagement from without and consequently less than ideal testing of claims.

Thompson et al (2008) question the legitimacy of practice development as an academic pursuit. Paradoxically, the failure of the nursing academic community to engage in a more robust challenging of the claims made in the name of practice development has probably contributed to the flourishing number of descriptive accounts of initiatives and often unsubstantiated claims about core values such as person centeredness. Notwithstanding the adopting of particular definitions for practice development, the idea of developing the practice of nursing is of concern to the whole nursing community and wider healthcare arena. Questioning the direction of nursing practice; the role of nursing in any healthcare modernisation agenda; policy reform; human rights and in our understanding of the dimensions of person centeredness therein, are all part and parcel of questioning how we develop nursing practice. How and why we address particular initiatives in our clinical practice development in a given way needs to be in conversation with the bigger questions concerning the direction or nursing practice. The definition advanced by Garbett and McCormack (2002), and their group makes claims to touch on some of these in their use of terms such as transformation of culture and person centeredness. As Walker (2009) and Thompson et al (2008) point out, these terms are, at best, vague. Significantly, the definition fails to defend a delineation of their view of practice development from a wider questioning of how nursing should develop.

A broader view of the development of the practice of nursing towards improving the quality of care immediately demands thought and debate about the historical-politico-social factors influencing any understanding of how increased effectiveness in patient care is determined and pursued. How, for example, is person-centred care defined? What contingencies are there for mediating person centeredness within the current managerial and risk oriented climate, knowledge economy (Drummond 2007) and determinants of evidence in healthcare evaluation? Such questions support the importance of academic focus on the practice development literature rather than the disengagement suggested by others (Thompson *et al.* 2008; Watson and Thompson 2008):

> We are quite happy to see practice being developed but does the word practice' not belie the nature of the activity? It is practice oriented and, therefore, probably better addressed and implemented by those in practice (Watson 2008:73).

Presumably, these senior academic authors would view questions about the theoretical underpinnings (and all their philosophical, social and political complexities) of practice activity as relevant to nursing academia. If so, then divorcing themselves from practice development activity and by default scrutiny of that activity, simply does not make sense.

An alternative view of practice development might be to find ways of scrutinising the historical, political, clinical and cultural factors in the decisions and choices made while changing practice to advance the quality of care provided. Taking this view, we develop practice through our engagement with policy directives, trends in advancements in clinical care, patients' illness experiences and professional development. Put another way, practice development is a response to different calls from the System, Nursing profession, patients and changing discourses in healthcare each exerting different pressures at different times. How we engage with those calls and pressures, the scrutiny we apply to them and consequent choices and decisions we make in patient care determines the degree of influence and responsibility we assert on our practice development.

This project seeks to respond to needs identified by the system as described by policy documents (Department of Health & Children 2001) through development of respiratory nursing practice by generating knowledge on care of patients with

end stage COPD. However, the guiding principles for this practice development approach are acceptance of patients' own expertise in and experience of their illness (Kleinman 1988) and the importance of the patients' voice in any such initiative (Frank 2002a; Charon 2006); the knowledge within palliative and respiratory nursing, and need to respond to the System's call for equity in palliative care (Department of Health & Children 2001). I am therefore, taking a view of practice development as one which recognises and draws on different voices within healthcare i.e. system including policy and management; professional disciplines; nursing and patient; towards generating understanding and continuing the conversation about practice. In particular, how we understand and engage with these voices will determine our capacity for awareness of the practice choices we make and their consequences for patient care and our practice development. In this sense, practice development reflects our ongoing conversation with the often competing discourses in healthcare.

Approaches to Developing Practice: Pragmatism and Continuing the Conversation

This view is congruent with Dewey's and Rorty's pragmatism as a philosophy of practice in which the practitioners' inquiry seeks both to respond to society's need for change while also seeking to bring a practice-based knowledge towards influencing delivery of care. Pragmatism holds an idea of truth as that which is most useful but the plurality of truths is contended giving rise to accusations of relativism and differences among pragmatists. At it most fundamental argument, there are significant differences among the 3 founding fathers of pragmatism: Charles Pierce, William James and John Dewey. For Pierce, truth is what works until such time as it no longer works and a new truth emerges always drawing on scientific method until such time as one truth will be agreed by all. Ultimately truth is the opinion upon which everyone will converge in the end after a process of inquiry. Thus he had an idealized conception of truth. William James differed in his acceptance of a plurality of truths: truth is what works and what it is useful to believe.

Dewey moved away from focusing primarily on theoretical issues and towards social application, a line that has since been developed by Rorty (1980). For Dewey, epistemology should give way to a focus on inquiry and the practices of inquiry. The character of inquiry is collective and social starting with a problem to

be solved. He replaced truth with his notion of warranted assertability whereby for a claim to be warranted assertable, the claimant must have sufficient reason to state it as true to another person. Knowledge (or truth) is simply the outcome of a competent inquiry.

Dewey shared with Pierce and James a rejection of the notion of truth as correspondence with a separate independent reality. Rather, knowledge is practice. Truth is internal to our inquiry; truth is available to us and is what we have reason to think is true. Dewey brought pragmatism into society as a means towards finding solutions to our problems through social endeavour and support for democracy. With his focus on reform, Dewey saw inquiry in historical terms wherein the state of evidence changes and develops over time while that which we regard as good evidence also changes over time. These ideas are closer to the central ideas of action research as debated today (Greenwood and Levin 2007).

More recently pragmatism has become associated with Richard Rorty, regarded by many as a neo-pragmatist (linguistic pragmatist)[6], who holds that what matters most is not some theoretical argument on the nature of Truth but rather how we can make social progress and solidarity that allows people to take up shared values. According to Rorty the dominant epistemologically centred philosophy holds that 'man has an essence – namely to discover essences' (Rorty 1980:357) in a world 'that is made up of 'very simple, clearly and distinctly knowable things'. Knowledge of the essences of these knowable things provides us with a master vocabulary which transcends all discourses.

For Rorty (1980), we need to set aside any notion of having this essence to discover all essences if we are to push away the idea of epistemologically centred philosophy. In short, there can be no foundation for any overarching theory of Truth. This anti-foundational stance is central to Rorty's work in the tradition of Dewey (Rorty 1980) and the other classic pragmatists. Objectivity should be viewed as 'conformity to the norms of justification' for facts about us. To view objectivity as being the means to know all about us simply reflects self deception. He draws on hermeneutics as the counter to epistemological centred philosophy

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[6] Rorty expressed a preference to be referred to as a pragmatist rather than a neo-pragmatist see, for example, McReynolds, Philip. (2007) The Putnam-Rorty Debate and the Pragmatist Revival. American Philosopher http://www.youtube.com/watch?v=GlrEbffVVjM accessed 28th February 2008

where he sees hermeneutics as 'another way of coping rather than 'another way of knowing' (Rorty 1980:356).

> Hermeneutics sees the relations between various discourses as those of strands in a possible conversation, a conversation which presupposes no disciplinary matrix which unites the speakers, but where the hope for agreement is never lost so long as the conversation lasts (Rorty 1980:318).

The hope expressed here is not for some discovery of external truth, but rather, it is hope for agreement and fruitful conversation.

For pragmatists, relevant questions concern not whether a belief represents reality be it mental or physical, rather they ask for the purposes that make such a belief useful (Rorty 1999). Truth is not the goal for inquiry. Rather, the goal is to achieve agreement about what to do and to bring about consensus on what is to be achieved and the means to be employed towards that achievement. Scientific theories are simply instruments or tools for coping with reality and are judged by their consequences as distinct from exclusively their relationship with principles or antecedent facts. As Rorty (1999:xxv) puts it

> Inquiry that does not achieve co-ordination of behaviours is not inquiry but simply wordplay.

It is this point that rejects truth as the goal of inquiry among pragmatists and, for Rorty, to hold that irrespective of whether the question relates to the natural or social sciences, the underlying issue remains how best to use the tools at our disposal in order to make technological, political or sociological progress.

> All areas of culture are parts of the same endeavour to make life better. There is no split between theory and practice, because on a pragmatist view all so called 'theory' which is not wordplay is already practice (Rorty 1999:pxxv).

The point of departure for pragmatism from the portrayal of qualitative or quantitative inquiries into the social world, is the view that the social world is a matter of practice. Where qualitative research claims to offer more than the stereotypical presenting or tabulating of facts associated with quantitative

inquiries of the social world, pragmatists argue that the problem remains that such inquiries move us away from practice. Rather than looking to depict various views of social realities, pragmatists are concerned with how these realities are 'brought to bear on our understandings of who and what we are, both in relation to what we apparently are within and to what we believe we share as members of the social world we take for granted' (Seale *et al.* 2007:5). In short, the focus is on getting an understanding of how reality enters our daily lives. The means towards such a focus lies in recognising that social worlds are comprised of parts, linkages and wholes (Seale *et al.* 2007).

Inquiry is a problem solving process that, to follow Dewey's line of pragmatism, involves experimentation. We cannot inquire effectively without experimentation that is to say to manipulate or change reality in certain ways. Knowledge develops from our attempts to manipulate or change the world while seeing what happens as a result. Consequently, knowers are therefore agents: 'the ancient dualism between theory and practice must go by the board'[7]. The view of knowers as agents is central to the "experimental theory of knowledge," which is Dewey's alternative to the discredited spectatorial conception.

In summary, pragmatism brings to research inquiry a view that truth is what works and a stance that we need to stop asking questions about reality. Rather we need to start solving real problems, and have freedom to choose the methods that most need their specific needs at a given time. Inquiry is a continuing conversation with our world. The goal of thinking becomes not for knowledge but rather the continuously remaking of ourselves. Rorty draws on Gadamer's notion of Bildung (Gadamer 2003) to explore this.

Bildung

Bildung is a German word and concept that has no direct English translation. It has been likened to the idea of liberal education by philosophers in education but always with a proviso that this is at best a crude attempt to capture what is seen as a big concept that is a complex world of meanings and application (Løvlie and Standish 2002). It is an ancient term that has evolved but always referring to self cultivation through engagement with other. In its modern meaning, Hans Gadamer devotes some time to this theme in his work Truth and Method

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[7] http//www.iep.uym.edu/pragmati/

(Gadamer 2003). Through Bildung, learning takes place through cultivating the inner life that forms through conversations with others, drawing on past history, recreating the self and seeing the world differently (Gadamer 2001, 2003):

> To recognise oneself in the alien, to become at home in it, is the basic movement of the Spirit whose being consists only in returning to itself from that which is other (Gadamer 2003:14).

Through the process of Bildung, the individual learns to move out from and to bring back to the self differing views of the world through conversations with other professional groups, patients and discourses. A historical conscious is central to Bildung; the individual's understanding of the world is built upon from that which went before. Rendering conscious the assumptions upon which the individual understands the world is integral to the self formation or self cultivation that is Bildung.

In bringing back to the self these differing worldviews, there is formation of the self that stands apart from the narrow experience of being *a nurse* or other healthcare professional. This moving towards experience of encounter and engagement with what is other is, as Gadamer puts it, looking to the alien and returning to the self from the alien. The essence of Bildung is this alienation or difference and, crucially, returning to the self. That is to say it is recognising other diverse (or alien) ways of viewing the world and bringing these back to one's own self. Thus, Bildung in its modern meaning may be viewed as self-cultivation linking the self to the world in an animated interplay (Løvlie and Standish 2002).

Bildung reflects a constant process of engagement, self-criticism when facing different and often alien perspectives, an ever-developing self. It is a dialectic between the possible and what appears as the limits of the possible in a given professional or social culture. The relationship between self and the world is a necessary opposition that generates interplay. Bildung does not come from gaining competencies, but rather grows out of an inner process of formation and cultivation (Gadamer 2001, 2003). As such, Bildung constantly remains in a state of Bildung. Thus Bildung extends well beyond the notion of cultivating talents and reflects a historical spirit; all that we receive is absorbed and preserved.

From its ancient mystical sense, where Bildung reflected the notion of man carrying in his soul the image of God and seeking to cultivate that image, there has evolved a humanistic concept of a sense of man seeking to move beyond his naturalness towards an ideal. This historical spirit reflects not so much our knowledge of historical facts, rather it is what we can get from nature and history for our own uses. Thus our knowing historical facts 'is merely propaedeutic to finding a new and more interesting way of expressing ourselves, and thus of coping with the world' (Rorty 1980:359). In essence, a historical consciousness is a foundation to moving towards new ways of understanding and engaging with our world.

Rorty replaces the word Bildung with the notion of edification to describe finding new and more fruitful ways of speaking. The process of edification consists in the hermeneutic activity of making connections between the self and other whether that other be a different culture, discipline, historical period or simply different ways of describing ourselves (Rorty 1980). Through this, we develop new ways of thinking and what Rorty describes as the inverse of hermeneutics, that is to say, *re*-interpreting familiar surroundings with new and unfamiliar terms. In essence edification is working towards communicative clarity and keeping the conversation going. Edifying philosophers are those on the edge of their field countering accepted ways of thinking and argument. Edifying discourse is meant to seem abnormal to use Rorty's term in that it is meant to take us out of our comfort zone of old selves.

Pragmatism, action research and practice development

Greenwood and Levin argue that action research is 'neopragmatism in social research, an attempt to keep the conversation going and to democratize our society further' (Greenwood and Levin 2007:73). Their cogenerative learning action research model draws directly from the idea of keeping the conversation going. In this model, insiders deemed as those who own the problem work with outsiders who are typically academic or professional researchers who look to facilitate co-learning to address the problem. Both insiders and outsiders engage in a process of problem definition, communicative action and reflection, problem solving through action and reflection. This model draws directly on Gadamer's emphasis 'on the interpretative, dialogical, and practice oriented character of human knowledge' (Greenwood and Levin 2007:72). Thus action research is a means of 'keeping the conversation going' (Greenwood and Levin 2007:72).

Others have made similar points viewing pragmatism as a way of bringing an emphasis on active experimentation (Wicks *et al.* 2008). In his conversation with Richard Rorty, Peter Reason (2003b) highlights commonalities between pragmatism and action research namely: that importance of human discourse in knowledge generation, and re-description as a means of looking differently at our problems and assumptions of reality and social justice.

The idea of keeping the conversation going appealed to what I saw as a recurring issue in my reading about palliative care in non-malignancy, re/presentation through research methods and in my own respiratory experience. This issue could be summarised as mediating between disease and illness oriented care approaches in an acute care environment. For patients with advanced COPD, whether admitted to hospital for management of acute exacerbation or attending to OPD for follow-up care, bio-medical markers such as arterial oxygen levels, respiratory failure, bacterial infection and signs of co-morbidity such as heart failure dominate decisions to admit or discharge and when to recall. COPD research as reviewed in chapter 2 demonstrates the dominance of such markers in patient assessment. Any nursing approach that seeks to attend to illness oriented care reflecting issues of chronicity must find ways of engaging with this disease oriented perspective. At the same time, how we frame COPD within a discipline such as nursing needs to be explored if we are to attend to the dangers of re/presentation of the COPD lived experience. How we develop practice will depend on our engagement with these different conversations at different levels rather than seeking to silence any one. My particular inquiry approach therefore, centred on the idea of seeking to converse with different voices and care narratives. Central to this conversing was the idea of self and *Other*.

Action Research

Definition and Principles

Action research is an established framework for developing practice (Waterman *et al.* 2001; Hope and Waterman 2003; Marshall *et al.* 2006; McCormack *et al.* 2006; Hardy *et al.* 2007; Jinks and Marsden 2007; Hughes 2008) and drawing on the ideas of the specific pragmatism of Dewey and Rorty (Greenwood and Levin 2007). Reason and Bradbury state as their working definition for action research as follows:

> Action research is a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities (Reason and Bradbury 2008a:4).

Action research begins with the premise that creating knowledge is a practical affair (Reason and Bradbury 2008b) seeking to 'forge a more direct link between intellectual knowledge and moment to moment personal and social action' (Reason 2006:188). Action research is thus characterised by:

1. Primacy of the practical
2. Encompasses many ways of knowing
3. A participative and democratic process
4. An emergent process

1. Primacy of the Practical

Action research privileges the practical and the production of practical knowledge that is useful to people in their everyday lives but in so doing resists a purely outcomes-based view. In other words, action research goes well beyond simply being about what works by looking to understand the whys and hows of what works.

2. Many Ways of Knowing.

Action research is concerned with how we make sense of experience and accounts; the congruence between our theories and practice; and testing the validity of our claims to knowledge against evidence derived from practice. This involves different ways of knowing which have been linked with Aristotle and phrónêsis (Eikeland 2006) and practical philosophy (Carr 2006). For Reason and Bradbury (2008a) ways of knowing in action research can be understood as experiential, presentational, propositional and practical.

We bring to any inquiry our own experiences and tacit knowing or embodied know-how, and contribute to knowledge formation drawing on experience and tacit knowing (experiential knowing). This experiential knowing recognises that knowledge that comes from working within a social situation, a group or an

institution. This kind of knowing reflects self and others within a context. As Reason and Bradbury put it:

> ..such knowing is not a thing, to be discovered or created or stored up in journals, but rather arises in the process of living, in the voices of ordinary people in conversation (Reason and Bradbury 2001:9).

We make initial representations of what we see and find through presentational knowing. Representational knowing simply provides explanations through identifying patterns and relationships between variables or interpretations of meaning. These may be expressed in different forms such as story or imagery. Using different forms of presentational knowing allows the difference between that which is real or familiar and that which seems unfamiliar or new (Reason 2006). From these we formulate theories (propositional knowing) drawing on concepts and theories, developing alternative theories that challenge existing assumptions and move towards new narratives. Propositional knowing in turn informs our practice as we become skilled in practice (practical knowing). Where propositional knowing is knowing-about-action, practical knowing is knowing-in-action. As Peter Reason puts it 'I can tell you how to ride a bicycle and describe bicycle riding in terms of its synamic mechanics, but this is not the same as riding a bicycle' (Reason 2006:196-197).

We test our claims to knowledge through studying practice and challenging behaviours such as consensus collusion and untested assumptions, drawing on Argyris's (2006) ladder of inference, and Torbert's action inquiry (Taylor et al. 2007). Chandler and Torbert (2003) stress the importance of attending to the moment to moment in our interactions and encounters so as to penetrate the interplay of different ways of knowing that each of us engages in all the time. Many ways of knowing or extended epistemology (Reason and Heron 2008) make explicit the interdependency among experiential, presentational, propositional and practical knowing.

3. A participative and democratic process
People have a right to have a say in decisions that affect them and which make claims on knowledge about them and is viewed as a human right by Heron (1996). Feminists and action researchers alike have problematised the notion of involvement and participation in our inquiry processes. Opie (1992b) refers to appropriation drawing on the ideas of the humanist Edward Said and his work on

orientalism (2003). Appropriation refers to social relations in terms of power. Where her focus is on research inquiry, Edward Said argued the importance of appropriation in textual representation. Applying these arguments to healthcare, we engage in the process of 'othering' in our relations within healthcare. A dominant group will sustain a particular representation or view of the other as part of a framing process. This is reflected in nursing's claims about advocacy wherein nurses may perceive patients to need nurses to advocate for them in a particular way. As nurses write about this within our professional journals we reference each other and the framing process becomes interlocking and self-fulfilling. Our writing gains referential power within the world of nursing. A textual authority on nurses as advocates for patients is constituted and nursing scholarship perpetuates that which is framed by referring to authorities within nursing scholarship to support their view.

The idea of participation in action research draws us towards challenging our most fundamental notions of patient centeredness as it is understood within a practice development context and how this informs nursing scholarship. Action research would ask us not whether or not we give voice to our patients but rather, how we give voice to them.

4. Emergent process

Inquiries therefore, evolve over time rather than working to pre-designed protocols. Thus choices made in the early stages of inquiry process may be quite different to those made later. The depth and scope of levels of participation, reflection and action may develop and grow over time and perhaps altering the direction and aims of the inquiry itself.

Principles in Relation to Pragmatism

The relationship between these principles and pragmatism is not without some problems. Rorty questioned the idea of action research seeking its own grand narrative or methodology. For him, any such grand design represents the antithesis of his pragmatism (Reason 2003b). Thus, any notion of 'expertise' in participation is removing what for Rorty is simply social democracy being allowed to unfold. Similarly, Rorty expressed opposition to the idea of extending ways of knowing as this, also, points to a view of knowledge as something to be discovered 'out there' (Reason 2003b). Nevertheless, Rorty's points, as Reason argues, place further importance on the value of the conversation between

pragmatism and action research (Reason 2003b). In particular, pragmatism cautions against action research presenting itself as another social science research method, developing grand claims and their underlying assumptions. Thus, our approach in action research to the claims we make in our articulation of our research orientation and underpinning assumptions, and our inquiry process in action must be taken in a questioning way or as an on-going attitude of inquiry. As Reason (2006) argues in a later paper (Reason 2006), an inquiry process presents us in all its stages with an unfolding series of choices that we need to approach in a reflexive manner and articulate clearly to the observer/reader.

For Reason, the purpose of action research inquiry warrants further examination in terms of distinguishing between what we know we want and what is good. Thus action research is 'not just about solving the immediate problem but of articulating the subtle ways in which the inquiry is affecting the world' (Reason 2006:194). Practice development like the practice of action research is not a value free process, there are questions regarding values, morals and ethics of inquiries. Since there are no absolutes, choices are matters of compromise between competing goods rather than an absolutely right and wrong approach. The point here is that where the quality in action research should render transparent our interrogation of the purposes of an inquiry and the moral choices made, so too the quality in our development of practice should make explicit the short and long term purposes of our work. Interrogating our purposes in this way should help articulate conflicts and congruence between the consequences of immediate responses to competing calls and our longer term view of our practice.

First, Second and Third Forms of Inquiry

Action research projects have been described as first, second or third person inquires (Coghlan and Brannick 2005; Reason and Bradbury 2008b). First person action research addresses the researcher's inward inquiry, mindfulness and reflection. Second person inquiry addresses inquiry with others while third person inquiry looks to extend outwards from single case/project inquiries towards creating greater impact, for example through building or connecting with networks of inquiry.

First person inquiry brings to the fore, the individual researcher's own engagement with the world and its impact on others. There is what Coghlan and Brannick (2010) refer to as intended self study of the researcher in action. Judi

Marshall describes first person inquiry as 'both an approach to inquiry in itself – as I research my own practice – and, in my view, foundational to overtly collaborative forms of research' (Marshall 2004:309). In this way, in first person inquiry the researcher may be mindful of her engagement with issues such as power. Marshall (2006) describes her first person inquiry as consisting of 3 elements: 1) holding together inner and outer arcs of attention as in attending to one's own perceiving and assumptions (inner arc), and questioning or testing possibly with others one's assumptions, sense-making or ideas; 2) attending to cycles of action and reflection, and 3) being both active and receptive for example, in testing one's own sense-making.

Second person inquiry 'addresses our ability to inquiry face to face with others into issues of mutual concern' (Reason and Bradbury 2008a) focusing on the development of interpersonal dialogue and applying planning, action and reflection cycles to the process. Third person inquiry, in seeking to develop networks of inquiry, does not necessarily involve face to face inquiry in all instances. Rather, the focus is on engaging a wider audience.   None the less, the planning, action and reflection cycles remain a focus.

Many projects involve all 3 forms of inquiry (Chandler and Torbert 2003; Marshall 2004; Reason and Bradbury 2006, 2008a) reflecting the argument that 'the most compelling and enduring kind of action research will engage all 3 strategies' (Reason and Bradbury 2008a:6). Drawing on earlier work by Argyris (1970) on types of intervention, David Coghlan (2003) makes a further distinction between forms of inquiry in action research in what he terms mechanistic and organistically oriented action research. Mechanistic-oriented action research encompasses traditional action research including participatory action research that leads to pragmatic outcomes such as the management of change or addressing a particular problem. Action research cycles are applied to address the predefined problem and already articulated desired outcome. In this instance, the researcher's first person inquiry focuses on her skill capacity to work with the group while second person inquiry focuses on actualizing the change.

Organistic-oriented action research takes the primary focus away from practical outcomes and more on to what is being learned, and how the process of inquiry challenges values and ways of working' (Coghlan 2003:455). In this instance, inquiring into ways of thinking, assumptions and sense-making are to the fore. Thus, 'Organistic-oriented action research is more complex and subversive

because it is guided by a primary aspiration to study the inquiry process and help it transform through increasingly intensive learning in action' (Coghlan 2003:452).

While Coghlan's focus here is on insider research, nevertheless, his mechanistic and organistic distinctions point to the importance of attending to subtleties of first and second person inquiries. For second person inquiries, traditional and often rigid distinctions between instrumental and transformational or emancipatory inquiries (Hart and Bond 1995), and single and double loop learning (Clarke and Wilcockson 2001) give way to a more nuanced distinction. A mechanistic approach is instrumental but the resultant change may reflect more what Argyris (2006) refers to as double loop learning. Neither is organistic-oriented action research 'transformational in the sense of pre-identifying a transformation' (Coghlan 2003:455). It is what is sought at the outset of an inquiry that distinguishes mechanistic from organistic.

For Coghlan, even the most mechanistic oriented of inquiries include first person inquiry but with a focus on skills base. Thus, he brings to the fore the importance of first person inquiry in *all* action research inquiries irrespective of their foci. Additionally, the relationship between first and second person inquiry is brought into sharp relief. It would appear difficult if not impossible to justify an organistic oriented second person inquiry without a similar focus on first person inquiry. Put simply, the researcher's inquiry into her own engagement with the process is an integral part of the whole inquiry process. Conversely, in a mechanistic oriented inquiry, the researcher can extend her own first person inquiry beyond examining her skill base.

Summary

In summary, our nursing practice development may be understood as how we respond to different calls from the system, profession, patient and different but often competing societal and healthcare discourses. Responding to these calls while attending to knowledge re/presentation informed the inquiry orientation of this project. Pragmatism offered a way of viewing our responding as keeping the conversation going with these different calls while also engaging with the inequity among competing discourses. The idea of Bildung with its rich and ancient history added to this conversation the importance of recognising and engaging with *Other* where *Other* may be found in different calls, discourses, and points of

view. Significantly, Bildung renders important a historical consciousness, that is to say, awareness of the embeddedness of our history of nursing practice, and societal and healthcare discourses that permeate our practice. Action research offers a broad set of principles and inquiry framework that can make explicit the values and choices that underpin our practice development conversation. First person inquiry elements provided an important balance to a second person mechanistic oriented inquiry aimed at practical outcomes.

Chapter Six Framing the Inquiry

Introduction

The inquiry question was how might palliative COPD care be understood and addressed through developing respiratory nursing practice. This informed an overall aim to develop respiratory nursing practice to address palliative care needs of patients attending an acute hospital with 3 objectives namely:

1. Identify palliative care needs among patients attending hospital for COPD management in an Irish healthcare context;

2. Develop an understanding of how palliative COPD care might be construed by nursing within an acute hospital context;

3. Identify how unmet needs can be in the acute hospital context.

These gave way to a two-phased action research project plan (Figure 6.1) based in a general hospital in Ireland. The project was informed by my understanding of practice development as conversing with and responding to different calls from System, nursing, patients' illness experiences and shifting discourses in an acute hospital context. Action research represents a broad church or family of approaches and the purpose of this chapter is to position or frame the inquiry drawing on the core principles of action research in general and co-operative inquiry specifically.

Phase one focused on identifying palliative care needs of patients with COPD and was informed by mixed methods research design to examine health status and illness experiences of patients with advanced COPD. Findings from phase one informed the second phase which was a co-operative inquiry involving palliative and respiratory nurses (Figure 6.1).

The co-operative inquiry (CI) sought to develop an understanding of palliative COPD care in an acute hospital environment with reference to the 3 levels of palliative care (Department of Health & Children 2001). This centred on firstly making sense of respiratory nursing care in the context of the findings from phase one and care practice experiences of the group. Secondly, the CI centred on articulating how palliative COPD care might be understood in the hospital environment and with reference to ward-based, and specialist respiratory and

palliative nursing care. In an effort to address the limitations of an open-boundary inquiry, participants from phase one were invited to a meeting with members of the CI group to discuss the project, findings to date and themes emerging from the CI and possible practice development strategies to address needs.

Figure 6.1: Initial Project Structure
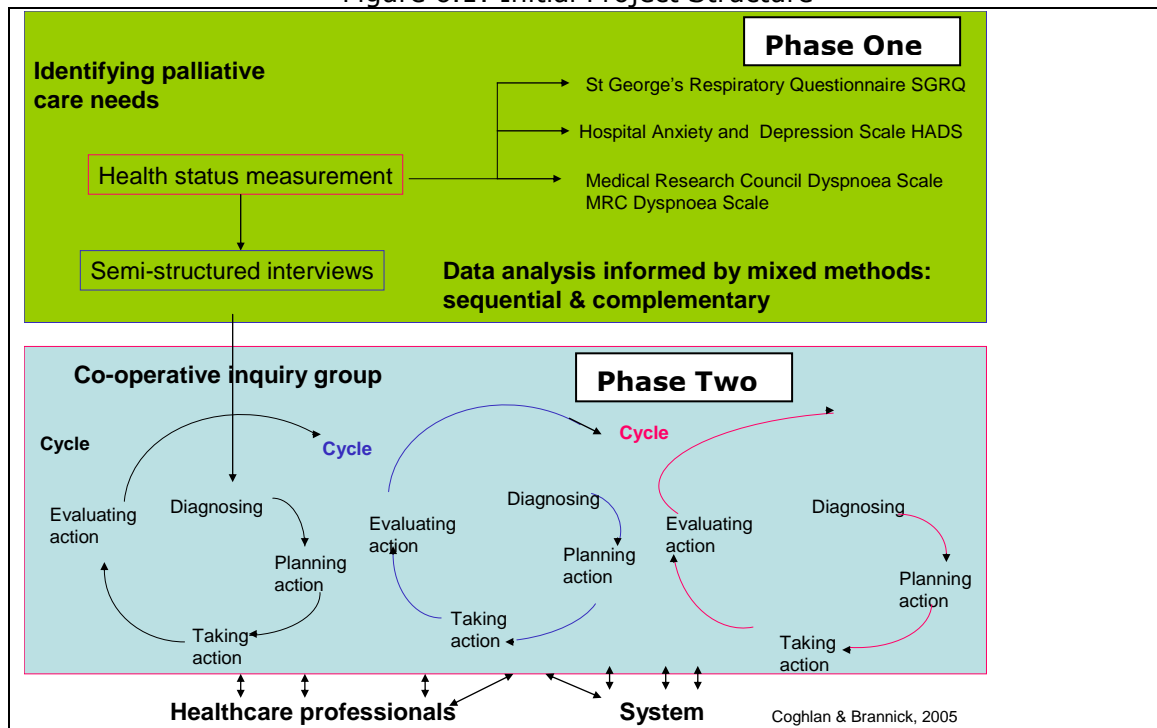
In this chapter, I begin with the overarching action research framework and the setting in section one. I follow this with gaining access and issues of positionality. Following this, I detail the theory informing inquiry methods in each phase. In section two, I detail the methods applied in both phases including participant recruitment, interviews in phase one, co-operative inquiry in phase two, ethical considerations and, inquiry quality and rigour. The planning of the project was itself, informed by first, second and third person inquiry. The original structure as shown in Figure 6.1 became less clearly bounded following a pilot of phase one interviews (Figure 6.2). Thus, framing the inquiry and ultimately arriving at the chosen methods was part of the action research story or as Herr and Anderson (2005) put it: designing the plane while flying it. I have struggled through different drafts of this chapter in an effort to reconcile the usual more logical format of presenting methods then findings, with reflecting the framing process as an iterative one and part of the overall story. In my final attempt here, I have adapted a technique used by one of my supervisors, David Coghlan, in which the process informing the next step is presented in a separate box. This,

I hope, will serve to both present the framing and methods while telling the story behind the planning process.

Figure 6.2: Phase One Planning Process Post Pilot of Structured Interviews

Cycle Two

Cycle 1

Review of design

Participants asserting control over structured interview responses

Collaborating with site

Participants in greater control; Rich narratives during health status measurement

Diagnosing: issues relating to power and knowledge re/presentation

Pilot plan

Allow interviews to unfold with focus on co-generation

Pilot study

More fluidity re boundary between structured and semi-structured Interviews

Cycle 3

Diagnosing: Recruitment slow; loss of original site collaborator;

Review focus on generalisability; optimise awareness about the study but balance with participant desire for qualitative dimension within structured interviews

Increase promotion; develop links with new R-CNS

Dissemination of leaflets: attend hospital OPD clinics

Coghlan & Brannick, 2005

Section One

Action Research Framework

Action research focuses on particular articulated problems involving iterative cycles of constructing, planning, acting, and evaluating that informs further constructing[8] and so on (Coghlan and Brannick 2010). Through these cycles, action research generates knowledge seeking to 'forge a more direct link between intellectual knowledge and moment to moment personal and social action' (Reason 2006:188). Coghlan and Brannick (2010) refer to two overarching cycles. The first is the project's overall cycle, in this case that of developing respiratory nursing practice to address palliative care needs. A second cycle is a reflection cycle which focuses on the action research itself. This second cycle forms the meta cycle, consisting of content, process, and premise.

[8] In their most recent edition Coghlan and Brannick have replaced the term 'diagnosis' with 'constructing' to reflect the view that organizations are socially co-constructed and comprise multiple meanings. Thus there is no single truth to be diagnosed. See Coghlan D. and Brannick T. (2010) *Doing Action Research in Your Own Organization*. 3rd edn. Sage, Los Angeles ; London.

The content of what is constructed, planned, acted on and evaluated is studied and evaluated. The process of how constructing is undertaken, how action planning flows from that constructing and is conducted, how actions follow and are an implementation of the stated plans and how evaluation is conducted are critical foci for inquiry. There is also premise reflection, which is inquiry into the unstated, and often non-conscious, underlying assumptions which govern attitude and behaviour, such as might be embedded in language (Coghlan and Brannick 2010:12-13) (italics in original).

Figure 6.3: Meta Cycle of the Inquiry as a Whole
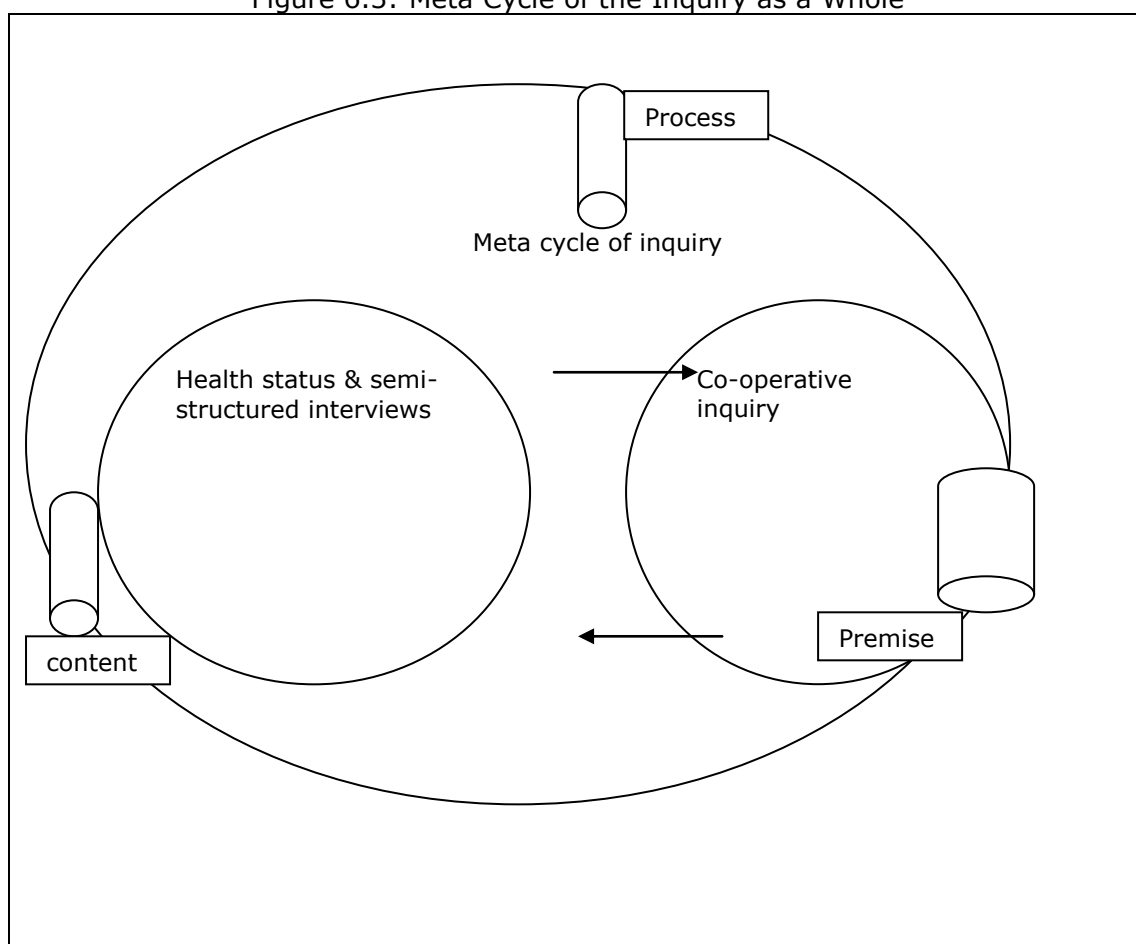
Adapted from Coghlan and Brannick (2010)

Put simply, the meta cycle focuses on inquiry into the action research project and is therefore the focus of an action research thesis. The framework for this project addressed both the inquiry into palliative COPD care and the inquiry into that inquiry (Figure 6.3). Both phases of this project were underscored by first person and second person inquiry, and attention to temporality: our relationship with the

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past, being present in the moment (Chandler and Torbert 2003) and oriented towards a mutually agreed understanding of care needs.

Setting the Scene

Research site

This project was hospital based in an acute general hospital serving a combined rural and urban population of greater than 185,000. The hospital is in a large town with a population of 20,000 (Ireland. Central Statistics Office. 2007). Of the 721 whole time equivalent staff, 250 are nursing staff[9]. Of the 6 consultant-led medical specialist services, one consultant has a particular interest in respiratory medicine and COPD specifically. CNS specialist fields cover 6 services: respiratory, cardiac rehabilitation, palliative, diabetes, oncology and tissue viability. Of the 8 units including coronary and intensive care, one has a particular focus on respiratory care and high dependency with 31 beds. The outpatient services dealt with almost 35,000 attendances. The hospital has a busy Accident and Emergency department with over 27,000 presentations in 2007. Of the admissions to the hospital in 2007, 91% came through Accident and Emergency[10]. Typically, all those with acute exacerbations of COPD are admitted through Accident and Emergency.

Gaining Access

Through the Irish respiratory nurses association, in the two years leading up to this project, I was one of a small cohort that had tried to generate debate in palliative care in COPD. A respiratory CNS (Ann)[11] from the research site, had been a long time member of the association. The impetus for my initial approach to her regarding her possible interest in this project was driven by my awareness of our shared interest in developing palliative COPD care. A protracted lead in period followed during which I developed a proposal leading up to a grant application and following that application for ethics approval. During this time, I had informal meetings with the respiratory CNS and her CNS colleague (Beth) and subsequently with the respiratory consultant. I also met with the Director of Nursing before formally seeking access and ethical approval. The lead in period

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[9] http://www.hse.ie/eng/HSE_FactFile/ Accessed 06th March 2009
[10] http://www.hse.ie/eng/HSE_FactFile/ Accessed 06th March 2009

[11] The CI group members were assigned names with initials in alphabetical order according to their appearance in the project.

was intended to ensure that the ultimate proposal and design was co-developed. The overall design and specific instruments used in phase one were a direct consequence of this early process. The health status measures were chosen by Ann on the basis of their use in respiratory research and pulmonary rehabilitation in the hospital. Comparisons could therefore be usefully made between the phase one findings and those from other respiratory research undertaken by the wider team.

Reflection on use of health status measurement

The team's interest in health status measurement challenged my own ideas about participation in terms of giving voice to patient participants. However, the idea of an interview rather than a self-administered questionnaire approach offered scope for participants to articulate comments about the questions. I subsequently contacted the SGRQ research team and planned 5 pilot structured interviews with the chosen questionnaires. These were followed at a later date by semi-structured interviews with the same participants.

Positionality

Drawing on Herr and Anderson's (2005) arguments on positionality, I was acutely aware of mine being complex and multi-dimensional. My academic background meant that my future co-inquirers would include former students and my current full time researcher status set me apart from those engaged in clinical care. My profile within the respiratory nurses' association reflected my founder member and chairperson role. Conversely, my clinical respiratory background was in primary care; I was a 'low-tech' nurse relative to those working in acute care. The pace and intensity of acute care had changed inexorably bringing a harsh reality check to the rhetoric of nurse as advocate. In short, my positionality might have been construed as a mix of expert and lay background; referent power and naivety; and positional power and marginalised place (Herr and Anderson 2005). I was an outsider but also an insider in terms of a shared disquiet about the plight of our patients with advanced COPD, the development of respiratory nursing practice, and struggle to forge a nursing role within a respiratory team. My first person inquiry and the idea of *Other* in positionality was the basis for a mindfulness of and negotiation through these complex layers of positionality and are addressed later.

Phase One

Identifying Palliative Care Needs

The purpose of phase one was to identify the palliative care needs of patients with advanced COPD and who were patients attending the hospital research site. This was intended to inform the development of an understanding of palliative care in COPD that would reflect the illness experiences of patients while also providing evidence that would engage competing discourses within the healthcare environment and ultimately support the CI process later.

Reflection on narratives arising from health status measurement interviews

In the pilot interviews participants responded to closed questions with narrative accounts of their illness experiences. These accounts were repeated in the semi-structured interviews. The narratives that emerged from the 'closed' questions shifted the interview process from one directed and controlled by me to a more participative process. This called for a mindfulness of shifting power and, illness and care experiences being raised by participants. The narrative accounts also raised questions about the purpose of the semi-structured interviews and my own pre-conceived notions of structured and semi-structured interviews. I subsequently presented to my PhD colleagues and supervisors my review of the pilot process and reading arising from this. I proposed an approach to the structured interviews that would involve strict adherence to the wording of the questions[12] but allowing participants to respond and/or challenge the questions as they wished. I saw the narrative accounts arising from the questions as an integral part of the structured interviews.

There were 3 strands to phase 1 namely:
1. health status measurement;
2. qualitatively exploring illness experiences through capturing qualitative data from expanded responses given to the structured questions of the health status instruments, and a round of follow-up semi-structured interviews determined on a case by case basis;
3. first person inquiry.

The purpose of the health status measurement was two-fold: 1) to provide one element of an overall expanded view of the impact of living with COPD (Kleinman

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[12] I am grateful to the SGRQ research team for advice in relation to assisting participants with completion of the questionnaires.

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1988); 2) to provide information in a format that would be of benefit to the CI group when seeking support from the worlds of management and medicine. The qualitative dimension was developed in an effort to examine the impact of COPD on day to day living, relationships, and social interaction, in addition to experiences with healthcare and healthcare professionals. The decision to seek a semi-structured interview was influenced by the degree of breathlessness and frailty of the individual participants. Importantly, we aimed to bring the voices of patients into the CI bringing their COPD life experiences and their assessment of care needs. Drawing on Chandler and Torbert's (2003) focus on first person inquiry and 'presencing', I sought an interview approach that allowed stories to unfold over the course of the health status measurement. In other words, when structured questions from the health status measurement instruments prompted narrative accounts of experiences these were welcomed and woven into a conversation about everyday life with COPD.

Health status Measurement

Instruments

In her introduction to HRQoL instruments in COPD Elizabeth Ståhl (2008:7) refers to the importance of 'reducing the personal and social burden of disease by improving subjects' symptoms, functional status and health-related quality of life' as important goals. Thus, for her, HRQoL represents the illness experience that lies beyond the symptoms and functional status that are assessed in the SGRQ and CRQ, and also using diagnostic aids such as spirometry. Notwithstanding the controversy as to how healthcare needs might be understood (Asadi-Lari *et al.* 2004; Habraken *et al.* 2007) and how patients evaluate care (Staniszewska and Henderson 2004), health status measures have become a key constituent of respiratory studies. Difficulties with the notions of seeking objectivity and confirmability (Jones 2001a) in COPD research must be acknowledged. However, since this project was informed by the idea of opening conversation with different perspectives, the issue is less one of rejecting outright health status measurement and more seeking to find ways of conversing with medical and management disease oriented, and patients' illness oriented needs assessment. The choice of health status instruments was determined by their COPD specificity and relevance to information about care needs. For the research site, the SGQR, HADS and MRC (Appendices 1-3) dyspnoea scale were the most appropriate allowing scoring comparisons to be made with those recorded in the hospital's

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pulmonary rehabilitation programme, and national and international COPD research.

Qualitative Dimension

The qualitative dimension was intended to explore with participants how life was for them and to seek to move beyond the focus on symptom burden and physical impact in the structured interviews. My aim was to gain an understanding of the participants' points of view; to open time and space for participants to share with me their thoughts on living with COPD that were not addressed in the structured interview process including their experiences of healthcare, social interaction and changes in their lives as a consequence of advanced COPD. In this, I was seeking 1) greater insight into participants' illness experiences, and 2) a way of giving voice to participants in the inquiry process. The *giving voice* to participants had a particular bearing on the interview process given that patient-participants were not members of the co-operative inquiry group in phase two.

In planning phase one, I began with certain assumptions that were informed by firstly, theory concerning illness narratives (Kleinman 1988; Frank 1997, 2002a, 2004; Charon 2006), and secondly, issues concerning participation and power from both feminist and action research perspectives (Opie 1992b; Heron 1996; Kvale 1996; Wengraf 2001; Knapik 2006; Kvale 2006; Reason 2006).

Lessons from illness narratives

Lessons from illness narrative literature pointed to the importance of getting beyond the anticipated focus on symptom burden to explore from the participants' perspectives the issues that were important to them. In this, Arthur Kleinman's (1988) illness meaning as that related to symptom, lifeworld, culture and explanatory model, influenced a broader exploration of the illness experience. Addressing these different aspects of illness meaning in the interview process seemed important to how we might later construe palliative care. In her approach to patient consultation, Rita Charon's (2006) focus on what her patient sees as important to his life at that point, demonstrates the inter-relationship of different illness meanings.

Issues Concerning Power

Wengraf's (2001) concern regarding participants presenting 'official responses' that bear little relation to their different realities had particular resonance for this inquiry. The portrayal of COPD illness burden in terms of hospitalization, exacerbations, symptom focus, lung function tests in COPD research in the Irish context reflects particular *re*-presentation, values and positions of researchers. The complexity and contentiousness of claims about appropriation within the interview process are illustrated by Opie (1992b). The core of her argument is that in practice oriented research, the focus may be on exposing marginalisation but this may in turn be done with little acknowledgement or examination of the strategic location of the researcher or context of agents, interests and contentions:

> There is a pretence of equality where the researched are understood to have some knowledge not yet possessed/appropriated by the researcher…The researcher is consistently privileged, particularly through her location in a more ideologically correct position (Opie 1992b:66).

Opie's appropriation combined with Wengraf's concerns about official responses raises issues concerning the importance of creating distance from the conventional wisdom about COPD illness burden and space to explore the more 'unofficial' realities aired by participants. Allowing these 'unofficial' realities to surface seemed important to better inform our construing of palliative care in the 2nd phase of the project.

Giving Voice to the Participants

Creating a space to enable participants to assert their own stamp on the overall inquiry process was important not just in terms of my response to potential power inequities based on my, as academic/HCP relationship with participants as patients. Rather, in planning the interviews, I sought an engagement that was less consultative and more co-generative in order to allow participants a greater ownership of and control over the inquiry process. Thus, the interviews needed to address the basic standpoint underpinning this project and in line with action research principles namely that participation of all participants be as full as possible particularly for those who are targeted by the project (Heron 1996;

Reason and Bradbury 2008a). Nevertheless, the patent challenges in relation to power remained to the fore in the interview planning. I, as researcher, by virtue of my background and institutional support was seeking to converse with participants, who were also patients, experiencing significant disability, isolation and reliance on the institution with which I was identified.

An Anthropological and Historical Framework

Wengraff (2001) places at the centre of his interview model, the relationship and communication between the interviewer and informant. He views this as constantly changing 'involving constant *emotion* and constant *evaluation* on both sides' (Wengraf 2001:42) (Italics in original). The nature of the communicative event may differ considerably for the researcher and informant. The former is influenced by the interview as a research event and while the latter may be influenced by his perceptions of the researcher and the subject, and the manner in which he was invited to participate. The interview takes place within a given cultural and social setting that in turn has its own historically evolving setting and perceived norms. The social setting for the interview includes factors as varied as type and time of day, location, and social constraints. The interview interaction is illustrated as a see-saw 'which represents the *evolving power-balance* between those involved' (Wengraf 2001:42) (Italics in original). This evolving power balance is mediated by the histories and social roles of those engaged in the interview process.

The power balance at the start of the interview interaction may be quite different to that at the end of the process as power resources are mobilised and shift throughout. Importantly, the shifting power-balance is not necessarily on a win/lose basis. Rather 'both interviewer and interviewee may struggle for power within an interview and both may emerge from the interview more powerful than when they started' (Wengraf 2001:42). The social roles and history dimension to the interview interaction recognises that we each bring to the process our individual personal histories. These will influence our expectations, strategies and 'future histories'. The strategic intent that all bring to the interview interaction will influence the individual strategies for interview interaction. These may emerge as particular researcher and informant agendas, presentation of self and control. Significantly, for Wengraff (2001:158-160) the presence of anxiety and the notion of 'defended anxious subject' heightens the need to cater for and monitor its presence in the interview process.

Addressing Issues of Power in Interview Process

The use of survey methods and closed questions is criticized by action and feminist researchers for its potential to dis-empower. Political participation in action research conflicts with the idea of using pre-designed instruments, the design and use of which corresponds with treating people as objects (Heron 1996). Feminist researchers eschew survey research for similar reasons though there is a dearth of debate within the literature on feminist influences on survey methods and interview data (DeVault and Gross 2007). Reid and Frisby (2006) argue that despite their differences, feminist research and action research share mutual goals concerned with addressing power and inequities. Much of the feminist comment appears to centre on issues of uniformity in survey design and questions. The possibility of respondents as participants exerting their own influence on shaping the conversation that develops from responses seems largely ignored within the feminist or action research literature.

Feminist and action research have grappled with the problems of power within the interview process arguing that the detached relationship associated with objectivity 'exercises control and power over the participants and can run the risk of exploitation and abuse' (Hesse-Biber and Piatelli 2007:247). In terms of power and knowledge in re/presentation, values and positions taken are brought into sharp relief by feminist researchers (Opie 1992a; Harrison *et al.* 2001; Hiller and DiLuzio 2004; Knapik 2006). Self-completed and most interviewer administered health status measurement instruments represent knowledge re/presentation and the exertion of control over patients whose voices are already silenced by the dominant disease oriented models of care (Kleinman 1988; Frank 2002a). However, while challenging disease oriented models of care, Kleinman, nonetheless, includes health status instruments in his ethnographic model of care. His point seems to be that these instruments may be useful as *part* of a wider more open-ended assessment in his attempt to widen rather than narrow his dialogue with his patient and medical team.

The silencing effects of typical survey research attracts opposition from action research theorists (Heron 1996; Reason and Bradbury 2008b). However, for Chandler and Torbert (2003), Marshall (1999) and Marshall and Reason (2007), addressing this silencing is more complex than simply rejecting particular data collection methods and opting for others. These authors have in common what

Marshall and Reason name an attitude of inquiry in which the inquirer is present in the moment, questioning and testing her assumptions and sense-making, being open to contradictions and engaging with the emergent nature of the research process. It is this attitude of inquiry that brings a first person inquiry dimension to the interview process and seeks to give greater voice to others who are silenced through Opie's (1992b) knowledge re/presentation and Frank's (2001) ruling relations across different data collection methods.

Qualitative Dimension to Health Status Measurement

Bringing this notion of attitude of inquiry to bear in the initial pilot interviews promised greater mutuality in the interview process. Participants asserted their own stamp on the process by expanding the typically closed dichotomous and polytomous questions of health status measurement by stories concerning their individual experiences. Typically, a true false question of whether or not *getting washed or dressed* makes one feel breathless led to a narrative account about morning routine, fatigue, dependence/independence and creative interventions to control symptoms. So, in essence the structured questions opened a space for people to tell their story about what each of these questions meant to their unique illness experience. By choosing to enter into a conversation with the participants about these narratives, it became possible to both 1) gather the data needed to present to management; 2) develop a greater insight into the stories behind everyday life; 3) open a space for participants to assert control over the interview process and 4) turn full circle the knowledge re/presentation of health status. Rather than consigning these expanded stories to footnotes in the inquiry, they became a central part of analysis. Significantly, these expanded responses spanned lifeworld, cultural and explanatory models of meaning that I was aiming to explore in the semi-structured interviews. The data collected during these expanded interviews was repeated in subsequent semi-structured interviews such that little if any new information was shared.

Tom Wengraff's (2001) anthropological-historical conceptual framework places emphasis on the real-life context of and power mediation within interviews and provided a framework my interview approach. My own respiratory nursing background provided potentially positive and negative influencing factors to the interview interaction. They were positive in the sense that participants could rely on my clinical knowledge for understanding their breathlessness and the brittleness of their condition. Negative factors included my association with the

hospital and consequent reluctance on the part of the participants to articulate their criticisms of care. The interviews were intended to follow a conversation format holding to the view that 'interviews are *inherently interactional events*, that both speakers mutually monitor each other's talk (and gestures), that talk is locally and collaboratively produced' (Rapley 2007:16) (Italics in original). In this way, I was aiming towards an interactive space that would allow us (researcher and informants as joint participants) to acknowledge and work with our shared and different histories. I was drawing on the view that interviews are 'social encounters where speakers collaborate in producing retrospective (and prospective) *accounts* or *versions* of their past and (or future) actions, experiences, feelings and thoughts' (Rapley 2007:16) (Italics in original).

Phase Two

The primary aim of the co-operative inquiry (CI) was to develop an understanding of palliative COPD care in an acute hospital environment with reference to the 3 levels of palliative care (Department of Health & Children 2001). A CI typically involves people with a common interest coming together to share knowledge e.g. respiratory and palliative, and in so doing extending knowledge horizons in this case palliative COPD care. The 3 levels of palliative care highlight the importance of embedding palliative care principles in respiratory nursing practice while also developing ties between palliative and respiratory care teams. The CI gave scope to develop an understanding of a palliative care approach that was oriented towards the specific issues of COPD patients and their care in an acute environment.

Cooperative Inquiry (CI)

Co-operative inquiry (CI) is a form of action research that is aimed at generating knowledge about human experience through action and joint reflection. The defining features of co-operative inquiry include (Heron 1996; Heron and Reason 2001):

- As full involvement as possible of all subjects as co-researchers in all aspects of the research process in which participation is epistemic and political
- Intentional interplay of reflection, making sense of experience, experience and action

- Explicit attention to the validity of the inquiry and its findings through a mindfulness or heightened awareness of the process using inquiry cycles of action and reflection
- Extended epistemology integrating experiential knowing (through meeting and encounter), presentational knowing (through use of aesthetics and expression), propositional knowing (through words and concepts) and practical knowing (through practical skills). These different ways of knowing are 'extended epistemology' because they go beyond the propositional or conceptual knowledge that is privileged in academia.
- Skills required for an all-purpose experiential inquiry including discernment, attentiveness, emotional competence, ability to bracket and reframe concepts
- Inquiry can be both informative about and transformative of any aspect of the human condition
- Primacy is given to transformative inquiries that involve action.
- Access to the full range of human sensibilities for the inquiry.

CI Elements

Co-operative inquiry encompasses participation in both the epistemic and political sense (Heron 1996). In epistemic participation, propositions about human experience are grounded in the co-researchers' experience. We cannot step outside the human condition to study it (Heron 1996). Therefore, we must study it through our own embodiment and jointly with others who are similarly engaged. Epistemic participation thus addresses different forms of knowing and also the strategic intent that all bring to an inquiry process (Reason 2003b). In political participation, action researchers place importance on the right of participants to have a say in how knowledge is generated about them and this includes having a say in the design of research that seeks to generate such knowledge (Heron 1996). Political participation addresses disempowerment, silencing and misrepresentation by researchers' values that some argue are implicit in other research designs. There is clearly a tension between this espoused political participation and the use of traditional data collection methods to generate data about people who are targeted by action researchers as is often the case in action research in healthcare.

Co-operative inquiry is associated with professional development (Reason 1999) including that within nursing[13]. There are criticisms about action research in nursing on the basis that issues are not addressed in relation to authorship and passivity of patients and carers despite high levels of participation among the action researchers (Munn-Giddings *et al.* 2008). In CI, the principles of participation and co-generation of knowledge seek to address such criticisms. In addition those outlined above, this research recognized two basic principles that further supported a CI approach. Firstly, those with advanced COPD and their carers have developed their own knowledge and expertise for living with the condition. The principles of CI address the importance of integrating this knowledge and expertise. Secondly, the development of an understanding about what palliative nursing care might mean in COPD rested on a bringing together of those nurses with palliative and respiratory care knowledge. Furthermore, in-patient COPD and respiratory CNS care in COPD differ in approach: the former focuses on ward-based acute care while the latter seeks to address care in between exacerbations and their prevention. Thus, a CI approach enabled the coming together of nurses from palliative and respiratory care to jointly explore the palliative needs of patients with advanced COPD.

Addressing Open Boundary Issues

Heron (1996) distinguishes between closed and open boundary inquiries. The former are concerned with what is happening within the group. A closed boundary inquiry does not address interaction between the group and others in world outside. Open boundary inquiries, on the other hand, include as part of the inquiry actions phases, interaction between the group and others outside the group. This research is an open boundary inquiry with the co-researchers inquiring into their practice with patients. Open boundary inquiries are fraught with challenges to the integrity of a cooperative inquiry since decisions must be made regarding data collection from those outside the inquiry group but who are not part of the inquiry process:

> If no data is generated, a valuable source of relevant feedback and information is ignored. If the data is generated, but the people by whom it is generated remain outside the inquiry and have no say in

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[13] See, for example,
http://people.bath.ac.uk/mnspwr/Participationinhumaninquiry/CHAP5.htm

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how it is explained and used, then a norm of co-operative inquiry is infringed (Heron 1996:44).

As part of our struggle with the open bounded nature of our inquiry, we sought a meeting with a patient group comprised of participants in phase one. The purpose of the meeting was to explore the project process and findings to date, and ideas emerging from it. In addition, throughout the lifetime of the inquiry a 'patient expert' offered advice and comment on the inquiry process and emerging themes. The interventions that emerged from the CI focused on developing a greater partnership approach to care and indirectly brought the voice of the patient to the inquiry.

Section Two Methods

Phase One

For the purposes of this study, admission to hospital in the previous year on at least one occasion, for treatment of acute exacerbation of COPD was used as a broad indicator for advanced COPD (Kinnunen *et al.* 2007), deteriorating health status (Andenaes *et al.* 2004) and greater risk of readmission (Aimonino *et al.* 2007). We anticipated that this would include patients who met the criteria for stages III and IV of disease severity (Global Initiative for Chronic Obstructive Disease 2008). Since my intention was to assess the illness experience on day to day living, this pointed to the interviews being undertaken in between acute exacerbations and admissions to hospital. For those who were breathless for the first interview and who wished to proceed, I encouraged them not to feel pressured to respond in detail. For these participants, the option of a further interview was intended to relieve any pressure to tell their whole story in one sitting.

The combination of quantitative and qualitative methods was informed by the mixed methods research literature. This mixed methods approach was not intended as an effort at triangulation. This would have been difficult because follow-up semi-structured interviews sometimes took place some weeks later possibly after an acute exacerbation. Rather, the focus was on recognizing different forms of knowing and their resonance, to some extent, with the idea of complementarity in mixed methods (Greene *et al.* 1989). Whilst mixed methods research literature falls well short of the scope of different forms of knowing or other characteristics of action research, the debates concerning the sequencing of

different methods and the value given to each was a useful guide for planning data collection and analysis. In essence, the intention to recognize while also avoid privileging the dominance of health status measurement informed the interview approach incorporating the qualitative dimension in the interviews and an integrative or layered approach to analysis (Greene *et al.* 1989; Lee and Greene 2007).

The interview process included 4 stages: 1) patient sample; 2) recruitment; 3) interviews; 4) data analysis.

Patient Participants

Inclusion and exclusion criteria were defined as follows:

Inclusion Criteria

- Have a diagnosis of COPD
- Admitted in the previous year for treatment of acute exacerbation
- Understand the purpose
- Agree to participate

Exclusion criteria:

- Required hospitalisation in the past year for reasons other than COPD
- No COPD diagnosis
- In intensive care unit or acutely ill at the time of selection
- Unable to participate in the interview process
- Do not understand the purpose and process of the research
- Unwilling or unable to participate in the study

A list of potential participants was derived from the Hospital Inpatient Enquiry (HIPE) database[14]. This provides information on COPD activity including admissions and discharges. The number of admissions over a one year period from June 2007 to May 2008 was 317. The list was further screened by gatekeepers and patients whose condition was viewed as too frail or currently unstable or those who were confused and unable to participate or who had died, were excluded. The final number of patients who were invited to participate was 160.

While there has been some debate as to the usefulness of HIPE in research (O'Loughlin *et al.* 2005b, 2005a; Wiley 2005), its usefulness here included the

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[14] http://www.esri.ie/health_information/hipe/

addressing of ethical considerations in accessing patient information. The hospital HIPE staff can provide the details of discharges without the researcher accessing patient records or full details. In practical terms, the HIPE database offered an efficient means of accessing the patient group. Its accuracy was augmented by the involvement of respiratory nurses as gatekeepers who were also familiar with the patients attending the hospital.

Recruitment Process

With the help of gatekeepers, letters of invitation were forwarded to patients and included with each letter was a participant information sheet, consent form for information, a reply slip with my contact details and a stamped addressed envelope (Appendices 4,5,6). On receipt of a reply slip, I arranged to meet with the participant. The date, time and venue were chosen by participants. The day before an interview, I contacted the participant to confirm that s/he was still interested and felt well enough for the interview to go ahead. At the start of the interview, the participant information was revisited, consent form was signed. For the semi-structured follow-up interview, I contacted participants again by letter, repeating the process of recruitment (Appendix 7).

Over the course of phase one, I maintained a presence in the hospital OPD area during the respiratory clinics in order to address any questions patients or their carers might have. This allowed the respiratory CNS's to point me out to patients who expressed an interest in the project during clinic visits or who had questions following receipt of their letters. Patients could then approach me if they wished.

Just 10 interviews were completed following 100 letters of invitation. We anticipated a poor response rate given the overall frailty the patient group, and the volume of information that accompanied the letter of information. While detailed information on participant involvement was important, because of our intention to invite patients back for a group discussion in phase two, this led to a lengthy participant information sheet. We were conscious that the detail could prove off-putting to many frail patients. Following a review of the process by the respiratory nurses involved in gate-keeping, further ethical approval was sought and given for additional steps in the recruitment process. These included dissemination of posters and leaflets by the respiratory CNS in the outpatients department (Appendix 8).

While I had expected a poor response rate to the letters of invitation, this was still very low. I was conscious that just over a month before these letters were distributed, Ann and Beth went on extended leave. Since they would normally have been the first port of call regarding any hospital related queries for the patients I was targeting, it was possible that this was an important factor impacting on the response rate. Ciara, who was transferred from her ward-based work to step into the R-CNS role, was striving to learn the ropes. I was conscious that this project was also new to her and responding to queries was therefore difficult. While she suggested leaflet and poster dissemination, this added further to her work. After 2 months, Ciara was joined by Denise who was also new to the role and the project. A further 60 letters were distributed. Some patients mentioned having received the letters but were unsure about the study. This supported our reasoning that the poor response rate was in part related to Ann and Beth's departures. The added leaflets and poster plus delay in sending the next round of 40 letters was intended to allow time for Ciara and Denise to become established in their roles and familiar with the project.

Data Collection Process

Once participant information and consent procedures were completed, demographic details were requested (Appendix 9). Participants had the choice of self completing the questionnaires or have me read out the questions. The same order of completion was maintained throughout the process namely firstly the SGRC, then the MRC and lastly the HADS. Towards the end of the interview, I invited the participant to comment on the interview process and our discussion, their expectations from the interview, the research inquiry, care needs and any other issues they wished to raise. Venues for interviews were chosen by the participants. Some participants opted to have their carers present during and contributing to the interview. Interviews were recorded; field notes were written up afterwards.

As participants expanded their responses to the closed questions, follow-up clarifying questions were raised before returning to the questionnaire. Over the course of the interviews, I regularly checked with the participants about how they were and if they needed to stop. In those instances where interviews were curtailed because of the participants' frailty and breathlessness, or time constraints, we discussed the option of a follow-up semi-structured interview.

Time constraints usually arose when carers were present and participants were anxious to talk about their illness experiences. Most carers were daughters who had other family commitments such as collecting children from school.

For the semi-structured interviews (Appendix 10), the opening question, *Please can you tell me how life is for you* was intended to invite a long response (Wengraf 2001) and acknowledgement of illness as meaning in terms of lifeworld, culture and explanatory model as well as symptoms (Kleinman 1988). Follow up secondary questions or prompts were intended to explore illness meaning as multi-dimensional and inter-related with current feelings about illness and future, and relationships with family and other significant persons in their lives (lifeworld as meaning); social interaction, experience of healthcare and physical functioning (cultural significance as meaning); living with symptoms, physical functioning capacity and activities of daily living (symptom as meaning); understanding of COPD, illness impact on life and coping mechanisms (explanation and emotion as meaning). The sequence of these prompts was influenced by the response to the opening question and the ensuing conversation. Towards the end of the interviews, I invited participants to comment on what, for them, would be the ideal care. The sequence of this question was intended to allow a response that would be informed by a view of care beyond symptoms.

As a consequence of my being present during the respiratory clinics, most participants saw me following their interviews. In these instances, they called me over to talk about how they had been since we had met previously. This brought a longitudinal dimension to the first phase and field notes. Meeting participants when they arrived at the clinic also opened up conversations about the planning involved in everyday activities when participants spoke about the work involved in getting to the clinic and the cost in terms of breathlessness.

Data Analysis

Data analysis was informed by the mixed methods research literature and specifically a complementarity mixed method study (Greene *et al.* 1989). The idea of complementarity in mixed methods research is to 'measure overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon' (Greene *et al.* 1989:258). This allows the characterization of the use of different methods as akin to peeling layers of an onion. Where mixed methods are commonly linked with the idea of triangulation,

complementarity involves sequential use of qualitative and quantitative methods. Using this idea, a three-staged model for analysis was developed. This involved an integrative approach to data analysis. These stages ran simultaneously and analysis proceeded on an on-going process during phase one data collection.

SPSS and NVivo software packages were employed. Though the number of participants limited quantitative analysis to descriptive statistics, SPSS offered an added advantage in being possible to import into NVivo to allow an integrative analysis. NVivo enables both efficiency and transparency in qualitative analysis. In terms of efficiency, the software offers scope to question the data and pursue avenues of enquiry as propositions and patterns emerge. In terms of transparency, all processes of analysis from coding to querying the data and demonstrating patterns can be tracked and presented in a clear audit trail.

Stage one

A descriptive analysis was undertaken of the data from the SGRQ, HADS and MRC dyspnoea scale. The SGRQ was analysed using the SGRQ calculator presented as an excel spreadsheet. From this, scores were calculated for the 3 domains: symptom, activity and impact. These were then entered to SPSS along with the MRC dyspnoea and HADS scores.

Stage two

The structured and semi-structured interviews were transcribed verbatim and transcripts imported as cases to NVivo 7 and later NVivo version 8. Audio files were uploaded to allow analysis to include aspects such as laughter, pauses, and emotion. Audio files were connected directly to nodes as appropriate. Memos documenting field notes related to each interview were also uploaded to include initial impressions and aspects of interview context including the physical space within which participants were confined most days. Initial broad coding involved reading each transcript while simultaneously listening to the recording. Topics were identified and coded from sources into 3 types of nodes (Table 6.1).

Table 6.1: Nodes Used to Analyse Data

Node Type	Description
Free Nodes	Stand alone repositories for broad thematic coding
Tree Nodes	Parents of related free nodes that are grouped into categories of themes
Case Nodes	Used to create a case file of all data pertaining to an individual participant.

Initial broad coding of the data generated free nodes. The coded data was examined for relationships across other codes (Appendices 11-12). The content of nodes was examined and sub-categories or child and grandchild nodes were generated (Appendix 13). Codes were thus grouped into tree nodes or themes with their sub-themes. Coding queries were used to validate the coding process wherein the data was searched using the text search tool and the relevant coding was examined (Appendix 14). Case nodes grouped files related to each participant (Appendix 15).

The use of questioning and making comparisons were applied as primary tools for analysis (Corbin and Strauss 2008). Asking questions meant probing the data. These included sensitizing and theoretical questions. The responses to the opening question of both the structured (related to how the participant would describe his current health) and semi-structured (tell me what life is like) were often made with a short phrase (e.g. *Terrible* or *A complete disaster*) and followed by a long explanation: *how life was a complete disaster*. Applying sensitizing questions (Corbin and Strauss 2008) to these responses included what were the principle messages that participants wished to convey to me in terms of their agenda for the interview? Examples of early theoretical questions included: what facilitated the isolation process described in interviews and how experiential knowledge and lay support influenced self-management strategies?

Constant comparative analysis was undertaken across each transcript, between transcripts of structured and semi-structured interviews of each individual participant and finally among transcripts of different participants. Similarities, differences and contradictions were sought in this process.

Stage three

The SPSS data was uploaded into NVivo as attribute data of the respective cases. An integrative mixed methods analysis (Greene *et al.* 1989; Lee and Greene 2007) was applied in a stepped or layered approach:

- The descriptive statistics were 'fleshed out' through the coded narratives that emerged from elaborated responses and coded data (Appendix 15)
- Matrix tables were generated intersecting nodes with cases and health status measures (Appendix 16). The dimensions of emergent themes from the

qualitative analysis were explored with reference to health status measures. For example, self care strategies emerged as a theme from the qualitative data. This was further explored in the context of dimensions to restricted capacity to self care and subsequent implications of that. (Appendices 16-17)

- Themes or their dimensions were explored that emerged in the qualitative data e.g. diagnostic event or loss (foregrounding) but not overtly in the health status results (backgrounding) (Appendices 18).

Ethical Considerations in Phase One

The project was granted ethical approval by the Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin and that of the Hospital in which the project was based. Follow up amendments referred to earlier in relation to the recruitment process, were granted approval by both committees.

The normal ethical considerations in respect of research process were applied. The sensitivity was acknowledged of the subject focus of the project as a whole and the patient interviews. The specific ethical considerations of phase 2 are discussed under that heading. In relation to patient interviews, the potential frailty of this patient group was of concern and safeguards were put in place to avoid further illness burden. These are addressed in more detail below.

Sensitivity of the topic

Detailed information sheets (Appendix 5) were distributed to all potential participants following screening by hospital gatekeepers. This information was important in making clear what was meant by advanced COPD namely: necessitating admission to hospital for treatment of acute exacerbation. Hospital-based nurses as gatekeepers were alert to any queries from patients in the respiratory clinic. In addition, key ward-based nurses were aware of the research underway and were alert to any queries.

At the time of interview, the information sheet was revisited and care was taken to allow time for questions to emerge. At the end of the interview, participants were invited to comment or question any issue that arose for them before they gave their written consent. For those who participated in the follow-up semi-structured interviews, the information sheet was again revisited and participants were invited to comment on their experience to date with the process.

Frailty of participants

Patients attending the hospital for treatment of advanced COPD were known to the hospital gatekeepers. This allowed screening of those patients who were at the time of recruitment experiencing worsening symptoms and in hospital. At the time of interview, participants were invited, if they so desired, to have present their carers for the duration of the interview. Eleven participants chose to have carers present. The carers of 8 participants were available in an adjacent room in the event of participants needing assistance. The venue for the individual interviews was determined by the participants and this was intended to ensure they had control over the process, and had, where applicable, their medication and oxygen to hand. My respiratory background enabled ongoing monitoring during the interview process of participants' breathlessness and comfort.

The right to defer the interview was stressed in the research information (Appendices 5 and 6) and at the start of the interview. While several participants rescheduled their interviews because of worsening symptoms, no one sought to defer once the interview had begun. Several spoke of relief at being able to talk about their illness experiences and their frailty.

Other Ethical Considerations

Normal ethical considerations relating to consent and anonymity were applied. Consent forms (Appendix 6) for information purposes were included with the study information in initial letters of invitation. The consent statements were discussed at the time of the interviews and written consent was obtained before each interview. Anonymity was assured and all participants were assigned number identifiers known only to me.

Phase Two

The focus of the CI was on developing an understanding of palliative COPD drawing on findings from the first phase, practice experiences and sharing specialist respiratory and palliative care knowledge. While nurses were aware of the project and some had involvement through gatekeeping roles, this was the first inquiry of its kind for the respiratory team. For the inquiry, intended participants included palliative and respiratory clinical nurse specialists, and

nurses from the respiratory ward. This would enable us to share and make sense of different aspects of respiratory nursing care and to explore how we might construe ideal palliative COPD care. In order to allow space for the group to become familiar with and take ownership of the process, and to explore current practice in relation to the phase one findings, we initially focused on conversations about practice allowing topics to emerge. As these conversations became more focused, potential actions became clearer and our responses to these became the subject of further reflection.

Recruitment

Nurses (12) from the respiratory ward, the palliative (1) and respiratory CNS's (2) were invited to the CI. Information on cooperative inquiry, participant information sheets and consent forms (Appendices 19, 20, 21) were disseminated. Initially, 4 nurses from the ward, one palliative and 2 respiratory CNS's respectively joined. Of the ward-based nurses, 2 subsequently moved to other wards and withdrew from the CI although they were invited to continue. The core CI group thus was 6: 2 from the ward both of whom were clinical nurse managers, the palliative and respiratory CNS's and me as researcher.

Towards the latter stages of the inquiry (14-15 months) we invited patients who had participated in phase one, to attend a meeting with the CI group members Appendices 22,23,24).

Meeting Structure

At the suggestion of the ward-based members, most of the meetings took place in a room on the ward. This facilitated the ward staff in the event of their needing to be nearby. Again, at the suggestion of the ward-based members, meetings ran on a monthly basis at 15.00hrs, this usually being a relatively quiet time of the day for staff. Ground rules were set during our third meeting and these included a closed membership. After 9 months, as specific activities were planned by the respiratory CNS's, we formed a subgroup and met informally on a weekly basis.

The CI group meetings were recorded and transcribed. Transcripts were distributed among the members both as a verification process and a way of reviewing discussions at the previous meeting (Appendix 25). In the respiratory

CNS subgroup, the meetings took place informally before the weekly clinic and on occasion in a nearby lunch café. These meetings were not recorded. Notes were written up immediately after each meeting and these were emailed to the respiratory CNS's.

Cycle analysis

Themes from the previous meeting were revisited and agreed at the start of each meeting. At 10, 16 and 17 months, a summary of the inquiry process and emerging themes to date was circulated and explored (Appendix 26). This served to both review our ongoing analysis of meetings and also to establish convergence/ divergence within the group on emerging themes. Though intended as an integral aspect of addressing quality and rigour, a group meeting and discussions with individual members about drafts of my findings chapters led to further refinement of themes such that analysis was a continual process. Typically, at a group meeting in December 09 that was called to discuss feedback on my write up of the findings chapters, we re-visited our sense-making of the inquiry process and understanding of palliative COPD care. In particular, we explored further our individual reactions and responses to discussions in the early months of the inquiry with new insights to different voices within an apparently homogenous CI group. This late analysis resonated with the experiences of others (Wicks and Reason 2009) in terms of gaining new insights from ongoing iterative analysis.

Ethical Considerations: Phase Two

While action research is built around the process of participation and collaboration, ethical considerations immediately arise for those entering the process without prior knowledge of or experience in action research (Coghlan and Brannick 2005). The information leaflets and explanatory briefings may appear abstract initially. Moreover, the emergent nature of the process makes difficult meaningful consent at the start.

In addition to the information leaflets and one to one briefings prior to the first group meeting, the focus on the first 3 meetings was on exploring CI. My purpose in this was to ensure people felt able to withdraw at any point. The participant information sheet was revisited at the first meeting and consent forms

were signed. However we agreed that these should not be taken as commitment to continue the process.

Confidentiality was considered when setting ground rules for the group and revisited regularly over the course of the inquiry. Transcripts were made of each meeting with names and identifiable features of persons omitted (Appendix 25). One member expressed a preference for a summary rather than a transcript of each of our meetings. Meetings that took place in public places including a café were not recorded.

As the inquiry progressed, interventions identified by the group were planned as hospital-based activities and thereby owned by the members and the hospital. The political consequences of our inquiry were explored as an integral part of our cycles. Typically, these issues included the organizational readiness for change, resistance among certain groups or individuals and protection of the CI members from hostile reactions when challenging the status quo. This influenced the pace of our inquiry, and choice and timing of interventions.

Attention to the needs of the organization was also of concern. I was mindful of the sensitive nature of palliative care, the vulnerability of the patient group and my possible blindness as an outsider to the micro-politics of the organization. Consequently, I had regular six-monthly meetings with the Director of Nursing. During the CI process, members also attended these briefing meetings. The purpose of the meetings was to offer a broad briefing on our progress without divulging the content of the CI group meetings. It must be said, that these meetings also served to ensure ongoing support for the project and so win support for the interventions that emerged from the CI process.

Quality

In his articulation of quality in action research, Reason (2006) eschews the terms validity on the basis that it suggests only one validity. Instead he argues the use of the 4 dimensions of action research as the basis for quality considerations: 1) pursuing worthwhile purposes; 2) democracy and participation; 3) many ways of knowing and 4) emergent inquiry.

> ..action research is full of choices: it is not possible, either
> theoretically or practically, to engage in an inquiry that addresses all

dimensions fully and completely, rather, there will always be choices about what is important to attend to at any particular moment (Reason 2006:198).

Identifying and exploring choices with reference to these 4 dimensions or action research characteristics that emerged over the course of the inquiry guided our ongoing assessment of the quality of our inquiry. Issues of validity, reliability, trustworthiness and credibility in our use of traditional data collection methods to inform our inquiry were explored with reference to the action research dimensions.

Inquiry Quality and Rigour

The quality of action research rests 'within the criteria of its own terms' (Coghlan and Brannick 2005:27) with broad agreement that these reflect explicit choices and actions directed towards participation; knowledge generating and plurality of knowledge, practice focused in outcomes; and use of iterative cycles of planning, action and evaluation. In CI, quality takes into account the importance of coherence among the 4 ways of knowing, that is to say there needs to be a clear relationship and interweaving of experiential, presentational, propositional and practical knowing. On extended epistemology Heron notes (1996:168):

> It is extended because it takes the notion of truth beyond its traditional restriction to propositional knowing and applies it to experiential, presentational and practical knowing also. It is integrated because it is concerned with the congruence of its extended forms.

Dimensions of Action research and Quality

For Reason (2006), quality of action research rests with attention to its 4 dimensions. An action research project needs to demonstrate its contribution to creating a better life. Action researchers need to attend explicitly to action research as a participative and democratic process focusing on relationships. Action research gives primacy to the practical and needs to reflect the value of practical outcomes in its account. Action research needs to draw on and integrate different ways of knowing appropriately and clearly. Since action research is an emergent process, there needs to be a clear account of the unfolding inquiry and its first, second and third person inquiry elements.

Ortrun Zuber-Skerrit and Margaret Fletcher (2007) summarize these in relation to the write up of an action research thesis pointing to the importance of practice orientation; participative process, focus on a significant and explicit problem; use of multiple perspectives of knowing, appropriate methods and theories; rigor in action research approach and generation of new knowledge; and explicit argument about assumptions underpinning the work.

Addressing quality

In his argument on addressing the quality of an action research process, Reason (2006) refers to the importance of both identifying the choices that emerge during the process and critically attending to choosing actions arising from these choices. Since, in any process, the potential choices may be many and near infinite, we must be explicit about those on which we focus and why we focus on those. In this project, the ideals of a counterpartal inquiry (Heron 1996) by necessity gave way to an inquiry that sought to engage with different voices in a hierarchical system, the more silent of which were the target of but not in the CI process. Thus our struggle with the participative and democratic process dimension of action research became an important aspect of our attention to the quality of this project. The patient participant group meeting during phase 2 was intended to reflect our concerns about the open boundary nature of the inquiry. During phase one, I invited as 'expert patient' a person who had advanced chronic respiratory disease but who was not attending the hospital site. This person, acted as commentator and critic bringing an insider and outsider voice to the inquiry as a whole. We met on 3 occasions to discuss the project, emerging themes and my own reflections on the process.

Our attention to different voices in a healthcare organization informed our intention to maintain a conversation involving often competing discourses. Our choices in relation to appropriate inquiry methods were made with attention to our engagement with different ways of knowing. Our ultimate aim was to develop a framework for meeting palliative care needs of a group of patients that would bring to the fore a partnership between those affected by COPD.

Addressing quality in phase one

The importance given to expanded responses was intended to increase participant control and say over the knowledge being generated about them as patients and participants. While the questions were read out in adherence to their original wording, the possible impact of qualitative responses and elaborations on validity and reliability as defined in the positivist sense is unknown. In other words, the expanded responses may have interrupted the flow of the questionnaires. Interviews reached saturation in relation to impact of illness on life. The staged approach to analysis enabled the questioning of themes as they emerged across structured and semi-structured interviews and forms of data. This was not intended to further validate in some way a truth or accuracy in responses. Rather, the staged approach to analysis was aimed at expanding an understanding of living with advanced COPD.

Addressing the quality in phase two

The iterative process of the CI group meetings enabled exploration of themes arising from previous discussions to be examined at the start of each meeting. Themes were tested in between meetings allowing greater exploration of our learning from the process. These themes included attention to interactions with patients, the concerns being raised and implications for practice. The presence of an 'expert patient' as a resource and critic facilitated these exploratory and evaluative discussions. Themes were explored at 2 levels: firstly our learning about COPD palliative care, and professional and organizational enablers and constraints. Secondly, we explored our personal engagement with the values underpinning our practice and our desire for something more: our Bildung.

Summary

In summary, a 2 phased project developed following a lead in collaborative planning period. The first phase sought to identify palliative care needs of patients with COPD using established data collection methods but inviting a more conversational approach in their use. This gave way to a CI in the second phase that sought to inquire into respiratory nursing practice and explore ways of developing practice to address needs. Issues in the inquiry design and implementation were acknowledged in relation to participation and different ways of knowing.

Chapter Seven Advanced COPD Experience

Introduction

The findings from phase 1 are presented over 2 chapters. The purpose of this chapter is to present an overview of phase one and the themes that emerged from the qualitative data. This will lead into a further chapter focusing on the health status measures, integrative analysis and findings. This is not intended to reflect a sequential mixed methods structure since participants did not separate the structured questions and responses from expanded narrative accounts. I have simply chosen to present the findings in this way for clarity.

The Participants

A total of 26 patients were interviewed using the health status instruments; of these 9 were interviewed a second time in semi-structured interviews. Ten participants requested that their family carers join them in the interviews. Three participated in a focus group in phase 2 and a further 4 were followed up over a 6 month period following changes in their condition. Follow up included meeting these participants during OPD visits, hospital inpatient stays and, in one case, in the participant's home. These follow up meetings were at the invitation of the participants. Of those who participated, 5 are known to have died before the end of the study period. One was diagnosed as having lung cancer one month before he died. A summary of demographic detail is presented in Figure 7.1.

Figure 7.1 Participants

Number of Participants: 26
Gender:
 Males: 8
 Females: 18
Average age: 69 (range 52-89)
Living Alone: 6 (sheltered accommodation: 1; beside carer: 3; relative close by: 1)
On Home Oxygen: 11
On Nebulised Medication: 17
Interviews in presence of caregiver: 10

One patient had expressed interest in participating in the research. However, appointments for interview were re-scheduled on 4 occasions because of exacerbation. At her request, I visited her in hospital but was unable to formally interview her since doing so would have been outside the research protocol. This patient died before being discharged from hospital.

The venues for all interviews were chosen by the participants. With the exception of 2 participants, all initial interviews took place in the home. One interview took place in a hospital room and another in the home of the participant's daughter. Family carers sat in on some interviews at the request of participants.

Overview of Phase One

The interviews were moving events in which COPD was less something that I needed to draw into our conversations. Rather it was always to the fore in our preamble conversations and interviews. When arranging a time and date for an interview, our conversation typically centred on the window in their day when the effects of medication were at their best, energy levels at their highest and breathlessness was most contained. On arrival, participants were typically breathless from the effort of opening their front door to me or had pre-arranged with me to come in via their back door in order to lessen the work of meeting and greeting me. Some had pre-arranged for carers to be present to greet me on arrival. Thus, COPD was not so much a topic that we needed to get to but rather it so dominated participants' lives that it was difficult to find a natural break between our preamble and the start of the interview. In several instances, I would suggest that we sit and wait for a few minutes to allow a participant recover from the effort of opening a front door and walking along their hallways. Though strangers to one another at that point, we sat together in silence for up to 5 minutes. I was conscious that my suggestion was a taking control of the situation and placed me wearing my respiratory nursing hat. However, typically, these conversations would start with a reference to the challenges of meeting people including family members who did not fully appreciate the degree of breathlessness being experienced. Thus, I was positioned within a more intimate circle that 'understood' the problem.

Being positioned thus, became an increasingly dominant theme in my own personal sense-making of the interview conversations and what I came to view as breaking the silence of their illness experiences. Even those participants who

were still leading relatively active lives spoke of increasingly contracting and isolated worlds that were little understood by many including family members and healthcare professionals. The responsibility of breaking or speaking through the silence has, at times, felt daunting. However, our talk was often exploratory with participants linking statements back to their personal biographies or setting accounts of illness experiences in a wider context of the environment in which they lived or sought help. Thus, there was a *breaking silence* in our mutual conversation and sense-making.

The preamble conversations were often lengthy, and filled with details about life now and everyday concerns such as the effort of routine chores. Participants' references to medications including oxygen use placed me as being a nurse with respiratory expertise but not part of their hospital. In other words, I was part insider and part outsider in terms of their relationship with their hospital and healthcare professionals.

Ultimately, I grouped the participants into 3 clusters (Table 7.1)

1. Those who were still struggling to engage with family events and different pursuits such as gardening, interest in horses, and community and family roles;

2. Those whose lives were severely limited in terms of social interaction, family roles, and living space;

3. Those who were entering a more severely limited stage such as increased dependency, experiencing difficulty taking routine everyday journeys including driving, or frightening breathlessness and fatigue not encountered hither to fore

These clusters do not necessarily represent degree of symptom severity or clearly defined categories but rather the diverse issues or concerns that participants were experiencing at that moment in time. Nevertheless, those who were severely limited were generally also severely disabled. However among those in the first group were 2 participants who were oxygen dependent, one of whom used BiPap overnight. Both had experienced frequent hospital admissions over the past 2 years. Similarly, I placed one participant in the second cluster who was not using home oxygen and had had just one admission to hospital in the previous year because her experience was of living a severely limited life restricted to her cottage with just a weekly outing to her Church and local shop.

The 3 groups or clusters reflect the recorded interviews and field notes arising from the interviews and subsequent interactions in outpatients. However, I do not wish to ignore the contradictions and conflicting accounts that were part and parcel of interviews and conversations. As might be expected, the clusters were not static; some participants whom I met in outpatients over a one year period experienced elements of all 3 clusters at different points even though their stories broadly fell within one cluster's parameters. Equally, participants who initially described their lives as severely limited might later in the same interview or conversation re-describe their lives as less limited. In the brief outlines below, I aim to show the convergence and divergence that was evident within each cluster.

Table 7.1: Clusters Reflecting Current life and Dominant Concerns

Clusters	Continuing Struggle to Engage	Severely Restricted Lives	Entering More Severely Limited Stage
Number of Participants	11	9	5
Participants' ID	2,9,10,11,23,25,29,30,31,32,34	1,3,4,7,8,21,26,28,33	5,6,20,24,27

Continuing Struggle to Engage with Family Events and Different Pursuits

Within this group 2 participants were home oxygen dependent, one was living alone in sheltered accommodation, another was living alone but with support from a sibling living close by, while another was living alone with minimum support. The remaining participants were living with family members. Continuing struggle to engage with everyday pursuits thus ranged from survival for those living alone to maintaining family roles and identity for others. Typically, these interviews were marked by long preamble conversations following my arrival. A comment from me about a nice garden, pet or chickens could lead on to talk about the struggle to maintain routines against a background of increasing breathlessness.

Participant 9 lived in a rural area with her husband and teenaged children. Her husband worked some distance away and her everyday life included the demands one might expect for a parent of active teenagers. Her everyday routine demanded minute planning, gauging her breathlessness and pacing. The

planning involved trading one activity against another, balancing the daily driving, negotiations and support that are integral to being a parent of teenagers. She spoke of guilt at not being a proper mother to them. She lived on a fine line between being active and retreating to her kitchen or bedroom. Panic attacks were frequent and a slight change in plan or feeling of chest tightness was enough to bring on an attack of breathlessness. She struggled between awareness of her condition and sense of being smothered by her family which could lead to conflicts.

Participant 23 also lived in a rural area. He was a retired farmer and had set his land. He lived alone with his dogs one of which never left his side and was also clearly unwell. He had 3 horses that were pets in a field and stable adjacent to his home. His home was half a kilometre from the road and he lived about 2 kilometres from the nearest village. He no longer drove and so had to walk into the village for provisions and contact with neighbours. Participant 23 had one severe acute exacerbation that had been a particularly frightening experience because he could not get help in the middle of the night. He is fearful of something similar happening again and revisited the experience several times over the course of the interview. His daily routine includes physical work attending to his horses and getting provisions from the local shop. However, he thought he was managing well apart from his breathlessness and fear of another attack. His horses and the welfare of his failing dog were important to him and he needed to be well enough to care for them.

Participant 25 lived alone in sheltered accommodation in an urban area. He was oxygen dependent and experienced frequent admissions to hospital. Following his first life threatening exacerbation some years previously, he moved into sheltered accommodation and began to eat better than before and exercise as much as possible. Despite experiencing severe breathlessness by simply climbing the single step at his front and back doors, he maintained a strict routine of walking everyday and doing exercises and stretches some of which he developed himself and aimed at loosening bronchial secretions. He baked his own bread and managed his shopping by walking everyday to the shop to buy a few things depending on their weight.

His everyday routine was planned with care to minimise breathlessness. His daily walk was carefully paced and even then induced light-headedness. Despite his evident disability, he spoke about having a better lifestyle than previously

because he was looking after himself. However, he also spoke about the rules of his sheltered accommodation that included being able to live independently. Thus, his strict self care routine was key to his being able to stay in his home. He was well versed in his medication and oxygen equipment. He believed that his body had developed a certain degree of resistance to reduced oxygen levels. This meant that he felt better able to read his body than those doctors who relied exclusively on test results. He believed his consultant understood this and always asked about symptoms and his self-assessment. When he spoke about his daily walk he spoke about his slow pace crossing the road but not being afraid to die. Later in the year he decided against using BiPap as advised but maintained his own strict self care routine.

These accounts reflect the everyday struggle to continue to actively engage with life. The struggles were different and sometimes contradictory but nonetheless framed life with COPD. Careful planning and pacing meant consciously relinquishing roles and activities. While care needs clearly include optimum management of breathlessness, managing fear, help with adjustment, and informed and supportive decision-making seemed a priority.

Severely Limited Lives

Within this group 7 participants were home oxygen dependent and spent most of their days confined to kitchen and livingroom. Five participants used wheelchairs when out and about while others used walking aids. Getting washed and dressed demanded strict routines and pacing. Five were dependent on carers for intimate care. Others needed carers on constant standby. I was aware of the deaths of 5 from this group before the end of the project.

My first interview with Participant 1 took place in a room in the outpatients department. She said that she enjoyed getting out of the house. When we first met she described having had a good year with one hospital admission only. However, over the final year of this project, she had several admissions and subsequently died in hospital. Participant 1 was home oxygen dependent and used a wheelchair for moving about outside her home. Trips to the hospital clinic required the presence of 2 daughters and she had a number of family carers at home: 2 daughters, husband and granddaughter. She became increasingly dependent on her daughters for help with washing, dressing and toileting. Her increasing dependency on steroids added to her weight problems and she spoke

about the trade off between steroid benefits to her breathing and effects on weight and mood. In her final months, she needed the help of 3 family members to walk from one room to the next.

In our interviews, Participant 1 described her life as 'not good'. Though she engaged in banter with her daughters, she described her loss of role within the home such that loading the washing machine was an achievement of note. She was unable to prepare meals, do housework or move about independently. Despite this she had command of her home through organizing routines and jobs with her family carers. One daughter lived at home while another lived close by. Grandchildren visited on a daily basis. We met regularly in OPD. She would express delight if found to have lost weight. She disliked to an intense degree being in hospital. However, in her final year she experienced co-morbidity and her condition was increasingly difficult to manage at home. Hospital admissions grew more frequent and when we met she and her family were increasingly confused about what was happening to her. Since her symptoms changed in the final months, their ability to read her condition also changed. As a consequence, they made several trips by ambulance to A/E not all of which resulted in admissions but which added to distress all round. Her daughter spoke about the difficulties in not knowing what was happening, not getting answers in the hospital, sometimes feeling unsupported by the medical team and as a consequence of the ensuing uncertainty, conflict among the carers.

Participant 21 lived at home alone in a rural area when her condition deteriorated. She had 3 daughters living close by, one of whom lived just a few meters away. When I first visited Participant 21, her daughter greeted me and brought me into the kitchen. At one end of the kitchen, Participant 21 sat in her armchair, surrounded by a small table, nebuliser and oxygen concentrator. There was space for a commode. She spent her day in that space and told me that she liked to sleep there also when she felt unable to make it to her bedroom next door. Her daughters arranged their own routines so that one was always present and managed the house and care. She had several admissions to hospital over the previous 2 years and following her last admission was clear that she did not want to return to the hospital. Her voice was weak and I had to lean forward to hear her above the sound of the concentrator. Nevertheless she seemed to take pleasure in talking about the changes in her neighbourhood and her garden. I was anxious not to tire her and suggested returning for a semi-structured

interview. However, on the designated week she was unwell and was subsequently admitted to hospital. She died before the end of the project.

Participant 28 lived in an urban area with her daughter and also lived in a small space in their kitchen/living room. Participant 28 was oxygen dependent and became breathless even shifting position in her chair. Despite this she described her health as not bad and did not like using her oxygen all time. She liked to leave all decision-making to her daughter on whom she was dependent. She expressed greater independence in self care than intimated by her daughter later. On fine days, they both went out using public transport. On these occasions, Participant 28 used a wheelchair and their outings included visits to her husband's grave, local shops and sometimes nearby towns. She had previously had major surgery and several hospital admissions for different conditions.

Summary

These participants had become almost fully dependent on carers for everyday care. Everyday life was limited to a small living area. The presence of co-morbidity and deteriorating health status added further pressure on carers in reading signs and symptoms resulting in increasing journeys to the hospital. Despite expressed desire to remain at home, participants often ended up in hospital for management of acute symptoms or as a consequence of uncertainty.

Entering A More Severely Limited Stage

These participants were experiencing a marked change in their condition and were losing aspects of their previous lives such as activities with friends and in the home. They had literally lost their footing and their struggle to articulate what was happening was similar to Frank's (1997) chaos narratives. Their degree of disability varied from being home oxygen dependent to still managing gardening chores. However, they all had in common a sense of losing control. Our preamble conversations were infused with grief, fear, questions about what treatments were available and their condition.

When I met Participant 5 she was using inhaled medication and had not been prescribed a nebuliser. However, the strength of her inhaled medication had recently been increased on a few occasions and each time the benefit was short-lived. She was frightened by this. She had also recently returned from a holiday

with her son and his family. This had been a traumatic experience because her breathlessness grew increasingly worse and had governed the holiday for everyone despite her best efforts to underplay it. She believed that she would never again go abroad but that her family still did not realise how serious her breathlessness was. Where previously she enjoyed an active social life, she was no longer able to go out alone but was embarrassed by her breathlessness if with friends. Up to recently she managed her home but suddenly found it difficult to even hold a saucepan. Her days were now reduced to having to plan and pace in order to minimise her breathlessness. She lived with her daughter who worked full time. Participant 5's father and brother died from emphysema at younger ages than she was now. She recently visited a friend in hospital and saw another patient struggling to breathe. She wondered if this is what was facing her and was frightened by it. Prior to our meeting she had been in touch with the hospital in order to get her OPD appointment moved forward. She was planning to try and have it brought forward again as an urgent one.

Participant 20 took early retirement but enjoyed gardening. He lived with his wife and his daughter lived nearby. His wife was still working and so he was alone during the day. He used nebulised medication. They had a large garden of over one acre with a high hedge, lawn and shrubs. He was finding it increasingly difficult to maintain the garden and this worried him. He had recently had a frightening experience of severe breathlessness when outside during a routine chore. Added to that, he was finding it increasingly difficult to engage with his grandchildren as he would normally do and this worried him. He was frustrated at the lack of help being offered by the hospital and acknowledged he was having difficulty in accepting that there was no cure for his condition. He had given up smoking but that had not helped. He felt much better while on steroids and had argued with his GP for more or something similar. He could not see the point of having to wait for a hospital appointment instead of being able to get help when needed.

Summary
Participants within this cluster were struggling to come to terms with loss and sensing that their world was out of control. Their care needs were immediate and encompassed regaining control of their breathlessness, help with reappraisal of their condition, support through the losses and fear being experienced at that point.

Interview Themes

Participants developed their responses in the structured interviews through telling stories. Their stories or mini-accounts particularised the structured interview questions to their situation and were told in vivid detail often about an incident some time previously but that continued to have a particular illness meaning. The stories were often revisited in the semi-structured interviews as illustrations of the COPD experience. Symptoms fluctuated in the intervals between interviews and follow up conversations in OPD. Five themes emerged from this qualitative data (Table 7.2).

Table 7.2: Themes from All Patient Interviews

Theme	Description
Breathlessness	The state of living with severe everyday breathlessness
Contracted World	Retreat from or curtailing engagement in everyday activities
Lifeworld & Emotional Response	Illness effect on self and personal meaning derived from illness
Contextualising Meaning	Explanatory meanings developed for current state including life events, family history and deaths from lung conditions
Mediating Illness with Others	Engaging with the world

Living a life under the threat of a severe breathlessness attack underpinned all themes. Thus, COPD became one's life; life could not be separated from COPD. Illness in this sense subsumes one's world wherein all aspects of one's life is defined, experienced and lived through one's COPD. Sub-themes were identified for each theme (Table 7.3). Weighting charts were generated of subthemes Appendix 27)

Table 7.3 Themes and Subthemes

Theme	Sub-theme	Sub-theme Description
Breathlessness	Everyday Nature of Severe Breathlessness	Severe breathlessness as part of everyday life
	Frightening Experience	Fear of dying and relationship with panic attacks
Contracted World	Physical Contraction	Loss of physical strength and functioning
	Contraction of Social World	Response to struggle with relationships and engagement in everyday activities
Lifeworld & Emotional Response	Illness Effect on Self	Experience of loss or changed identity
	Discipline and Pacing	Asserting control through self discipline and strict routines
Contextualising Meaning	Explanatory Meaning-making	Situating current illness experience in personal biography
	Smoking	Dealing with smoking history
	Diagnostic Event	Marker in illness trajectory that signified new illness phase
Mediating Illness with Others	Mediating Illness in the Everyday	Mediating illness through relationships and citizenship, and roles therein
	Engaging with Healthcare Services	Citizenship in healthcare and confronting power imbalance in the user/system relationship
	Experiences with HCPs	Response to adverse and meaningful interactions: examples of knowing the case versus knowing the person experiences

Breathlessness

All participants spoke about their breathlessness as having far-reaching consequences in terms of their lives similar to that described in other interpretative research on the COPD experience (Guthrie *et al.* 2001a; Booth *et al.* 2003; Barnett 2005; Fraser *et al.* 2006; Gysels *et al.* 2007; Ek and Ternestedt 2008; Clancy *et al.* 2009). Breathlessness was always described in the context of the everyday and as frightening. All participants had experience of feeling their

lives under immediate threat:

> You'd think you were getting a heart attack. It is terrible and you'd say oh my God is it worth this, do you know, but what can you do.
> <Internals\Patient interviews\P8[1]>

The Everyday Nature of Severe Breathlessness

For all but one participant, severe breathlessness was part of everyday life. The most mundane everyday tasks could be linked with severe breathlessness:

> I don't feel as bad as I did the worst I can be is in the mornings and I can't very well [move], I have to sit on the side of the bed and I can't (cough) I have to sit inside there. [That's] the first thing I have to do before I get out or stir anywhere or put my leg into my trousers, that has to be done or I'd be on the floor. So, I'm fighting to catch my breath and that calms me down and then I dress myself
> <Internals\Patient interviews\P1_qual interview>

Similar to findings elsewhere (Barnett 2005), anticipation and experience of this degree of breathlessness was built into daily routines such that the act of getting up in the morning could take up to 2 hours for some participants. The severity of everyday breathlessness could overwhelm simple routines. For this participant who was oxygen dependent, breathlessness could be bad enough as to leave him unable to go without oxygen even for the few moments it took to use his chairlift:

> I mean at times if it's bad enough, I have to bring this up [portable oxygen] on the chair with me till I get up to the other one (oxygen concentrator in bedroom).
> <Internals\Patient interviews\P7_qual interview>

Everyday actions could frequently increase severe breathlessness to a degree that speech was difficult if not impossible, typified in a memo I wrote following one interview:

> I waited for about 3 minutes for door to be opened but waited because I heard movement inside. She was very breathless when she opened the door having got up from her couch (about 8 - 10 steps to door) When we sat down, I waited for about 5 minutes while she

recovered her breath. I learned that her daughter who is her carer
had just slipped out to a neighbour for a few minutes and hence P28
had to answer my knock

<Memos\P_28_interview brief>

The memo illustrates the fragility of managing everyday breathlessness and the burden on family carers to minimize such attacks. For other participants, stepping outside to accompany their respective carer shopping or simply to help in chores demanded heightened carer support. Of one participant who sought to help with washing dishes, his carer said:

Well, it's very very seldom he gets through the washing up.
<Internals\Patient interviews\P7_qual interview>

Frightening Experience

All participants referred to frightening episodes of breathlessness. Typically: 'I think it's like, if you have ever been short of breath, it's an awful feeling. I think you feel that you're never going to breathe properly again' <Internals\Patient interviews\P 34_structured interview>. The vivid accounts of episodes graphically illustrated the all consuming fear of a severe breathlessness attack:

You get sort of dizzy-ish when it hits you, you know and you think
you're never going to be right. You get frightened alright [because]
the breath is gone
<Internals\Audio Files\P_20_08071400>.

The graphic and detailed nature of these stories was similar to that found by Patricia Bailey in her narrative research on breathlessness (Bailey 2004). Many accounts were 'near death' stories describing a particular episode of life threatening breathlessness usually associated with an acute exacerbation. One participant who lived alone, vividly described in detail a night of severe breathlessness with a chest infection that happened 2 years previously:

I went to the doctor, he gave me tablets and they didn't work at all. I
went the following day and he gave me more tablets and that night
me breathing went altogether and I rung the doctor and he never
come till morning …Oh I had a very bad night a bad night a terrible

night. That was very frightening especially here on my own…(long pause)
<Internals\Patient interviews\P23[1]>

Participants also described in vivid detail everyday events that were marked by severe breathlessness. For another participant, the exertion of a GP visit followed by a walk from the car into the local supermarket prompted severe breathlessness:

I went into the shop to get a few things and I just stood at the counter and the girl that was serving, I asked her would she gather up my shopping for me and there was a girl there that carried it out and put it in the car for me. I wasn't able to go around.
<Internals\Patient interviews\P8[1]>

While these experiences reflect singular if not unusual events that illustrate the frightening nature of severe breathlessness, they are indicative of how such episodes can generate fear of something similar happening again. For Participant 23, his descriptions of his current breathlessness, self management and daily routines were checkered with repeated reference to that night 2 years previously when he was alone and ill.

Similar to that found in earlier research (Gysels *et al.* 2007), many participants referred to panic and breathlessness as integral to one another typically:

You try to relax and try to relax and the more you try to relax the worse it gets and the next thing is you can't breathe and you panic. Then you're finished
<Internals\Patient interviews\P26>

Several struggled to make sense of the panic/breathlessness cycle and causal links seeing breathlessness as leading to panic:

If my breathing gets very very bad, that's mostly what gets me into [hospital], I take a panic attack
<Internals\Patient interviews\9_3rd[1]>

Well, if I thought I was going to get an attack I would get panicky, you know. If I got a fit of coughing, say something catches in your throat say and you lose your breath, *then* I panic you know because I actually feel that there's no one here

<Internals\Patient interviews\P27[1]>

This participant, in her subsequent interview described her working through the relationship for her between panic and breathlessness:

I know and I often though of that myself, is it that I get uptight about it [breathlessness] but no, I proved it that I really get it because I've gone a few times on my own and I would have to stop and recover. Like, it's ok to go down there when you know you're only going a short distance and a short distance back, you know, and I'm just not able

<Internals\Patient interviews\P27 Qual>

However, Participant One saw the anticipation of breathlessness as sufficient for bringing on a panic attack:

Well, the panic attacks only happen when I'm under pressure to go somewhere and then it starts and then I get, I can't breathe, I can't talk, I can do nothing,

<Internals\Patient interviews\P1_qual interview>

For her, the panic attack/breathlessness cycle was contingent on a threat to her rigid daily routine and self management of her COPD. Though she experienced severe breathlessness at home, the panic attacks were less evident there.

Contracted World

All participants had in common their engagement with an increasingly contracted world. A contracted world is that in which patients withdraw from or limit activities of daily living and social interaction in response to living with the unpredictable nature of symptoms. Contraction in this sense is an ongoing process, that is to say, each exacerbation or severe breathlessness attack marks

a further retreat from a previous life. Typically:

> I have no energy now sometimes. I'd go and do a bit of work and
> then sure I'm flattened. I get disheartened and say feck it I'll leave it
> till tomorrow.
> <Internals\Audio Files\P_20_08071400> -

For participants, their world was contracting both in terms of loss in functioning capacity to undertake everyday activities (physical contraction) and also the increasing isolation from the 'outside' world of social networking, community activities, and extended family. As this participant put it:

> It's like you die you know. It's just, I don't know. It's hard really
> sometimes to put it into words and that's the only way I can explain
> it, it's like a flower opening up and then it dies. It opens up for so
> long and then it loses whatever it had and it's gone, you know. It's
> just something else.
> <Internals\Patient interviews\Par_5_1> -

Physical Contraction

Losing strength demands further effort to undertake core tasks however pared down they might be. This participant described in detail the effort required for her morning routine:

> I, first of all when I get up I usually make the bed because I say if I
> let that go, I mightn't make it at all, like, you know. I come out and
> get my cup of tea and my breakfast so to speak which isn't very much
> but it's all I like and my medicine and then I go and wash myself and I
> dress myself and God I'm tired then. I could sit, I could sit then for
> an hour and go to sleep, I think and I'm tired.
> <Internals\Patient interviews\P27 Qual>

Though this participant was oxygen dependent, she was not housebound and, on a good day was able to potter in her garden. As with other participants who were not housebound undertaking additional activities depended on whether or not this was a 'good day' as illustrated by Participant 7 who had planned on attending a family celebration:

one night for [son's] 40th, I knew I wouldn't last the night and then of course [wife] nearly had a heart attack and she was running and racing and trying to get ready at the time and then she'd be trying to ring the doctor ah sure don't be talking to me.
<Internals\Patient interviews\P7_structured interview> -

Being able to continue driving maintained a crucial check on a contracting physical world. However, issues such as parking and walking distance from car to shop, and fear of an attack of severe breathlessness some distance from home limited the sense of independence normally associated with having a car. Moreover the effort of getting in and out of the car, maneuvering the car for parking left little energy for other things:

I can't park my car and go for messages, you know, that I find that, I'm afraid that I might not be able to complete it on my own. I find that a difficult thing to do
Internals\Patient interviews\P27 Qual> -

Loss of engagement in other everyday activities such as gardening had consequences for greater time spent indoors and by default a contraction of their physical world. Several participants were almost housebound such that:

So you're stuck in the house. Even walking out to the gate is the problem, so you're actually confined indoors.
<Internals\Patient interviews\P8_structured interview>

For many, trips outside their homes were rarely taken and those that were, were usually for hospital appointments. For Participant 21, her family caregivers moved about in and had charge of her kitchen. Though the division of this participant's kitchen was stark with all its meanings, there were similar patterns in the homes of other participants. Participant 26, for instance, lived alone but next to her daughter's house. Daughter and granddaughter popped in to prepare meals and snacks. For some women, though they were no longer able to cook or manage their kitchens, they were able to maintain a degree of control in decision making. Participant 1, for instance, oversaw meal preparation, housework and even gardening despite her disability and dependency. Though oxygen dependant, Participant 26 continued to do his own shopping by managing his walk quite literally step by step.

Contraction of the Social World

Participants spoke of struggling to maintain relations and engaging in everyday activities outside the home such as attending church and going shopping. This struggle was partly related to loss of exercise capacity and a response to a contracting physical world. However, there were other interrelated aspects to their contracting social world. A contracting social world could be an invidious process over time. Several participants acknowledged internal conflicts between sense of loss regarding their social life while also aware of a conscious withdrawal or as Participant 9 put it: 'you get used to sitting in'. A decision aimed at limiting risks of breathlessness could have far reaching consequences for previously important activities such as attending church. Participant 10 made a conscious decision not to attend Sunday Mass but rather listen to it on the radio. Though her local priest made regular visits, her decision marked her ending of an important weekly activity and link with the outside world.

Others spoke of fracturing of the normal reciprocity in relationships with others as illustrated by Participant 7:

> I mean it's just, a simple thing now we used to do, we used to enjoy going up to see a cousin of ours, we'd go on holidays and his wife and they used to come down to us, but like, I have no hope of going up there now. I used to love, I love music and love dancing but you know I can't go anywhere.

The sheer effort and toll involved in maintaining relations with others was a significant factor as Participant 1 illustrated:

> Just the fact that I have to get up and I have to go through all of that, getting dressed, dragging my oxygen out, getting in the car, me breathing is going and everything else and I have to sit in the car for the best part of an hour until I calm down.

While Strauss et al (1984) refer to the work of the chronically ill patient, this is largely task oriented including self care. Participants in this research placed emphasis on the work of managing social interaction and family's interaction with the illness. As a consequence of the work involved in social interaction, some withdrew both physically and emotionally:

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Yes, it stresses you out completely, you know you just oh God, you just feel dead, you come in and sit down away from everyone, you don't want anyone looking at you and that's it, not that they'd be bothered I'm sure but I'd feel they would.

<Internals\Patient interviews\Par_5_1>

Another participant described her decision to stop going to Bingo.

We used to go of a Sunday night to [town], but getting in and out of the bus was too much for me, I just was not able so I said, the last night I went, which was last year, on the bus, I said to [X], that's my friend, that I, I said to her that this is it, I'm not coming here any more. I'm not able for this, because I'd come out and get on the bus and all I could see was those little stars in front of me eyes and I said it's not worth that.

<Internals\Patient interviews\P8[1]>

In deciding to give up Bingo, she was also withdrawing from her close friends with whom she played. She had not met them since that decision. It was not necessarily the effort involved in making a journey to see friends or relations though that effort had become considerable rather, the effort of engaging with another was a struggle:

When I'm on my own I'm OK, a friend now, we were at school together, she comes to visit me on a Wednesday and when she goes tomorrow evening I will be knackered and that's just sitting talking and I'll be knackered

<Internals\Patient interviews\P26>

Others simply wished to withdraw:

My life is an awful bore, an awful bore. You know, you're tied to that all day and that's the feeling I have. Whether I get over it or not I don't know but I don't feel it. I don't talk about it to anyone. I try and hide the fact, well not hide it because my friends know I'm on that thing, you know, the oxygen therapy but I don't talk about it but you know I can do nothing really. It's a pain in the butt.

<Internals\Patient interviews\P27>

For these participants, their contracting social worlds were in part a conscious withdrawal from social interaction or engagement with others. An integral aspect of this withdrawal was a drawing inwards or emotional withdrawal from the normal reciprocal relationship with friends. In this sense, the withdrawal from Bingo nights in the company of old friends, the toll of sitting with a friend or simply wanting to hide away added a profound dimension to contracting social worlds. Others experienced their withdrawal as forced rather than desired:

> The worst times, I suppose, ah you get more worse times than you get good times you know what I mean. You can't go nowhere rightly. Like, the wife is going away on holidays next week with our son, son and daughter-in-law are bringing her, and my other son is already gone. [Spouse] goes next Saturday and I'll be on my own for 2 weeks
> <Internals\Audio Files\P_32_qual_2_08072501>

For Participant 7, visiting his son's home was no longer possible because of the stairs:

> Well, it's a very simple thing but it's one of the things that and I dread the thought of it because, if you're on the [diuretic medication], when you start to go, you have to go and that's it, and the stairs is like that [indicates vertical line]
> <Internals\Patient interviews\P7_qual interview>

For both these men, their contracting social world signified their forced isolation from the world. More than that, they were experiencing loss of their place in friendships and family by being unable to participate in activities that were once shared with their wives. In contrast to the emotional withdrawal described earlier, these participants were striving to maintain their connection with their worlds but felt obstructed from doing so.

Participant 6 continued to work a few hours per week. While she described managing the actual work to limit risk of breathlessness, walking from one room to another with colleagues was difficult:

> Oh yeah, I have to say to them hold on a second, pull back, or if I meet somebody I say no go on, I'll only hold you back, you can walk much quicker than I can.

Her struggle to continue to engage with the world demanded a continual balancing between drawing attention to her breathlessness and appearing up to her work.

Lifeworld and emotional response

Lifeworld encompassed the illness effect on self and the personal meaning derived from illness: the grieving, the experience of loss of or changed identity through roles. As one carer present in an interview commented: 'It's [COPD] like a third person in a marriage'. A consequence of advanced COPD is lost capacity to engage in previous taken for granted activities that are identified with identity and role. In this sense, identity and role merge as elements of one are expressed or manifest in core beliefs around the other. Attempts to counter the illness effects demanded rigid self-discipline and pacing.

Illness effect on Self

The accounts narrated by Participant 32 centred on his previous physical strength that defined him both in terms of his occupation and success in sport. Illustrating the COPD illness effects on him he relayed an incident about a delivery of turf for fuel. The delivery was made when there was no-one at home:

> He left 2 bags of turf there at the front door and I couldn't carry them.
> The son came and he picked them up. It feels terrible you know that
> I can't do it.
> <Internals\Audio Files\P_32_

The delivery exposed not just this participant's loss of strength but his now dependency on others and, especially, his son and by implication erosion of self identity as head of household. The loss of role and its relationship with identity is further illustrated by Participant 2:

> the wife didn't used to drive…. Now I wasn't stopped from driving, I
> can still drive if I want. I just don't, so she's been driving for the last
> ten years or more. I used to bring her and her mother shopping and
> I'd push a trolley around the supermarket and things like that. I'm
> not being smart, I wouldn't do it now if we went shopping and bought
> messages, it's embarrassing or I feel embarrassed that she has to
> carry the bag of messages and I'm walking along with my hands in my

pockets and I'm a man and I'm supposed to be carrying them for her. I'll tell you love, it's embarrassing. And she knows when we're walking along and I say I'll carry them and she'd be watching me and she'd say here I'll take that off you. And you don't want to but you have to give it to her.

<Internals\Patient interviews\Par_2_1>

Role is, in part, relinquished by no longer driving. However, this is juxtaposed with his wife taking over this role while also assuming responsibility for the previously shared but role-defined activities in shopping. His reaction is not only to feel redundant but more than that to bear the stigma of lost role and meaninglessness before the world. This sense of meaninglessness was expressed by several participants in terms of having little purpose in the day:

Just sit there and walk down to the room to do my nebuliser and go to the loo and do a bit of walking up and down so as to keep my legs from seizing up.

<Internals\Patient interviews\P1_qual interview>

The loss illustrated by both these participants reflects what Goffman (1997) describes as involuntarily lost roles in which the loss is greater than the particular act or capacity to act. The loss is proof of incapacity and loss of face. The accounts of these participants resonate with Goffman's use of the word humiliation for involuntary lost roles reflecting the profound character of the loss and its relationship with identity.

Experiences of loss articulated by participants were similar to those recorded elsewhere in chronic illness commentary (Ahlstrom 2007). For some their ability to maintain face or normal appearances was undermined. Lost interest in appearance appeared related to general loss of sense of self:

I have lost an awful lot of [interest] because in the first place I can't go to the hairdressers and in the second place I only take a bath once or twice a week. I take a shower but we've only got the shower in lately and it's too hard on me and I'm afraid to take it on my own in case. I like to have someone with me

<Internals\Patient interviews\P26>

I'm recycling rags now, I haven't bought anything new in the line of clothes and you need to do that, you know, you need to do that, and these are all rags now

<Internals\Patient interviews\P27 Qual> -

The impact of steroid medication on body image contributed to erosion of sense of previous self

I wouldn't say I've lost interest but I just can't, you know like I mean the clothes I'm wearing now like I would have been ashamed to say the size of them, you know, and things like that and like it's not easy to get clothes to fit you now.

<Internals\Patient interviews\P7_structured interview>

These accounts illustrate the sense of shame brought about the effects of COPD on their appearance. When invited to describe her life now, Participant 27 drew together her sense of loss that was symbolized by her discharge home from hospital to find her bed had been replaced by a hospital bed following a community occupational health assessment:

how could I describe it because how could you describe it because you don't know till it hits you and you can't even imagine how stupid I feel. The first day after I came back from [hospital] I got up, I was just dead tired and I said how the hell am I going to get out of this bed. I hated it the minute I saw it and I got out of it anyway and I sat on the corner of the bed and I threw off the duvet and I had a blanket on it and a sheet on it that day and I thought how am I going to pick those up. How am I going to pick the duvet up

<Internals\Patient interviews\P27 Qual> -

In this quote, Participant 27 illustrates the takeover of her life by her worsening COPD. Her bedroom had been medicalized by the new hospital bed in place of her older and comfortable large bed. In this sense COPD colonized even how she was to sleep in the future. More than that, her exhaustion following an exacerbation reduced her early morning activities to concern over how she would tidy her bed.

Discipline and Pacing

By way of countering illness effects and gaining a degree of control over one's life, participants described the importance they bestowed on self discipline and rituals as part of illness management:

> Well everything is an effort but you have to do it. You have to make yourself do it. Everything is an effort but you may make yourself do <Internals\Patient interviews\P26> -

For this participant, making an effort included a decision to eat well. This also meant he needed to shop several times in the week. He described the walk to the nearest shop in detail illustrating both the planning needed and the effort involved:

> I do it in stages, you see. Say if I left here, I go as far as the green box, at the corner
>
> Me
>
> At the corner, yeah
>
> P25
>
> I go as far as there and I stop [to] recharge the batteries, let the heart cool down Oh, it would be thumping sometimes, the thumping stops and you go further, I go as far as the silver box at the corner at the turn in here. It's not far, it's only a short distance and I see how I'm travelling (coughing) You see, there's a gatepost there and I'm able to put my elbows up like that (demonstrates) and that helps the whole lot……you see it's on the level then mostly. Well there might be a slight slope in the path but I go down as far as Murphy's, the solicitors, there (questioning tone)
>
> Me
>
> Oh, I know where you are
>
> P25
>
> Yeah, and then there's a big step down and that has an affect I just stop at the railing then, get my breath again and coming back is the time that I really struggle. When I get up that step I just have to stop at it and that's it No, I never cross the road, not there, I go down to the cross is where I stop before I cross the road to make sure everything is in working order before I cross. I'm nimble enough there

to get out of the way. At this stage, who cares (laughs) I used to go to Dunnes you see and there was nowhere really you could stop and rest, a wall to sit on or something like that Yes and you know the railing as you come out of Lidl's, you know as you go into Lidl's. There's a railing there I put my elbows on that and rest and make sure I'm completely charged before I move again Yeah, well milk would be the hardest part, a 2 litre milk.
<Internals\Patient interviews\P25b>

Though a long account, his is a vivid account of the struggle to maintain a degree of control over his life and the cost of the struggle. After our interview I retraced his walk and estimated it to be less than one kilometer. The breaking down into stages of his walk to the shop resonates with participants' accounts of pacing through basic activities such as getting up and dressed:

I do take me time now when I have to shower and shave now I spend half an hour I take it handy
<Internals\Audio Files\P29_08060901> -

For Participant 7: his morning ritual was described in detail of first taking his nebulised medication, proceeding to get out of bed and then walk to the bathroom. The process of getting up took an hour. However, taking a shower added a further hour to his morning routine:

If I wanted a shower, I have a long line [oxygen lead], we had a long line made up and it's connected to the concentrator up above and brought to the bathroom and I have the oxygen while I have the shower
<Internals\Patient interviews\P7_structured interview>

Routines and rituals such as these while important for a sense of control, also meant that these participants had little 'free time' beyond getting up in the morning, taking medication via a nebuliser, having meals, resting and where possible stepping outside. Even simple routines in shopping were important:

I'd go shopping but I don't put things into the trolley or I wouldn't load it into the car, he (son) does all that
<Internals\Patient interviews\P 31 Qual interview>

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> I would, I'd carry a bit of shopping out from [supermarket], leave the
> car quite near on the disabled place and then I take my time walking
> around the shop but I'd still be a bit breathless walking around.
> <Internals\Patient interviews\P 33 structured interview>

The self discipline, effort and time required to maintain these routine reflect the importance given to managing their illness.

Contextualising Meaning

Though viewed medically as a smoking related illness, participants saw their illness as more complex and bound up in their personal biographies. In their explanations for their illness, participants illustrated their attempts to derive some meaning in relation to what was happening them: the cause(s) of their condition, why this was happening to them at this point in time and what lay ahead.

Explanatory Meaning Making

They drew meaning from specific events that marked a shift in their illness and so became important moments in their life histories. While participants[15] acknowledged their smoking history as a factor, several focused on early occupational histories, family illnesses and hard lives as being of greater significance. The poverty in Ireland in the 1950s, limited work and extreme hardship of life were bound up in the explanatory accounts reflecting what Bury (2001) referred to as contingent narratives. This man began as a farm labourer at the age of 13:

> For 7 days, I done that for 6 year[sic]. I was driving as a young lad.
> My wages were 21 shillings a week in all weather. I worked away in
> all weather I had about 2 miles to go to get home
> <Internals\Patient interviews\P22[1]>

This man remained a farm laborer but his work became mostly to do with tillage including spraying crops and harvesting with no protective clothing or face masks. He went on to describe the effects of spray on his breathing and circulation. Others attributed their present condition to previous work in various factories where they were exposed to a range of irritants. Typically, these accounts included the lack of available work and therefore having little choice over types of

---

[15] One participant never smoked but developed COPD from earlier asthma.

work, and the lack of knowledge during those times about the risks associated with exposure to materials. One participant worked first with talcum power and later with glue both of which are now recognised as irritants. In these accounts, notions of fatalism were present.   In this sense within these explanatory meanings, COPD was more than a result of exposure to irritants; rather it was a consequence of a hard life:

> And sometimes I ask myself did I do right, did I do wrong on someone during my lifetime. I wouldn't discuss that with everyone……………. But I worked terrible hard, we worked, we had cattle, my mother, we owned all that land out there. I was often out till 11 o'clock at night milking cows after doing a day's work….Like, I had a hard life, I don't mean hard, but I sacrificed everything to my mother and the home
> <Internals\Patient interviews\P30> -

Cigarette Smoking and Family History

Not surprisingly, smoking was an important feature in how participants made sense of their life with COPD. For some, smoking was understood as the primary cause of their COPD and smoking cessation was an effective treatment strategy:

> Oh I'd be raging sometimes for ever lighting a cigarette. I'll never smoke again and I do feel I'm not going to the hospital as often. I notice that and cos sometimes I used to go in maybe 3 or 4 times a year. Now I'm not.
> <Internals\Patient interviews\P9_structured>

> Last year I was in the hospital 3 times. And one time was for a whole month. I was smoking that time
> <Internals\Patient interviews\P23[1]>

For others their relationship with smoking and its link to their COPD was more complex ranging from one of ambivalence to something akin to a battle.

> I don't understand my chest because if I was smoking, drinking, well drinking wouldn't affect your chest, if I was smoking, bar the bit of smoking at night
> <Internals\Patient interviews\P30>

This participant did not acknowledge his night time smoking as contributing to his current breathing problems. Participant 20 referred to his smoking on several occasions over the course of 2 interviews. In a linked memo to his first interview I noted:

> He returned to his smoking time and again. It was as if he was describing a raging battle within - he has had several relapses and even the recent incident reported here reflects the seemingly unrelenting fight against having a smoke. He clearly misses them dreadfully but it is the battle that is his focus.
> <Memos\Explanatory meaning>

Despite his accounts of frightening episodes of breathing difficulties, and general breathlessness that included at night he continued to battle with his desire for a cigarette. For Participant 2, smoking was an important mechanism for managing stress related to family life and dealing with bad news regarding a possible tumour in an xray report:

> I was back on the cigarettes for a few weeks, got my nerves settled and, grand, I was off them then and then in March when I was told, when Dr --- told me then I just said to the wife, give us a cigarette. I used to smoke 40 a day, I did for donkey's years and then I cut down. I still smoke a few cigarettes every day, for the last couple of months I did and hopefully now that's out of the way.
> <Internals\Patient interviews\Par_2_1>

For this participant, smoking had become a conscious balancing between attending to his COPD and stress management. Even for his COPD symptoms, smoking appeared beneficial:

> If I lit a cigarette, I know it sounds strange to say it, that coughing would stop. I'd be grand. I don't know why it does. I often found that happening, if I went too long without a cigarette. I'd just light a cigarette and I'd be grand.
> <Internals\Patient interviews\Par_2_1>

For some, it was after their giving up cigarettes that their breathing difficulties became severe:

I thought now oh this is going to be great, I'm going to be off the fags. I'm going to be able to do this and that; I'm going to be able to go here and there. A couple of weeks after the chest started to close down and that was it

<Internals\Patient interviews\P1_qual interview>

Several participants spoke about their family history of lung conditions and in some instances (Participants 9 and 30) cared for relatives with emphysema.

My brother died of it and he was only 53 when he died. And my father died of it, and the youngest when my father died was 6 months and my father was only 40.

<Internals\Patient interviews\Par_5_1>

the only thing is I was used to it because I've seen it all before, you know. My father had that very very early in life, he was got up with it, he lost terrible weight with it. He went from a fine big man to a tiny little man, but he would not give up smoking

<Internals\Patient interviews\9_3rd[1]>

The immediacy of death from COPD was evident in Participant Five's comments above. At the time of interview, she was past the age at which her brother had died from COPD. Though different generations, Participant 9 cared for an uncle who had emphysema and spoke of his final illness thus:

He couldn't breathe nor I couldn't. I found that, his funeral, oh God, very hard you know what I mean…

<Internals\Patient interviews\P9_2nd[1]>

Despite her finding in common their shared fight for breath Participant 9 also viewed her condition as differing from that of her father and uncles who died from emphysema:

I don't have asthma but there is a history of chest problems in my grandmother's side. All Daddy's uncles were never able to work or anything with bad chests and they all died in their thirties, you know what I mean. I know I have emphysema and I know I wasn't born with it or anything like that, you know what I mean

<Internals\Patient interviews\P9_3rd[1]>

For her, she was not born with a lung condition and her COPD was related to her smoking years now in the past.

Diagnostic Event

A diagnostic event represented a marker in the illness trajectory that signified a new phase in the illness trajectory or a worsening of the overall condition. The event came to have particular significance in their illness meaning making.

> On the Tuesday then I went down, no I was at home and one of the lads called and I sent him down to the doctor to see would he come up. He wouldn't anyway so he sent up tablets. That evening then I just kicked it out that's it [collapsed].
> <Internals\Patient interviews\P25b>

For Participant 25, this incident framed his experience of an exacerbation that marked a turning point in his illness experience. He had been living alone in poor conditions and following this life threatening exacerbation, he moved on to sheltered accommodation, better living conditions and hospital follow up. More typically, a marker included a severe exacerbation that resulted in long term changes in medication and/or increased disability:

> Dr --- was up there at the time and he wouldn't let me out until the oxygen was in the house that was it then
> <Internals\Patient interviews\P7_qual interview> .

For some a diagnostic event was a seemingly everyday occurrence that was experienced differently such as for participant 20 who experienced an episode of severe breathlessness while undertaking a routine everyday task in his garden:

> That day I was here on me own for the first time and the last times so I was lucky I didn't drop It frightened me.
> <Internals\Audio Files\P_20_08071400>

The episode marked, for him, his vulnerability while attending to routine chores outside while alone. Though he recovered quickly from this attack and had no need to seek medical help, the episode marked the end for him in undertaking similar chores when his wife was out. It had also been a frightening experience and signified a new intensity to his breathlessness to which only he was witness. Thus this episode reflected a dramatic shift in his illness trajectory that was not

made known to anyone beyond his immediate family.

Similarly, a diagnostic event could mark a significant loss or contraction of one's world illustrated by Participant 8 in her decision to give up her regular outing to bingo as referred to earlier. As such her decision marked a departure point in her illness trajectory and management of her breathlessness. Similarly, events could herald a review of the relationship between self and illness:

> Well it woke me up to if I want to live I have to straighten myself out… It's not a matter of lying down and dying. You get up and you say right, how am I going to plan this, without infringing on anyone else's because I am independent and that's it, full stop
> <Internals\Patient interviews\P25b> -

Thus, diagnostic events could be marked by reactions to a gradual or sudden worsening of symptoms prompting a review of self management that might feature conscious withdrawal or re-engagement with illness. Significantly, while some diagnostic events were easily recognizable reflecting marked increase in symptoms others were more likely to be recognized as such by the individuals concerned.   In the latter instance, events could signify dramatic shifts and meaning making in relation to the illness trajectory resonating with the idea of narrative reconstruction (Williams 1984).

Mediating Illness with Others

The chronic nature of COPD, its invisibility to others (Williams 1993) everyday breathlessness and increasing dependency brought to the fore the importance of mediating illness with others. In particular this mediation took place along the fault lines between disease and illness explanatory models of formal healthcare and lifeworld respectively. Mediating illness includes experiencing the mark and symbols of illness and focus on everyday relationships in addition to being seen not to abuse the health service through unnecessary admissions.   Thus, mediating illness encompassed a self consciousness of changed identity to that of an ill person and arising from that the need to negotiate through shifting roles and relationships within family and wider community circles. The mark of illness included using oxygen in public thus drawing attention not just to being ill but also having a smoking related illness.   Mediating illness through the health system addressed negotiating perceived rules of engagement with both HCPs and the health system where being seen not to abuse the system was important.

Mediating Illness in the Everyday

All but 2 participants lived near and were closely involved in their families. Their involvements were described in accounts of mediating their COPD through their relationships. Of the 2 who were not closely involved in their families, one spoke of the importance of maintaining and being seen to maintain his independence and ability to engage in everyday activities such as shopping. The other was a farmer and though now retired, his accounts relating his COPD management were suffused with his continued farm related activities. Thus, all the participants mediated their illness through their relationships and roles as wife, father, parent, sibling, friend and active citizens. Their illness imposed strains on their relationships:

> It can, it can cause absolute havoc between husband and wife and family
> <Internals\Patient interviews\P1_qual interview>;

and hold on roles as illustrated by this mother of teenage children:

> they want to go here and they want to go there and I just don't be able to do it, you know what I mean. Like, I've often gone to the gate in the car and had to come back in.
> <Internals\Patient interviews\9_3rd[1]>

While participants struggled to continue their engagement with everyday life and their relationships and roles therein, cultural meanings in this struggle were also evident. Illness and disability can be said to be mediated through culturally derived meanings in relation to performance expectations (Kleinman 1988). Becoming a patient within the family created tensions for some:

> They think they're doing right, you can't to this, you can't do that, shut the door. Like in a winter's night here I'll open the door here and stand there. [They say] that's how you're getting all them bugs, it gets on my nerves, you know what I mean. They'll say don't do this, don't do that, I hate that. I say well I'll take the chance and see how it's going to turn out, you know what I mean. I prefer that, yeah
> <Internals\Patient interviews\P9_2nd[1]>

Now I went out a couple of weeks ago and I managed to get 2 loads of washing done. Well he [husband] read me from a height.

Me

And how did you feel when you did that?

P1

I felt good, I felt good. Now I got one load into the dryer, and I couldn't take the other load out because he was after giving out hell to me because he wasn't there when I went out [to utility room].

<Internals\Patient interviews\P1_qual interview> -

For both these participants, their previous roles as mother and homemakers gave way to being made childlike through what they perceived as paternalism on the part of spouses and children. While illness influenced normal role expectations in these instances, for other participants, the invisibility of COPD masked the everyday risk of severe breathlessness:

A lot of people, my sister-in-law, I said to her now look it, I'm dead tired. And what have you been doing she said. For God's sake, like she doesn't understand that to make the bed is tough enough

<Internals\Patient interviews\P27 Qual> -

if I meet somebody I say no go on, I'll only hold you back, you can walk much quicker than I can.

<Internals\Patient interviews\P_6>

It's like my sister said, why don't you come to England, you know, go over for a fortnight. I wouldn't go because they'd be bringing you out and everything you know [and] you'd be you wouldn't know what way you'd be when you're out, you know that kind of a way

<Internals\Patient interviews\P10>

The importance of managing symptoms and continuing social roles was made more complex by feeling responsible for becoming ill in the first place for some:

But you get vexed with yourself with something you caused yourself you know what I mean. I did cause this myself, you know what I mean and you never think it's going to come to that, sure you don't.

<Internals\Patient interviews\P9_2nd[1]> -

Several participants preferred to hide their illness from strangers but were unable to explain why they felt embarrassed by their illness:

> Do I get embarrassed in public. I don't go to public places. I don't mix with the public you know I keep out of it.
> <Internals\Patient interviews\P27[1]>

> We were at a wedding and in the evening time now I had to use the inhaler and I couldn't use it there. I had to go you know, it was very awkward, you know
> <Internals\Patient interviews\P11[1]> -

> Ah, it leaves me very embarrassed, you know, and now I do see a few of the women in bingo with the oxygen, but I couldn't
> <Internals\Patient interviews\P8[1]> -

These participants had in common a need to hide their illness when in public and despite being with close friends or family. Participants 8 and 27, were dependent on oxygen and though in the company of others who were also using home oxygen, they felt unable to 'show their illness' in public.

Mediating Illness with Healthcare Services

The majority of participants experienced exacerbations that necessitated regular hospital admissions and in many instances hospital stays longer than one week. Length of stay in hospital and being seen not to abuse the system were frequently raised in conversations in the preamble to interviews. Interaction with healthcare frequently involved confronting a disease oriented approach to care that focused on the immediate and narrow range of symptoms with little acknowledgement of the patient's illness experience and lay knowledge.

Though several were admitted to A/E on a regular basis, the decision to go there was not taken lightly. In participants' accounts of getting to A/E, it seemed important to stress that this was done only as a last resort:

> They know it's my own fault and they'd say to me you left it very late
> and I'd know I'd left it very late and you'd think that if I'd copped on

that if I go sooner I don't have the same length of stay in hospital so it works out better.

<Internals\Patient interviews\P 34_structured interview> -

And you keep that way for quarter of an hour or 20 minutes and even at that if it still doesn't go, you may ring for help or get into the hospital

<Internals\Patient interviews\P26>

This participant had his own self monitoring approach to signs of an exacerbation to assess whether or not to call for help. Others reported similar self assessment of signs that were not indicative of the presence of infection but rather the severity of the infection. Three participants including participant 26 above, had self diagnosed chest infections on interview days but none saw the need to seek help from their GPs or A/E departments. Most participants saw little point in involving their GP during a crisis typically:

Now, I do be afraid to go into my doctor because Dr ---he won't even examine me. Once I go through his doors it's a letter straight away to get up to the hospital.

<Internals\Patient interviews\Par_2_1>

Some referred to being known to the local ambulance service and acknowledged by the drivers:

But now I don't, well as I was telling you the ambulance drivers will tell you ring us straight away, [they say] you're long enough going in and out and you know the procedures yourself.

<Internals\Patient interviews\P7_qual interview>

In this sense the ambulance drivers validated the decision to go to hospital. Familiarity with the routine of emergency care in A/E and what to expect in terms of response to treatment was evident and reassuring:

they're constantly trying to reassure you while they're working on you and, you know like, after, well I won't say immediately but they keep checking on you when they have you rigged up and all the rest, and little by little you come down off this high,

<Internals\Patient interviews\P7_structured interview>

It happens. When you're trying to get your breath, you're frightened. That's why you feel safe when you get inside the door in the hospital, thank God. The oxygen comes on and I'm very happy to but before that, you see, it's very frightening …

<Internals\Patient interviews\P 31 structured interview> -

As reflected in reports (Brennan *et al.* 2008), most of the participants had experienced hospital stays of more than 8 days and of being very ill on admission necessitating stays in intensive care units. However, others including 2 who were on home oxygen had more recent upsetting experiences that conflicted with their sense of being seen not to abuse the system. Participant 9 was dependent on home oxygen for the previous 7 years and was familiar with the admission process to A/E for management of acute exacerbation. He was admitted there by ambulance with increased breathlessness and the doctor on duty consulted with the specialist respiratory registrar:

He came back to me and said 'I've been consulting with a senior consultant Dr. –', but he [consultant] never even come near me. He was telling your man what to do and then your man comes out and said sure you have all the equipment. So your man [consultant] was after saying he has all his own equipment at home so what the hell did I go to the hospital for, so like, you say to yourself, you know, you'd be fairly bad and then the next time is why did you wait so long. You're wrong all the time. What are you coming in here for, go home and take your antibiotics and what have you, take off the bung, there's a plaster and off you go'

<Internals\Patient interviews\P7_qual interview> -

The account illustrates the process of 'othering' in which Participant Nine's own experience and knowledge is unacknowledged – his experience of an acute exacerbation was contradicted. Though a patient of the respiratory team with regular OPD appointments, he was not acknowledged by the specialist registrar who stood nearby. Finally, his justification for appearing in A/E in the first place was questioned if not explicitly then by implication based on the comment regarding having oxygen at home. Thus, this participant's own experience, his personhood within the respiratory team and integrity regarding his use of the system were all brought into question.

Several patients referred to what they saw as the pointlessness of OPD appointments typically:

> Every 6 months I go back. I think it's stupid now in a way because they keep bringing me back and they're not giving me anything extra. Do you know what I mean. I'm still on the same medication and I'm just told come back in 6 months.
> <Internals\Audio Files\P_20_08071400>

The process described by this participant and others suggested one that served the purpose of disease monitoring but with little apparent relevance to the lived experience of COPD. Despite the routine investigations that accompany these appointments and close monitoring of the disease process, the course of the illness experience ran in a parallel world in which everyday routines served as the greater benchmark for illness progression and loss. For one patient this dichotomy between the disease explanatory model perspective and her own illness and lifeworld explanatory perspective collided in this account:

> he said to me he was discharging me or something, I forget it now really, and I said to him that I really don't feel , you know, don't feel I'm right and he said oh, you'll be ok, go home and you'll be all right. Well, I said, I don't want to be coming back again or something. Well, he said to me, I'd expect you to be in and out of hospital much more often
> <Internals\Patient interviews\P27 Qual>

Though home oxygen and overnight non-invasive ventilation dependent, this participant was upset by the doctor's assessment of the seriousness of her condition. She went on to say:

> Oh no. He can't decide that, you know but I thought it was a very indiscreet remark and I thought it was not his place to say it. Let me arrive at that conclusion myself. I hope I don't meet him again.
> <Internals\Patient interviews\P27 Qual>

For this participant, her illness trajectory was more than the sum of assessment criteria pulled together by her doctor and bearing little relation to her own illness experience in the context of everyday life. Significantly, she had confidence in

her everyday knowledge gleaned from her illness experience to at the very least contribute to any assessment regarding her prognosis.

Several participants relayed accounts that ended with expressions of gratitude for getting a bed in overcrowded hospitals and being discharged from hospital while still unwell. These stories have in common the vulnerability of participants when facing the system and those from within it. Typically, participants spoke about being discharged while still feeling poorly typically:

> I literally felt that I shouldn't be discharged the day I was discharged.
> I was discharged feeling like death. I really was shook.
> <Internals\Patient interviews\P27[1]>

Some confronted the power imbalance inherent in the individual user/system relationship:

> so when I was brought back to [hospital] in that room where they can
> work on you, you know and next minute she [doctor] appeared and
> she says what's the problem. I said I told you what the problem was
> this morning
> <Internals\Patient interviews\P7_qual interview>

These confrontations referred to specific incidents usually those involving a decision to discharge or transfer.

Experiences with HCPs

Participants reported mixed experiences of interactions with HCPs. In these, participants differentiated between those healthcare professionals who operated under a *knowing the case* versus *knowing the person* (Liaschenko 1997) framework. Typically, in the former instance, interactions were disease focused while participants often felt unacknowledged:

> Well, do you see, you go to outpatients, you're trying to explain to a
> different doctor every time you go and 9 times out of 10 you get the
> impression that you are talking to yourself.
> <Internals\Patient interviews\P7_qual interview>

A knowing the case approach included instances that suggested poor decision-making combined with lack of knowledge about the individual patient:

he says you're ready for home and this was a Thursday and on the Friday he came back around and says are you ready for home. No, says I, I'm not and the lad that was Dr [consultant] house doctor came back on the Sunday and had a look at me. says he, they're not letting you go anyway

<Internals\Patient interviews\P25b>

In such instances, participants did not differentiate between *knowing the case* in the sense of clinical competence but limited engagement with patient from that of poor clinical judgment. In other words the *knowing the case* approach articulated by these participants ran along the fault lines between disease and illness explanatory models for interaction and decision making. These fault lines were evident in many accounts of frustrations regarding care. In these instances HCPs typically appeared to participants to be unsure about management while also failing to engage the patient:

Now maybe they have their own system but to me they open up a file and they keep going backwards and forwards and they're checking this and checking that and then they get a page with a bit of room on it and I'd say would you be interested to know what medication I'm on, [They'd reply] Oh very good, yeah, so I'll give them the card.

<Internals\Patient interviews\P7_qual interview>

This participant spoke of being further alienated from his medical team by his vain attempts to see his consultant:

I'd like to talk to her and I'd say there's been loads of changes medicine wise and everything, tablet wise and everything has taken place since I no longer see her, you know and it would give you a little bit more peace if you went to her and had a chat with her about this and she said well that's fine. Right you'd say well if she's happy I can afford to be happy.

<Internals\Patient interviews\P7_qual interview> -

In contrast, *a knowing the person* approach included knowledge of the nature of advanced COPD and instances where the fault lines were acknowledged by the physician between disease and illness explanatory models:

I was talking to her and she was saying, have you any family, no, says I, I'm separated and she says are you in a relationship. Says I, who'd want an old croc like me anyway. Says she you're young enough anyway, well says she, you look young enough anyway

Me

And how did that make you feel

P25

It makes you feel good She knows me now, she knows me better now. ……….. The time before that she'd have me in the hospital first

<Internals\Patient interviews\P25b> -

In this instance, Participant 25 relayed the effects of a growing physician/patient relationship in which the physician is acknowledging the patient's own illness narrative. Several participants referred to relationships with their GPs in which there was acknowledgement of the illness narrative and patients' knowledge of their particular condition. In an interview memo I noted comments made by a participant and her carer in conversation at the end of our interview:

[GP] calls her his survivor. He comes in and clears a space on the couch beside her and chats after giving her a kiss. Both mother and daughter seem very fond of him and daughter speaks of not calling him out unless mother is very ill 'he knows that.

<Memos\P_28_interview brief>

Acknowledgement did not require easy friendship of the kind experienced by Participant 28. Others' accounts implied an acknowledgement of other that implied moving towards the other's position:

The doctor came up a few times to me like that now. If I wasn't able to go down or P[wife] would send for him he'd come up alright. He'd tell you straight you know

<Internals\Audio Files\P_32_qual_2_08072501>

He was the third doctor that came to me, I can't know what his name was now, but the next morning I was so impressed with that chap, I said that that guy must have read my chart from start to [end]… because he gave that consultant any information that was in the

bloody file because I was listening to him. He was so concise, he was so precise and the consultant knew where he stood straight away you know and this took place at the end of the bed
<Internals\Patient interviews\P7_qual interview>

While Participant 32 was speaking about his GP and in the context of knowledge of a long standing relationship, Participant Seven's account related to a junior doctor whom he met on just this one admission. In this sense being familiar with a particular patient over a long period was not a pre-requisite for *knowing the person*. The scope for patient and physician to engage with one another was an integral feature however:

he was the consultant and I think I told you, he saw me earlier, we'll say on Friday or Saturday morning, I couldn't be sure now and I didn't see him for maybe a week and when he came back then he was interested in talking to me. He wasn't chatting away to the guys [medical team] and looking out the window and what have you, and he said on a scale of one to a hundred per cent he says where would you see yourself now as compared to when you came in. He said I know he says you're not great now but he says where would you be. Well I says you're the doctor. No, no, he says, in your case you're the one that can tell us, so I told him
<Internals\Patient interviews\P7_qual interview>

While most of the comments in relation to healthcare centred on physician related experiences, those that referred to nursing care also had a *knowing the case/knowing the person* theme. Staying with Participant 7, his story about one incident captures the acknowledgement of *other* in approaches to care:

I remember saying to a nurse one night I said I would love to have a shower but I said I can't go in on my own. I have to have the oxygen. She said you give me a quarter of an hour she said and I'll give you a shower. Now, this was at 12 o'clock at night and she did because I was able to go in and sit down in it, do you understand, and the oxygen was outside the curtain and she said you work away and I'll be back to give you a hand to dry yourself. She was brilliant and you just felt like a quarter pound had fallen off you because you can't wash yourself at a sink.

<Internals\Patient interviews\P7_qual interview>

Conversely, incidents were also relayed that implied failure to acknowledge the individual such as being left to wash when too breathless to do so and having to repeatedly ask for assistance. Participant 7 experienced an acknowledgement by the nurse of not just his basic need to wash at that point. Rather, for him, the nurse went further and reached out to him.

Summary

Participants described their lives as continually contracting in response to living with actual and constant threat of breathlessness. Impact on lifeworld was manifest in the ensuing losses of previous sense of self, roles and independence. Their contracting worlds and lifeworld impact resonated with research findings elsewhere (Williams 1993; Booth *et al.* 2003; Barnett 2005; Fraser *et al.* 2006; Clancy *et al.* 2009). Living under the constant threat of severe breathlessness generated stories describing cycles of dyspnoea/anxiety/dyspnoea similar to those described by Bailey (2004). COPD pervaded all aspects of the lives of these participants contracting their worlds resulting in loss of roles and relationships, and impacting on sense of self. For some, their worlds had contracted to the point that the physical space in which they lived could be limited to a corner in their kitchen or living room. Their social space was restricted in terms of engagement in activities of everyday life and social interaction such that contact with extended family and friends was limited. The loss of meaning to life for some participants resonated with the findings from a study that focused on COPD at end of life (Ek and Ternestedt 2008).

Chapter Eight Outcome of Patient Interviews

Introduction

The purpose of this chapter is two-fold, namely to present the results from the health status measures and the integrative analysis of the themes and measures in section one; and, in section 2, to consider the overall findings from phase one that informed the co-operative inquiry in phase 2. In the overall view, I draw on Kleinman's (1988) illness meaning by way of illustrating the all-encompassing nature of advanced COPD and implications for understanding palliative care needs.

Health status Scores

The breakdown of participants' scores are listed in Appendix 28 for MRC dyspnoea scale, anxiety and depression, and SGRQ symptom, activity, impact and total scores. Overall, scores reflect advanced stages of COPD with half the participants experiencing mild to severe levels of anxiety (Tables 8.1, 8.2, 8.3).

Table 8.1 MRC Dyspnoea Scores

MRC Grade	Participants
Grade 1: Not troubled by breathlessness except on strenuous exercise	2
Grade 2: Shortness of breath when hurrying or walking up a slight hill	0
Grade 3: Walks slower than contemporaries on the level because of shortness of breath, or has to stop for breath when walking at own pace	5
Grade 4: Stops for breath after walking 100m after a few minutes on the level	19

Participant 4, appeared to be unaffected by her COPD and had a total SGRQ score of 10. She was experiencing significant disability from hip arthritis and attributed her immobility to this rather than shortness of breath. She was reliant on a family caregiver for everyday support including shopping and heavy housework. Her disability from hip arthritis prevented her from engaging in activities such as normal housework. She had stopped smoking following her one and only admission to hospital for treatment of an acute exacerbation in the previous year. She had not previously had a COPD diagnosis. It is possible that her hip arthritis,

to some degree, masked her degree of breathlessness on exercise. Participant 22 reported an MRC score of one despite also reporting significant symptom impact (SGRQ score > 60) in his narrative.

Table 8.2 Summary of Health Status Measurement Scores

Measures	Mean	Median	Range
Anxiety	8	8	0-20
Depression	7	6	0-15
SGRQ Symptom	63	65	19-100
SGRQ Activity	76	84	0-100
SGRQ Impact	54	60	6-100
SGRQ Total	62	70	11-94

SGRQ

Mean and median values are included in Table 8.2 because of the possible outlying effects of the low total respective scores of 10 and 24 of 2 participants. One had a symptom score of 74 despite an activity and impact score of 10 and 15 respectively. This man had experienced a severe exacerbation in the previous year and had 2 previous admissions for acute exacerbations of COPD.

Figure 8.1: SGRQ Components and Total Scores
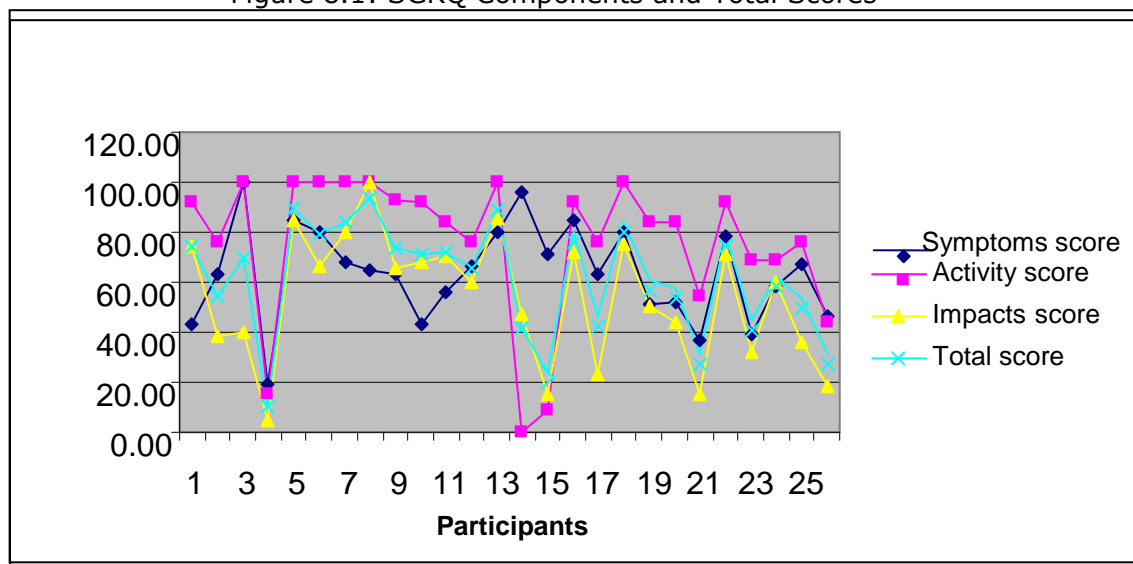
He was reliant on nebulised medication and his activity and impact scores conflict with his symptom scores and his breathlessness while walking beside me. A summary of health status measurement scores is presented in Table 8.2.

The SGRQ symptom, activity, impact and total patterns are shown in Figure 8.1. The mean scores for each component and total score suggest severe impairment and impact (Jones *et al.* 2003b).

HADS

While not intended to be diagnostic, scores on the HADS for both depressive and anxious symptoms are categorised as follows: normal range, 0-7; mild, 8-10; moderate, 11-14; severe, 15-21 (Snaith and Zigmond 1994). Over half (60%) of participants had scores suggestive of anxiety or depression or both. Table 8.3 refers to those participants (n = 16) with scores of 8 and over for anxiety and/or depression with anxiety scores arranged in ascending order.

Table 8.3 Anxiety and Depression Scores > 8

Participant	Anxiety Score	Depression Score
24	7	8
10	8	10
21	8	13
31	8	5
33	8	11
11	9	2
7	11	10
2	12	6
6	12	10
8	13	5
9	13	6
20	13	9
26	13	12
30	14	10
1	19	9
5	20	15

Regarding participants with scores suggestive of anxiety, 5, 8 and 2 fell into mild, moderate and severe ranges respectively. Of those participants with scores suggesting depression, 7, 3 and 1 fell into mild, moderate and severe ranges respectively. Anxiety appeared more prevalent. For those with depression scores of greater than 8, anxiety co-existed in all but one instance and anxiety scores tended to be higher (Figure 8.2).

Figure 8.2 Plot Showing Each Participant's with Anxiety and Depression Scores
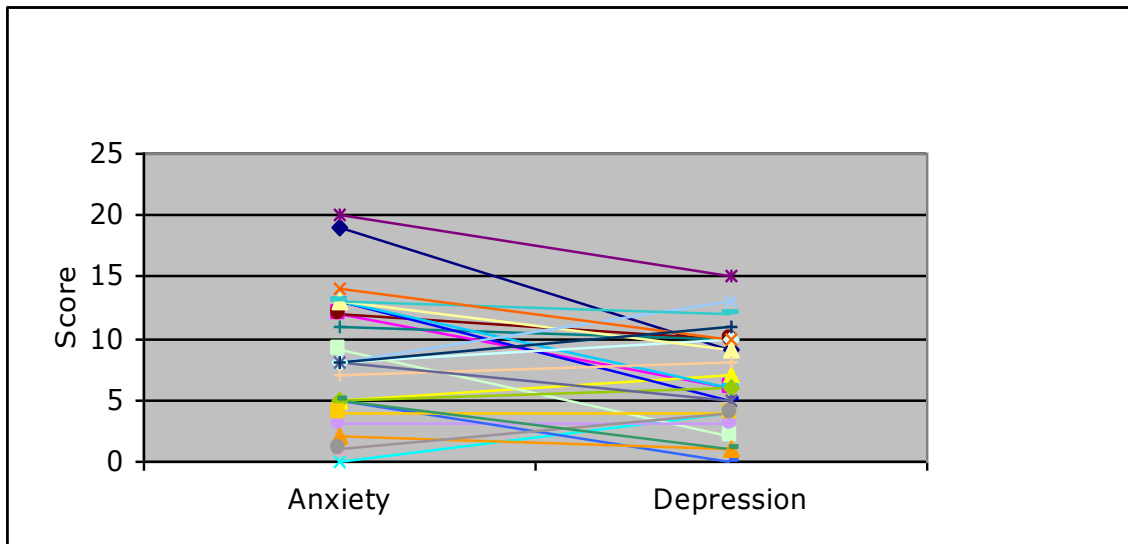
One participant has an anxiety score of 7 but a depression score of 8 while 4 have depression scores of less than 8 but anxiety scores greater than 8 (Figure 8.2). Anxiety appeared more prevalent (15 participants). Of those 11 participants with depression scores of 8 or greater, 7 also had anxiety scores suggesting moderate or severe anxiety.

Summary of Health Status

Health status generally reflected moderate to severe impairment and poor health related quality of life. The mean scores for each of the 3 SGRQ components and total score compare with those cited elsewhere for people with advanced COPD and experiencing exacerbations (Almagro *et al.* 2002; Wang and Bourbeau 2005; Medinas Amoros *et al.* 2009). The mean health status scores in this study compare with those associated with COPD Stage 4 (very severe) found by Gudmundsson et al (2006a) in a multi-centre study involving over 400 patients. The association between COPD, and anxiety and depression (Chang *et al.* 2006; Gudmundsson *et al.* 2006a; Oga *et al.* 2007) appeared evident in 15 and 11 of the 26 participants with scores suggesting anxiety and depression respectively. The suggested anxiety and depression prevalence in this study compare with findings elsewhere (Kunik *et al.* 2005; Gudmundsson *et al.* 2006a) though prevalence reports vary for anxiety and depression in COPD (Mikkelsen *et al.* 2004). In all but one instance, participants in this study appeared to have health status indicative of severe COPD stage 4. The poor health status of these participants resonates with other research findings regarding hospital admission as an indicator of advancing disease.

Integrating Patient Narratives

The integrative analysis strategy involved the joint display of and analytical linking between quantitative and qualitative data (Lee and Greene 2007). Quantitative data was imported as attributes into NVivo. All data for each participant, including the attribute data, recorded interviews, transcripts and memos were grouped as cases; each case represented an individual participant. Matrix tables were generated (Appendix 18) for each attribute with each theme and respective subthemes. This allowed each attribute to be checked against all coded data (Appendices 15, 29, 30). Each matrix table was scanned for the frequency and density of coding relative to scores for the given attribute (Appendix 17). By frequency, I mean the number of codes listed across cells. By density, I mean the concentration of different sources coded in each cell where sources refer to interviews. This process provided:

a) an overall picture of patterns in relation to coding and attributes
b) an evaluation of the coding thus far whereby patterns of coding were examined for possible gaps in the coding process.

Coding queries (Appendix 14) were then undertaken to cross check the coding process. Following that, the coded sources cited in the matrix cells reflecting high, mean and low scores were examined for contextualization of a given attribute (Appendices 29, 31). This was done by establishing congruence and discrepancies between interviews and the given attribute. This process brought the analysis focus on each participant's health status but in the context of the individual illness narrative thus particularizing health status similar to participants' engagement with the health status interviews.

Coded sources were spread across the scores of the SGRQ domain and total scores. Matrix tables for codes indicated a wide spread of codes across cells irrespective of the SGRQ scores (Appendix 30). Other than participant 4, all of these participants, lived with severe everyday breathlessness, experiencing contracting worlds, and impact on lifeworld. Since the SGRQ scores also indicated significant impact across all domains, a similar and corresponding impact across the main themes in the qualitative data would be expected. The themes from the qualitative data provide richer view of life with COPD for the individual.

Anxiety and Depression

The matrix tables for codes, and anxiety and depression are shown in Appendix 31. Congruence and discrepancy was sought for themes: Lifeworld, Emotion and Contracted World since these themes had the greatest density above the mean scores and also reflected expressions (Emotion) and consequences (Lifeworld and Contracted World) of both anxiety and depression (Appendices 29 and 31). Convergence reflects those accounts that support the anxiety or depression scores; divergence reflects those accounts that appear to conflict with the scores.

Table 8.4 Low Anxiety as Attribute, and Lifeworld, Emotion and Contracted World: Congruence and Discrepancy*

	Congruent	Discrepant
Lifeworld	No, it never got to that stage that it stopped me from doing anything, never. Now it wouldn't be the best of chests you know, but it never stopped me from doing things. No, I don't do the shopping anymore. Can't carry it. <Internals\Patient interviews\P4> (SGRQ 11)	I don't know what situation I'm going to be in, you know, like I'm afraid to go down the road Internals\Patient interviews\P 32(2)> (SGRQ 62)
Emotion	No, I don't, I don't panic. I'm gone used to it now that I don't, I'm able to handle it like, you know. Well, no I'd hold it together like, I don't, I really don't panic <Internals\Patient interviews\P22[1]> - (SGRQ 41)	Yeah, I would get that panic if I had a fit of coughing, I'd get into a panic. Now I know it's stupid and I try and do a TM or something in the middle of it but I still, I just still think I'm banjaxed, you know, that I can't do anything, yeah, that's right. <Internals\Patient interviews\P27[1]> (SGRQ 61)
Contracted World	Well then, I was just kind of coping with it, before 2003. Now I'm, as I say, I could only go about 5 yards before I'd have to stop. Now I can go an awful lot further. I feel fresher in myself, more able to cope <Internals\Patient interviews\P25b> (SGRQ 47)	I don't talk about it to anyone. I try and hide the fact, well not hide it because my friends know I'm on that thing, you know, the oxygen therapy but I don't talk about it but you know I can do nothing really. It's a pain in the butt <Internals\Patient interviews\P27[1]> (SGRQ 61)

*Congruence reflects quotes that seem in keeping with score while discrepancy reflects quotes that appear to conflict with score.

Anxiety

For Anxiety, all themes appeared more densely coded above the anxiety mean score (8) with the density greatest at a score of 13. Table 8.4 presents the linking of low anxiety with participants' own accounts of their life with COPD. The SGRQ scores are shown in brackets below each quote.

In convergent illustrations those with anxiety scores of 0-5 appeared not to feel disabled by their COPD even though they acknowledged breathing difficulties (Table 8.4). Participant four's apparently contradictory comment (Table 8.4) reflects the presence of co-morbidity wherein both a combination of arthritis and COPD have combined resulted in her being more house-bound.

A feature of this convergent group was a focus on learning to cope with and accept COPD to the point where in the case of Participant 25, there can be a felt improvement. Divergence was illustrated in fear of the unexpected such as an attack of breathlessness, and reluctance to present to others the face of COPD such as appearing breathless or being on oxygen. In this sense, divergence reflected the antithesis of the acceptance and coping reflected in the convergent illustrations.

For those with anxiety scores of greater than 8, divergence was less apparent in participants' accounts. In other words, participants illustrations of life with COPD converged with moderate to high levels of anxiety. Table 8.5 shows links between moderate to high anxiety and participants' accounts. Among the congruent accounts, participants related incidents that illustrated anxiety driven by fear of breathlessness and the impact of this on everyday life. Actual and anticipated breathlessness were likened by participants to panic attacks such that breathlessness and panic attacks triggered each other in a terrifying cycle as illustrated by Participant 9 (Table 8.5).

Divergence was less clear however. There was no apparent divergence in the links between anxiety scores of greater than 8 and lifeworld theme. In some instances, accounts bore conflicting claims that indicated partial divergence from high anxiety scores (Table 8.5). In these accounts, participants illustrated anxiety as contingent on their control over their everyday routines and environment to better minimize breathlessness attacks. Where control was achieved over one's environment and threats of breathlessness, then these participants spoke of coping and little anxiety. However, the price for this control

included further contraction of one's world and awareness that control itself was contingent.

Table 8.5: Moderate to High Anxiety (Score 11-20) as Attribute and Lifeworld: Congruence and Discrepancy*

Lifeworld (Congruent)	Lifeworld (Discrepant)
I don't go to football matches now or anything like that cause I don't be able to walk so far you know I don't like walking too far cause I know it will come on me you know and aah going to the pub is grand. And even the country show was on and I didn't go cause I'd be walking around and I wouldn't enjoy it you know <Internals\Audio Files\P_20_08071400> - (SGRQ 66)	I can cope with it, you understand, provided I can stick to my medication but when I get a chest infection, that's a different story, like when I have to go in all of a sudden. I go completely breathless, I can't breathe or I can't talk, can't do anything. It's like an asthmatic attack <Internals\Patient interviews\P 31 Qual interview> (SGRQ 45)
If the church was full the confirmation here, I got to the door and I knew I couldn't face it and I knew I had to get out and when I came out they were after locking the gate and weren't letting any more cars into the churchyard, it was packed and I panicked in the car, screamed at the man to just let me out of the cage you know. <u>\<Internals\Patient interviews\P9 structured></u>	It's like my sister said, why don't you come to England, you know, go over for a fortnight. I wouldn't go because they'd be bringing you out and everything you know you'd be you wouldn't know what way you'd be when you're out, you know that kind of a way <Internals\Patient interviews\P10> (SGRQ 71)
(SGRQ 73)	

*Congruence reflects quotes that seem in keeping with score while discrepancy reflects quotes that appear to conflict with score.

As might be expected, emotion as a theme converged with higher anxiety scores; there was no apparent divergence or conflicting accounts. However, some participants' accounts focused on the frightening cycles of breathlessness and panic attacks while others relayed a constant anxiety over what was happening to them and their world. Table 8.6 links anxiety with fear as a constant presence and panic attacks.

Since the threat of breathlessness attacks was an everyday occurrence, panic attacks were not viewed as discrete incidents but rather as an ever present possibility as illustrated by Participant 7 (Table 8.6). Participant 1 (Table 8.6) illustrates the overlap with anxiety and the themes lifeworld and contracted world. For her, panic attacks come with the anticipation of breathlessness and

interruption in her routine and controlled environment. For all but one, participants lived with or close to their carers and social networks. This support was an important source of achieving control; the absence of nearby support and experience in the past of severe breathlessness in the night left participant 22 fearful of a repeat episode (Table 8.6).

Table 8.6 Moderate to High Anxiety (Score 11-20) as Attribute and Emotion*

Emotion (Constant)	Emotion (Panic)
you're just waiting for something to happen, you know just <Internals\Patient interviews\P_6> (SGRQ 79)	There's no use in anybody denying it. They can't deny that because if they deny it they're telling lies because if you find you can't catch your breath and what happens then is by panicking, no matter how much you try you will panic and that makes it worse. <Internals\Patient interviews\P7_structured interview> (SGRQ 84)
I don't know what it is. I just, I work myself up into a state you know…I know that I start thinking of my husband and everything then, you know, and the family <Internals\Patient interviews\P 33 structured interview> (SGRQ 54)	
Well often times you can walk too far and get a bit het up, yeah. <Internals\Patient interviews\9_3rd[1]> (SGRQ 73)	the panic attacks, the panic attacks only happens when I'm under pressure to go somewhere and then it starts and then I get, I can't breathe, I can't talk, I can do nothing <Internals\Patient interviews\P1_qual interview> (SGRQ 74)
Yeah, (dying) that thought goes through my head here every day. I said no, I can't leave him, that's what I do be saying. Maybe I'm wrong thinking that way but that's the way I think, you know. <Internals\Patient interviews\P8[1]> - (SGRQ 94)	The only time I get that frightened feeling is at night when I know there's no-body around <Internals\Patient interviews\P26> (SGRQ 84)
Sometimes in the morning, touch wood, an awful sensation trying to get your breath..Terrible. I'd open the window. I'd take a sip of water <Internals\Patient interviews\P30> (SGRQ 79)	

*Congruence reflects quotes that seem in keeping with score while discrepancy reflects quotes that appear to conflict with score.

A constant presence of fear and worry is illustrated in the accounts of some participants in which they spoke of their fear of the future and consequences for loved ones. Participants 6 and 8 both reflect this. For Participant 33, the worry about her family was generalized and reflected her increasing disability and uncertainty about illness trajectory. For Participant 8, her worry was specifically

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related to fear of dying and leaving her husband. The uncertainty of their individual illness trajectories compounded this fear resulting in inability to discuss death and uncertainty about prognosis. A more constant state of anxiety was also linked with everyday activities that precipitate breathlessness.

Table 8.7 Moderate to High Anxiety (Score 11-20) as Attribute and Contracted World: Congruence and Conflicting*

Contracted World (Congruent)	Contracted World (Conflicting)
it's very annoying at times. You want to go somewhere and sometimes you can go .. walking, you know what I mean …and I'd say you'se go on ahead and just leave me and they won't do that and they'd be a bit annoying too, are you all right, are you all right. I said to X before, if you keep asking me am I all right, you panic me, you know. Don't be asking, leave me alone you know <Internals\Patient interviews\9_3rd[1]> - (SQRQ 73)	Sure the last time I was in hospital the district nurse came. She offered me meals on wheels … I did get the meals on wheels for a while but that was no use……….. we wouldn't have had enough but he wasn't able so I stopped that. The nurse stopped that. But I do the vegetables and everything <Internals\Patient interviews\P 31 structured interview> - (SGRQ 45)
It can come on anytime for whatever reason I don't know. You know I've often said why did I bring this on, you know, did I do something, did I eat something, that's what you'd be just trying to figure out, what caused it. I don't know what caused it.. you're all the time thinking, you know, because of the way you feel within yourself, within and you think Oh God… <Internals\Patient interviews\Par_5_1> (SGRQ 89)	

*Congruence reflects quotes that seem in keeping with score while discrepancy reflects quotes that appear to conflict with score.

The importance of controlling their environment as part of minimizing the threat of severe breathlessness attacks resulted in a contracting world. However, contracted world fuelled further anxiety as people responded by seeking to expand or arrest this contraction. The links between anxiety scores greater than 11, and the theme contracted worlds illustrated an interplay of consciously contracting one's world, carers' concerns and anxiety for Participant 9 (Table 8.7). For this participant, her contracted world was both a self conscious act to control threats of breathlessness and panic attacks, and a consequence of feeling smothered by family concerns when outside her home. Thus, her contracted world had both physical and psychological elements. In this sense, contracted

world might be understood less as the world within which she moves and more her core being.

For Participant 5, her conversation with herself (Table 8.7) reflected a diminishment of self brought on by that interplay of living with the threat of breathlessness and felt helplessness. In contrast, Participant 31 who spoke about her fear of breathlessness and contracted world, regained some control by returning to her role as housewife (Table 8.7). On discharge from hospital, she was offered and accepted meals on wheels. However, by re-entering her role as housewife to prepare meals, she reversed the contracting of her world. It should be noted that her total SGRQ of 45 was low compared with other participants. She spoke of coping well in between chest infections (see Table 8.5). Nevertheless, the degree of assistance upon which she depended for everyday activities such as hanging washing on a clothesline and shopping pointed to disability as a result of her breathlessness.

Depression

Coding density appeared clustered for depression scores of 4 and 6 (Appendix 31). However, the density relates primarily to 3 participants across a total of 7 interviews. Thus, the density reflects high number of sources coded from the 7 interviews rather than number of participants.

Table 8.8 Moderate to Severe Depression (Score 11-15) as Attribute and Lifeworld (Congruent Only)

This doesn't allow you to do anything, you know, it's either a little bit or you have a heart attack trying to do something. Well that's what I feel. <Internals\Patient interviews\Par_5_1>
I have lost an awful lot because in the first place I can't go to the hairdressers and in the second place I only take a bath once or twice a week. I take a shower but we've only got the shower in lately and it's too hard on me and I'm afraid to take it on my own in case. I like to have someone with me <Internals\Patient interviews\P26>

In contrast, a similar coding density in relation to depression scores of 9 and 10 reflects sources coded across interviews involving 6 participants. Appendix 31 presents the linking of scores suggesting mild depression with participants' own accounts of their life with COPD.

For the 4 participants with depression scores of greater than 11, lifeworld experiences reflected a focus on loss of a previous life (Table 8.8). There were no stories or comments that diverged from this focus. However, for Participant 33 adaption seemed more (depression score 11) manageable than for others (Table 8.9).

Table 8.9 Moderate to Severe Depression (Score 11-15) as Attribute and Lifeworld: Adapting

Reference 1 No, I go in there and have a shower and that now. I had a shower put in and the bars and the seat and everything is in there. Reference 2 - 0.75% Coverage I would, I'd carry a bit of shopping out from the, from Tesco, leave the car quite near on the disabled place and then I take my time walking around the shop but I'd still be a bit breathless walking around. \<Internals\Patient interviews\P 33 structured interview\>
Yeah I thought it was a miracle, I swear to God. I was so delighted with myself and I kept saying you know why does a little thing like this make you feel, it was making me feel good because I was feeling so bad when I went into the hospital, you see, but in saying all of that, it doesn't matter what medicine I have, if I have to do something with effort, no use, no use at all. \<Internals\Patient interviews\Par_5_1\> -
I'm never have good days these times. Most days are kind of not good they are a struggle [3:07.8 – 3:20.8] \<Internals\Audio Files\P_21_08031801\>

Participant 5 illustrates in her quote above, her cycle of hope and disappointment as an initial good response to a changed prescription generally proves temporary. For her, medication seems to have little positive effect on her ability to engage with everyday life. For Participant 33, life is limited to days being spent in a chair in her kitchen. Despair featured in the emotional responses of all of these participants no divergence Table 8.10

Table 8.10 Moderate to Severe Depression (Score 11-20) as Attribute and Emotional Response

No, it won't get better, I don't believe it'll get better. I wish to God it would. No. no, I'd hate, I think about it and I know, I remember when I was visiting in Naas Hospital and I seen this old lady and she was going, puff puff and I said God, it'll be me, now hopefully but you know. My brother died of it and he was only 53 when he died. \<Internals\Patient interviews\Par_5_1\>
I'd love to walk over with the home help but it would kill me before I'd get there \<Internals\Patient interviews\P 33 structured interview\> -

Degrees of mobility varied among the 4 participants with scores suggestive of moderate to severe depression. One participant was still driving though drove only short distances for shopping and church services. The participant (P 5) with the highest score (15) had recently become fully dependent on close relatives for any activities outside her home. She was no longer able to carry a shopping bag. She was also struggling to adjust to being increasingly limited in her own kitchen no longer being able to cook food for others:

> I wouldn't be able to pick up a saucepan I can tell you but I would be capable of cooking a dinner but in my own time but I could get stressed, <u><Internals\Patient interviews\Par_5_1></u>

In contrast, Participants 21 and 26 were both functionally disabled to the degree that they were fully dependent on their family carers for meals, shopping and help with washing and dressing. In this way, while all were experiencing severely contracting worlds, for Participant 5, hers was doing so with particular intensity at the time of our interview.

Participant 26 (Table 8.11) was able to look forward to her grandson's confirmation even though she was only able to attend a part of the celebration and that only with the help of her daughter. Similarly, though Participant 33 was unable to walk a distance of about 15 meters, she was able to drive to the local shop (see Table 8.9). Thus while all were acutely conscious of their contracting worlds, in the case of Participant 5, this awareness was suffused with an overwhelming sense of profound loss.

Table 8.11 Moderate to Severe Depression (Scores 11-15) as Attribute and Contracted World

No, my daughter is here with me. I couldn't live on my own....And this annoys me because I'm sure that people look at me and probably say you know, there's nothing the matter with her. Little do they know, because I would love, and I've lost loads of friends and all because of it, because they would keep in touch with me and then they'd probably get fed up because I'm just not the person I was <Internals\Patient interviews\Par_5_1>
Oh I do look forward to things, like my grandson's confirmation there that time, I was looking forward to that for ages <Internals\Patient interviews\P26>
I couldn't walk from here to the next door. <Internals\Patient interviews\P 33 structured interview> -

Summary of Health Status

Over half the participants appeared to be experiencing anxiety and or depression. Interview data converged with scores of greater than 8 for both anxiety and depression. Actual experience and anticipation of attacks of breathlessness were drivers for and consequences of anxiety and panic attacks becoming terrifying paralysing breathlessness/panic cycles. Fear of breathlessness was an impetus for participants to consciously contract their worlds in an effort to regain control over the breathlessness/panic cycles. A sense of loss featured strongly in scores suggestive of mild to severe depression. The nature of the loss seemed similar across scores: participants with lower scores were experiencing similar loss in roles and relationships as those with higher scores. In both anxiety and depression, adjusting to increasing functional disability seemed important for better coping. Moreover, it's possible that in a period when symptoms increase and loss is intensified, disabling anxiety and depression may be at their worst.

The impact of COPD described by participants here was all encompassing. In the following section I draw on the interview findings from chapter 8 and the integrated analysis above to explore the all-encompassing nature of advanced COPD with particular reference to suffering or total pain. I finish with questions arising from this that informed phase 2 of the inquiry.

Section Two Illness Narratives

The interview narratives resonated with Cassell's (1991) understanding of suffering as threat to or actual destruction of the person. Person in this sense is a living political being with a body and mind; a past, present and perceived future; a cultural background, identity and roles; personality and behaviours; self and self awareness, and human spirit. Thus, in suffering, the threat to the integrity of the person can therefore be about one's perceived future or sense of self in the world as it can relate to bodily pain.

Meaning Making

In this research, participants' narratives reflect similar threats to personhood brought about by severe breathlessness. These threats seemed to be continually evolving as the effect of severe breathlessness disrupted emotional and social selves provoking states of anxiety culminating in a shrinking of one's social world, loss and reinterpretation of illness meaning. Difficulty in boarding a bus for

Participant 8 marked the need to limit social interaction. Arriving home from hospital and feeling no longer able to make up her bed marked a new level of functional disability and exhaustion for Participant 27. In both instances, perceived future, past experience of severe breathlessness, previous identity and roles and relationships as part of personhood are brought to the fore. Importantly, these threats were recalled as ones that both followed and preceded other threats along the illness journey. In short these events could only be appreciated in the context of illness effects that were continually evolving and cutting the individual from life hitherto fore.

Symptom and Culture Meaning

Kleinman's (1988) 4 levels of illness meanings were illustrated in participants' COPD experiences as they confronted threats to personhood. At the level of symptom meaning, participants faced their own mortality when experiencing severe breathlessness. All but one (Participant 4) had experienced life threatening breathlessness. Everyday breathlessness represented risk of a serious deterioration. Subtle changes in breathing, cough, phlegm, pain, fatigue, mood, concentration etc were monitored closely and often noted as early warning signs of infection. At the level of cultural meaning, the worlds in which participants lived were altered, sometimes decimated, as they lost ability to engage in activities as they had done previously. Roles through which identities were affirmed were compromised as homemakers were no longer able to manage their homes; husbands were no longer able to undertake heavier home-based tasks etc. With personal responsibility for lifestyle to the fore in western society, guilt at having a smoking related illness was evident in illness accounts. In their interview narratives, some participants struggled with this.

Lifeworld

At the level of lifeworld, participants' lives and COPD were one. Life as they had previously known was changed as their roles as parents, spouses, providers, homemakers etc were lost. In their place, participants became patients in their families. Life was lived through COPD; interview narratives were suffused with loss and grief for their previous selves and bodily function, their self image, and past life. Participants 2, 20 and 32 were no longer able to undertake tasks that had previously defined their strength such as carrying heavy loads. For Participants 1 and 8, their place within their families changed from that of

homemaker to patient. For Participant 27 her active life of gardening, touring, golf and bridge had become one of oxygen dependency and almost being almost housebound. For all but one participant (Participant 4), living their life of advanced COPD meant relentlessly routinised days and avoiding or minimising any activity however mundane that might increase breathlessness. Despite strict routines and risk management, over half the participants lived with significant anxiety and/or depression. Just as Kleinman (1988:32) described the experience of his patient with complicated diabetes, Alice Alcott, the relentlessness of increasing breathlessness and functional disability for participants was prominent in interview narratives. His choice of metaphor for chronic illness was that of a volcano that menaces and erupts, and remains out of control or 'one darned thing follows another' (Kleinman 1988:44) echoed the experiences of participants in this research.

Explanatory Models

The fourth level of illness meaning for Kleinman (1988) was that of explanatory and emotion meaning.   In their interview narratives, past life and illness experiences were bound up in participants' meaning making. Several saw their worlds in which they grew up and worked as harsh and inhospitable. Developing COPD was part of the harsh reality in which they had lived. Participants 1, 2, 9, 22, 25, 29, 32, and 33 linked their early lives to their current illness. For some, the link was exposure to toxic substances at work but for others the link was simply the harshness of their early lives in the impoverished Ireland of the 1940s and 50's.

Most understood their medication as one aspect albeit an important one of their COPD management. Medication regimes were strictly adhered to in terms of time. In conversations pre and post interviews and in follow up, participants and their carers referred to instances when they would increase oxygen flow or decrease time spent on NIV or nebulised medication. These adjustments were done independent but fully cognisant of medical advice and were based on participants' own judgement of their illness state in a given period. In Carolyn Ellis's (1995) record of her partner's end stage COPD, changing oxygen flow became a flash point between the physician, and Ellis and partner often with Ellis caught in the middle. One carer spoke about the trade off between addressing confusion and staying 'within the rules' regarding oxygen use. Like Ellis, this

carer spoke about mediating between the advice of the HCPs on the one hand and the pleas of the care recipient on the other.

Daily rituals for getting up in the morning, diet, and minimising risks of breathlessness were also given importance. Significantly, explanatory meanings were edited in interactions with healthcare.   In their interview narratives participants referred to different strategies to help day to day symptoms such as meditation, drinks of hot lemon drink and exercises. Signs were recognised as indicating early stages of infection such as headaches, irritability and muscle tightness. In most instances, these strategies and signs were viewed as personal and were not shared with HCPs. This may reflect the awareness of patients and HCPs of the 'demands of different settings – home, public clinic, private office, disability agency courtroom - and how these help cast the story in different form' (Kleinman 1988:52). In his story of his cancer experience, Arthur Frank (2002a) refers to his managing his communication with HCPs choosing carefully what information to relay, when and how it should be relayed. The point was to protect himself and his wife from having their vulnerability exposed and dismissed. Put another way, participants recognised the chasm between their illness narrative through which they were living and the disease narrative to which HCPs responded. In Goffman (1971) terms, illness narratives were backstage when dealing with HCPs.

Back Staging Illness Narratives

The routine stabilization process in A/E and limited engagement with HCPs reflected a focus on the biomedical approach associated with acute hospital care (Charon 2006; Checkland *et al.* 2008) or the narrow range of signs and symptoms that categorise a patient's condition in technical terms.   For participants, this routine in A/E was reassuring both in terms of familiarity with the emergency management steps and expectation that these steps would arrest their severe and out of control breathlessness. However, participants' accounts of their hospital experiences were also suffused with struggles to negotiate with the biomedical organization and delivery approaches to care similar to those recorded elsewhere (Thorne 1993; Irvine 2002; Charon 2006; Checkland *et al.* 2008). Instances were recalled of participants' felt need for admission being questioned or being discharged too soon based on their illness markers. Participants 7, 27, 31 and 32 attributed relapses or compromised recovery from acute exacerbations to being discharged too quickly.   Despite follow up in OPD and phone

conversations with the Respiratory CNS, participants felt left to their own devices post discharge reflecting the importance of discharge planning and homecare in end stage COPD (Simonds 2006; Ambrosino and Goldstein 2007; Escarrabill 2009)

Similarly, struggles evident in accounts of interaction with HCPs resonate with those already articulated in healthcare commentary (Scambler 2002; Greenhalgh *et al.* 2006). The futility of OPD appointments felt by some reflected the disease rather than illness focus of interactions with HCPs. While some participants e.g. Participant 7 actively sought to engage HCPS in conversation, others e.g. Participant 20 did not. The increasing technological interventions in end stage COPD were also contributing to the back staging of illness narratives. For those on NIV, data is downloaded from their equipment and bringing the focus of interaction to oxygen saturation and usage rates. Patient issues are sought in relation to the equipment potentially limiting discussion about broader illness concerns. The effort involved in keeping an OPD appointment was illustrated in concerns about the walk from the car drop off point through to the OPD area. Participants described the hours required to get ready before journeying to the hospital, always allowing for breaks to recover breath. For Participant 22 a morning appointment meant getting up at 5am. Others described in detail the importance of particular parking spaces in terms of the incline of the path to the hospital entrance. Most were accompanied by carers who were under various time pressures. Yet, few of these concerns or experiences were shared with HCPs.

Continuing Reinterpretation

The changes that occur along the illness trajectory prompted a continual reinterpretation of the meanings of symptoms. An every day activity such as shopping or walking with friends could suddenly become a marker of increased breathlessness prompting a reappraisal of one's illness narrative and conscious shrinking of one's social world in order to address the new threat to personal integrity. This reappraisal was marked as a diagnostic event or new illness meaning in which further loss was experienced, everyday activities were more limited, and the threat of breathlessness became greater. A striking feature of these changes was that they occurred in the everyday. In other words, they were happening beyond the world of healthcare and disease management. In Carolyn Ellis's (1995) autoethnography of Gene Weinstein's (her partner) COPD,

markers of illness progression included everyday occurrences such as increasing breathlessness when walking in his office building or in the university campus where he lectured. Markers of his social withdrawal and increased dependency on her included an incident in which he publicly berated and humiliated her for stopping to chat with friends while he was focused on getting back to his oxygen. The reappraisal of his breathlessness in such incidents led to both a conscious and an unconscious withdrawal or shrinking or his world. In the former, a decision was made to limit walking in order to conserve energy. In the case of the latter, social withdrawal was gradual and sometimes imperceptible becoming evident only with hindsight.

Patient and Family Illness Narrative

Significantly, the same social withdrawal was demanded of Ellis also since his dependency on her was becoming absolute. As his tolerance for social interaction became lower, so too did his tolerance for her stopping to chat with friends. The increasing self absorption of Ellis's partner as he struggled with his COPD was echoed in Reynolds Price's (2003) eloquent account of his form of cancer that eventually left him with paraplegia. However, where they differ is that despite a great deal of pain and uncertainty about his illness trajectory, Price never stops looking outward. As a writer, his creativity increased and harnessed his illness experience. Thus, while his world contracted, it also expanded in different ways. Like Ellis and Weinstein, her partner, Price was an academic. All 3 analysed their illness experiences. Ellis's partner contributed to her diary of their illness experiences[16]. Yet, the continual contraction of their world was in sharp contrast to that of Price despite his total dependency on his carers.

The majority of participants were dependent on family caregivers to the degree that the COPD experience was bound up in family relationships so that appreciation of illness meanings 'belongs to the sick person's spouse, child, friend' (Kleinman 1988:8). Similar to the experience of Caroline Ellis, the COPD experience was bound within their family relationships for participants. This was evident in 2 ways. Firstly, participants described high levels of dependency on their family caregivers. Participant 7 needed assistance to wash and dress. Others such as Participant 5 never went out alone. In a separate arm of this

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[16] It was Ellis who later developed autoethnography as a method in her study of her diary of her nine year relationship with Gene Weinstein that ended with his death from emphysema.

project, interviews were undertaken with carers some but not all of whom cared for participants in this study. Carers experienced a heavy illness burden similar to that of participants here including loss and grief, symptom burden, and anxiety (Hynes *et al.* 2008). Secondly, family care giving is an integral part of the patient's illness narrative. Dependency is the flip side of loss of identity and role within the family. One illustration of this was in Participant 2's description of his self consciousness when shopping with his wife and unable to help with carrying bags. This was compounded by his awareness of her solicitousness towards him when they were walking. Returning to Ellis's autoethnography, she recorded the power struggles within their relationship as his dependency on her increased while both struggled with their changing roles and identities before friends and colleagues over the course of his illness.

Summary of Overall Findings

Anxiety and depression featured strongly in the illness experiences recorded here. Significantly, while anxiety was driven by anticipated and actual severe breathlessness, it permeated through all aspects of everyday life. Depression seemed to largely focus on loss and grief. Participants relayed experiences that resonate with those recorded in studies on severe chronic illnesses. However there were further dimensions to the notion of the work of chronic illness. The work involved in COPD went beyond tasks to include emotional work of constantly trying to mediate between an ever contracting world and lifeworld. Though advanced COPD had completely taken over the lives of participants, this was not reflected in their engagement with the healthcare system or HCPs. Rather, the biomedical reductionist approach to the organization and delivery of care continued to focus on the pathophysiological aspects of COPD or disease narrative.

Questions Leading into Phase Two

Phase one sought to identity palliative care needs of the participants and, in so doing, provide a basis for the co-operative inquiry in phase 2 into how we might address those needs (Figure 8.3). An overarching issue that framed participants' care needs was the disease/illness dichotomy evident in respiratory care. Thus, a broad problem posed for phase 2 was how to address illness oriented care approaches in an acute environment. The phase one findings invited a focus on the inter-relationship of values underpinning our care and competing discourses within the hospital environment. In other words, the questions leading into phase

2 were: how do we understand care needs in respiratory nursing and how does this understanding reconcile with phase one findings?

Figure 8.3 Phase 1 to Phase 2
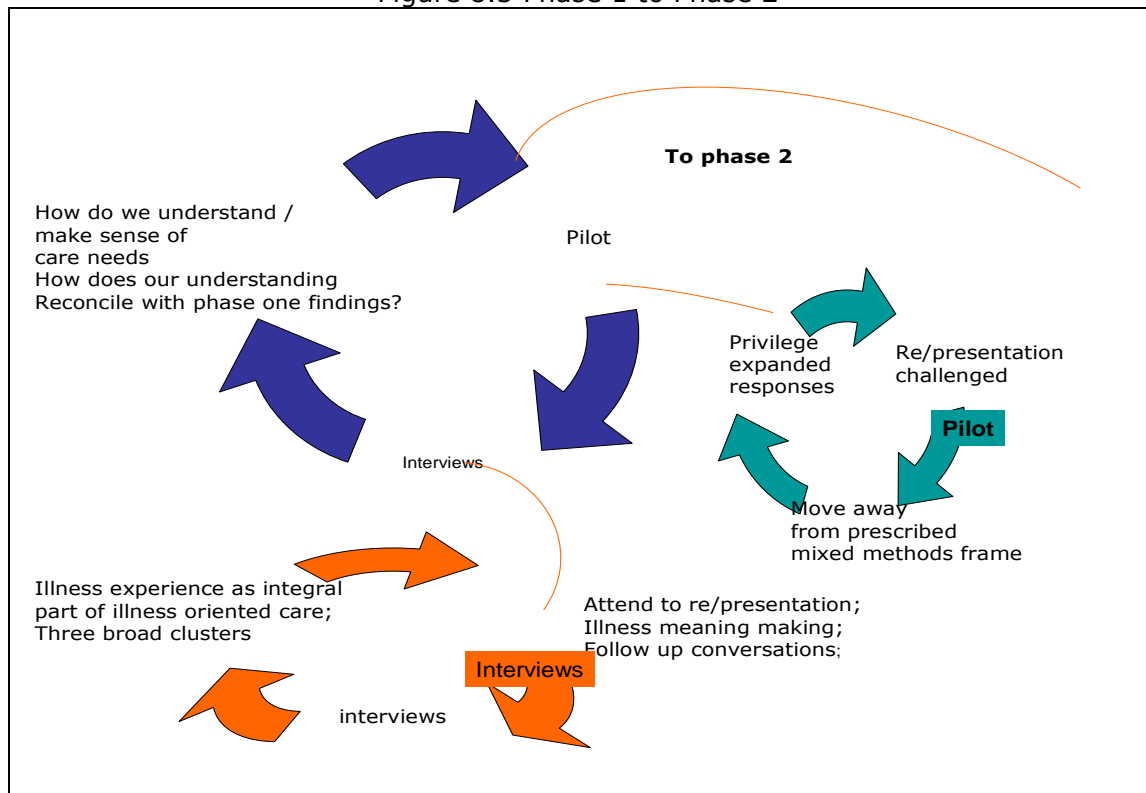
I was surprised by what appeared at first blush as a contradiction whereby on the one hand, participants' focus was on the all encompassing nature of COPD such that acute respiratory care was just one aspect of support needs. In other words, their care needs centred on their whole illness experience with needs shifting through various interweaving stages reflected in the 3 clusters I identified earlier. However, on the other hand, GPs and other possible community-based resources such as public health that might be more illness oriented in their care philosophy, were less represented in narrative accounts than I expected. Acute exacerbations and fine tuning medication management were managed by the respiratory team and included frequent hospital admissions. Moreover, those participants who sought support from their GPs were usually referred into hospital; the role played by GPs was a gatekeeping one.

Thus, healthcare support was predominantly hospital-based. This raises 2 issues. Firstly, Liaschenko (1997) viewed a knowing-the-patient-as-person relationship as more likely to occur in the community given the nature of acute care. However, these participants suggested that care reflecting a knowing-the-person

relationship is not only possible but that it happens in the hospital albeit sporadically not least because they have so much contact with HCPs there. Secondly, if a knowing the person relationship was brought centre stage then this could offer a basis for bridging the disease/illness dichotomy. In other words, notwithstanding the necessary biomedical focus in A/E and/or intensive care, an illness oriented care approach should be explored more fully in the context of acute care. The findings here supported the earlier discussion on palliative care, that where chronic illness experiences are left unacknowledged this increases suffering. Addressing suffering is synonymous with addressing total pain in palliative care.

Illness oriented care approach became the central theme of the CI group. Phase 1 findings invited a focus on the values underpinning our care and engagement with competing discourses. This brought an added focus on positionality and my effort to create an environment in which we could explore the values underpinning our approaches to care and any conflict therein. Initiating the co-operative inquiry required attention to positionality, specifically my relationship with the inquiry group as a whole.

Chapter Nine Co-operative Inquiry Process and Positionality

Introduction

The CI spanned 17 months during which time the focus of our meetings moved between the findings from phase one and practice incidents that resonated with our meeting conversations. As the inquiry progressed, we journeyed from an initial focus on guidelines to interactions with patients as action points. Practice incidents became an increasingly important mechanism for making sense of current and desired advanced COPD care, and relating them back to phase one findings. Typically, incidents were everyday events such as an interaction with a patient during a routine OPD visit or pre-discharge. Our inquiry eventually seemed less action oriented and more concerned with the values underpinning practice and the inquiry process. However, some members of the group viewed this attention to values underpinning practice as action because of shifts in their own individual thinking and practice. To the extent that our conversations became more concerned with the values underpinning practice, our inquiry became more organistic in the final months.

The purpose of this chapter is to 'tell the story' about the CI. The story is told as events unfolded in section one. An early and key event was the sudden and unexpected loss from the project of my colleague from within the organization. This presented difficulties in terms of establishing the CI and specifically my own positionality. In section 2, I focus on issues of positionality. I will draw on action research literature in particular to explore these issues and their importance to the inquiry process.

The Group

The pseudonyms that were generated for the CI participants were chosen by me with initials in alphabetical order according to their chronological first involvement in the project (Table 9.1). As discussed in chapter 6, Ann was an experienced R-CNS with whom I developed the project proposal. In the early stages of phase one, Ann left the organization. Her colleague, Beth, participated in the latter planning stages but was on leave throughout phase one.

Table 9.1 CI Participants

Name	Role	Abbrev.	Comment
Ann	Respiratory Clinical Nurse Specialist	R-CNS	Left role after the pilot stage.
Beth	Respiratory Clinical Nurse Specialist	R-CNS	On leave during phase one
Ciara	Ward-based Clinical Nurse Manager	CNM	Stepped into R-CNS role during phase one but returned to ward when the CI was forming.
Denise	Respiratory Clinical Nurse Specialist	R-CNS	Away on leave for the first half of phase one. Was initially working as staff nurse but took up the R-CNS role in place of Ann.
Eadie	Palliative Clinical Nurse Specialist	P-CNS	
Faye	Ward-based Clinical Nurse Manager	CNM	
Helen	Staff Nurse	-	Left ward in early stages of the CI

As Table 9.1 shows, at ward and CNS levels there was considerable movement among the group members over the course of the project. Significantly, we had not anticipated Ann's departure during the lifetime of the project. Two from the group were undertaking programmes of study during the CI phase. Both students brought their learning and findings into the CI discussions specifically in relation to addressing support needs in the acute care context.

Section One The Story

Overview

The CI group formed in March 2008. Meetings were monthly for the first 10 months. In between these meetings, we met in twos or threes on a more

informal basis but continuing a conversation about the inquiry or palliative care. In January 2009, the inquiry continued with a focus on the R-CNS role and practice development. We met as a subgroup for a 3 hour meeting and thereafter continued to meet weekly informally. The larger CI group met twice over this period. The full CI group meetings took place in a room on the ward to facilitate the ward-based group were members. The R-CNS subgroup usually met in their clinic room or over lunch in the hospital café. Apart from the 3 hour meeting with the R-CNS's, 'time out' for inquiry sessions was limited to the 30-60 minute average for meetings in everyday clinical nursing practice.

Initially and at the request of members, the time for meetings was limited to 30 minutes. However, this rule was relaxed by the third meeting and thereafter, we checked at the start of each meeting what time pressures we were under and worked from that basis. The full CI group's meetings normally ran to one hour and sometimes more. The more informal and subgroup meetings ranged from 30 minutes to over an hour. The first 2 meetings were intended as information meetings about the project and co-operative inquiry in order to give everyone space to decide if they wanted to join. For this reason, the meetings were not recorded or transcribed. However, during these meetings, conversations opened up on issues related to care and especially towards end of life. These issues subsequently proved to be a turning point in terms of distinguishing our inquiry from the more traditional clinical meetings for the group members. From the third meeting, we recorded our discussions and I distributed transcripts before our next date. One member expressed a preference for a summary of the previous meeting, while others preferred to get the full transcript. For the subgroup meetings, recording was not practical. Instead, I took notes and circulated summaries of our meetings.

The summaries and transcripts provided a means of reflecting on the previous meeting and subsequent experiences in practice that prompted further thought on our discussions. Meeting outcomes were thus linked to and informed experiences in practice through first and second person inquiry working in tandem. Experiences usually related to a particular nurse patient interaction, or a practice issue that arose between meetings. This focus on particular experiences in practice between meetings emerged in response to 3 difficulties we identified in the first 2 meetings. Firstly, we acknowledged our committee fatigue and wariness of additional workload that might spring from the project. In this, committees tend to generate work especially for members while also failing to

address underlying problems pertaining to organizational politics or hierarchical teams and hegemony. Secondly, we acknowledged our fears about engaging with patients' suffering and not being able 'to fix' or treat their distress. We were concerned about opening a can of worms in terms of patients' psychosocial needs. Thirdly, we were unsure about how much we could achieve within the clinical environment, and the hierarchical, resource and organizational constraints therein.

The CI group invited 8 participants from phase one to a meeting to discuss our inquiry and our sense-making of care needs and findings from the patient interviews. The 8 were known to have participated in phase one and were known to be well enough to participate and travel to the venue in the hospital. This was an attempt to respond to what I saw as the participation challenges for the open boundary nature of the project (Heron 1996). Thus, while constrained in terms of counterpartal and boundary issues (Heron 1996), we also sought engagement with others and most significantly patients. Drawing on the idea of *other* and conversing with other worldviews gave meaning to our meeting with patients and stakeholders. Over the project period, I continued to meet with the Director of Nursing (DON) on a 6-9 monthly basis. These were 'touching base' meetings that were primarily aimed towards providing updates on the project's global progress. In the CI phase, the R-CNS members participated in these update meetings.

Focus on Everyday Practice

Our plan to focus on our sense-making of practice experiences that arose between meetings set the work of our group apart from other committee initiatives at that particular time. In choosing a particular experience, each member could bring to the fore her direct experience of struggling to engage with patients in the context of the challenges of everyday practice. The process of identifying and attending-in-the moment to a practice experience such as interacting with a patient or doctor about a patient, was usually prompted by discussions in the previous meeting or emerging themes from the inquiry.

Bringing back to the CI group, this experience of attending to the particular interaction informed our subsequent discussions. In this way, we were consciously grounding the inquiry process in experiential, presentational, propositional and practical knowing (Coghlan and Brannick 2005; Reason and Heron 2008). The idea of cognitive distortions (Coghlan and Brannick 2005) was

applied for building awareness of the different factors influencing practice-based interactions such as the perceptions of skills deficit and time needed for interaction. Thus, the cyclical structure of the meetings was informed by and informed a cyclical response at individual level in between meetings.

Key Event

Our fourth meeting took place shortly after the death of a patient (KR) who had spent much of her last year in hospital. KR and her husband had developed close relations with the ward staff. She took a keen interest in staff and their lives such that her relationship with them was a reciprocal one. She had actively sought to be interviewed for this project. At her and her husband's request, I met her in hospital but was unable to formally interview her as this would have been outside the research protocol. Nevertheless she wanted to speak about the devastating illness effects on her life, and about dying and her fear of breathlessness in the end. Following her death, at our CI group, there was a sense of grief and shock at her passing. Our talk focused on our individual reactions to her death and worsening condition in the previous weeks. Some thought that she appeared frightened but that despite having such a close relationship with staff, these fears were not articulated or addressed. I noted in my journal following the meeting:

> Suddenly, we were on the difficulties in talking about dying with patients and the conflicts that can arise in relation to active management between patient and family. I feel she has somehow engineered our discussion. They talk about this study being important and interesting.
> Journal/April 2008

KR's death was a significant moment in our inquiry as her final days were revisited and from there how the quality of her care could have been improved and issues addressed at an earlier stage. The close relationship that the group members had built up with KR over the course of her frequent admissions in the previous year was explored and informed our ongoing search for ways of bringing lifeworld into our conversations with patients. The tensions between lifeworld and system oriented care delivery were revisited regularly when recalling the deaths of patients over the course of the inquiry. We explored relationships built up with patients with advanced COPD who spent increasing lengths of time in hospital in their final year.

Actions

Discharge Visit

The exploration of bringing the patient's lifeworld into nursing practice continued over meetings. Phase one identified discharge process as potential for a diagnostic event in illness trajectory. An action cycle arising from one meeting focused on a post discharge visit by Denise. Her report back developed our discussion on support needs. Our review of her experience revealed what we identified as a diagnostic event in process. The patient was discharged following an acute exacerbation and prescribed home oxygen for the first time. Neither the patient nor his carer was confident with the equipment. Both were distressed at their changed lifestyle as a consequence of the home oxygen. Denise's visit and our subsequent review of her experience led to questioning factors dominating discharge planning practices. These included:

1. At organization level: chronic bed shortages resulted in patients being discharged quickly with little scope for support.
2. At ward level: there was a focus on completing paperwork and preparing for the next patient arriving from A/E.
3. At CNS level, there was limited time for CNS/patient consultation.

We explored possible strategies to minimise the effects of a diagnostic event. Eadie contrasted the palliative care team approach to discharge with that of acute care. In the former instance, the approach was illness oriented with a focus on the patient's care needs. In the latter instance, the approach focused on a discharge letter to a GP outlining diagnosis, medical interventions and current medication. Planned actions arising from this included a review of the discharge letter and meetings with a community nurse with an interest in respiratory care to explore how the discharge process could be better linked with community nursing17. Denise undertook a small qualitative research project in which she interviewed 6 patients recently discharged following acute exacerbations of COPD.

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[17] Public health nurses (PHNs) are responsible for nursing in the community. Community nurses who do not have a public health nursing qualification work under the direction of the PHNs. The role of community nurses is generally associated with adult care particularly those who are older and/or have chronic illnesses.

Discharge Process

We identified an aim of the discharge process to minimize the risk of a diagnostic event related to a hospital admission and subsequent discharge. Action arising from this process included:

- Review of discharge letters from nearby hospitals with a view to aligning discharge information with that addressed by the palliative care team;
- Invitation to a community nurse with an interest in respiratory care to attend CI meeting to explore improved communication;
- Explore with management the possibility of incorporating into practice post discharge follow-up through home visits.

Ultimately, a hospital wide focus on a policy for standardised discharge letters and process in acute care resulted in no scope to re-design discharge letters. While pursuing the idea of home visits with management, Beth and Denise incorporated into their role, an emphasis on post discharge follow up calls. Denise undertook a small study as part of her course, involving patients' discharge experiences following an action cycle. She presented her findings to the hospital as part of an awareness raising of discharge support needs.

Confronting the System and Roles Therein

Most meetings touched on barriers and enablers to addressing our emerging understanding of palliative care. In some instances these were anticipated. However, we also experienced barriers and enablers as intrinsic to our roles and performances at organizational and interpersonal levels. For example, our CNS, CNM and staff nurse roles and related performances were mediated by rules of engagement and expectations relating to how we might react to ideas or experiences. We identified the conflict for the ward-based nurses between knowing the patient and knowing the case (Liaschenko 1997).

As our exploratory conversations moved towards talk about action there was growing reticence within the group. Engaging patients in conversation about illness meanings and fears was felt by members to be idealised practice rather than grounded in the reality of their everyday ward experience. However, they believed that a more realistic approach was to continue working with Eadie and seek ways to bring palliative care into interactions with doctors. This would improve symptom management and broaden awareness of patients' COPD illness experience. Working with Eadie in this way meant working 'unofficially' in the

sense that for a patient to be referred for a consultation with the palliative care team required an 'official' consultant to consultant referral. The 'unofficial' approach was meant as a means of opening up a conversation about palliative care at ward level.

The R-CNS's decided to explore ways of actively engaging patients in conversation about illness meanings and fears. We subsequently formed a subgroup to focus on the potential role of the R-CNS in identifying palliative care needs and ways of responding to needs. Our subgroup met initially over 3 hours after the R-CNS's had finished work and subsequently we touched base on a weekly basis. This inquiry led to a broad plan for role development to include responding to patients' illness experiences beyond the current focus on specific symptoms while also raising awareness across the hospital of advanced COPD experiences.

A proposal for a photovoice project with patients was developed. We also worked through ideas for generating time and space to work with patients through their illness experiences. For this, we engaged with nursing management. Despite support for these ideas from management, concerns were also raised about 'opening a can of worms' and time resources needed. I became conscious of a growing mismatch between my enthusiasm for pushing ahead with these plans and reticence within the sub-group. Issues surfaced such as fighting a losing battle to change mindsets of colleagues and wider team regarding the needs of patients with advanced COPD. The battle was being fought against a background of poor responses to R-CNS's entries to patients' charts and criticisms about the slow turnover of patients in the clinic.

Impact on Inquiry Process

The group struggled with an inner conflict between knowing what needed to be done in terms of developing practice, and knowing what was feasible in their current contexts of intersecting pressures relating to task focused care, in-patient turnover and limited engagement in discharge planning, nurse/doctor communication, system contingencies, and effecting changes in practice. Ciara and Faye withdrew from actively participating in initiatives. They decided to focus on influencing referrals to the palliative team. Beth and Denise decided to focus on their R-CNS roles and engagement with patients in OPD. Despite our focus remaining on the R-CNS/patient consultation, difficulties surfaced in relation to wider cultural issues that left the R-CNS's feeling isolated.

Enthusiasm for the project seemed to have waned. At this point, the issue of positionality re-emerged with me as outsider. To move practice towards engaging patients in conversations about their illness experiences and address concerns about the discharge process from hospital, the inquiry burden shifted onto Faye and Ciara in particular. We discussed the implications for working with ward–based staff to effect change in the discharge process at ward level. When Faye and Ciara appeared less than enthusiastic about this, I made a conscious decision-in-the-moment not to push or look to re-instil enthusiasm into the group. I was acutely aware that there were no competing staffing issues or additional workload for me as outsider. For the sub-group also, the inquiry brought to the surface the isolating effects of an interplay between the R-CNS role development and the status quo.

The conflicts that were surfacing were integral to our unfolding story. The conflicts exposed the gap between our espoused 'knowing the patient' philosophy of nursing, and the reality of system oriented practice. By allowing space to acknowledge the gap and our reactions we were able to avoid defensiveness.

Reforming

The full CI group met in September 2009 to take stock of the process so far. There was a consensus that they were more attuned to palliative respiratory care as we had come to understand it. There was also consensus that there had been a spread effect with increased referrals to the palliative care team and greater interaction with doctors about palliative care needs. However, there remained a mismatch between the points at which nurses identified palliative care needs and those at which the doctors saw a need for referral. New issues were emerging in relation to making this activity 'visible' in monitoring systems and thus embedding palliative respiratory care in the system. For the R-CNS's, their plan had not yet been operationalised despite involving management. We discussed the future of the group and decided to continue to meet and work through our understanding of palliative care.

I was surprised at the enthusiasm for continuing to meet. Members voiced the supportive nature of the meetings and being able to talk through issues. They saw as important the cross specialist make-up of the group and the positive fall out from that in relation to practice development. I was conscious of my looking

for tangible outcomes from the inquiry in relation to referrals to the palliative care team and changes in practice. The group seemed more focused on the supportive nature of the group and subtle cultural shifts taking place at the level of multi-disciplinary team decision-making. These were seen as the principle outcomes.

Section Two Positionality

Initial Framing of Inquiry

In laying the groundwork for invitations to join the CI and early meetings, I was conscious of each step being a marker for the form and quality of the collaborative processes of the inquiry as a whole. I was particularly conscious of the participation paradoxes illustrated by Ospina et al (2004; 2008) when seeking to open space or create the conditions for co-researching. In other words how can we devise a plan for working with participants as co-researchers *in advance of working with them to devise the same plan*? Another paradox asks how to open a democratic process inviting new voices without letting one's own voice be silenced. In other words, it is easy to self censor, devalue one's expertise and silence one's voice in the effort of privileging or engaging other voices. Thus, in laying the groundwork for the CI, I needed to attend to my own positionality and open space for the group to attend to the multiple positions we brought to the inquiry.

Attention to positionality reflected an early attention to quality in the context of choices made in relation to the collaborative process and early responses to the invitation to co-inquire. I have broken down the initial scene setting to 2 stages or cycles namely: 1) developing relationships and invitation to co-inquiry; and 2) the first meetings. Each stage demanded a reflection on positionality and choices this presented for continuing the process. Following a description of the 3 setting-the-scene stages, I explore our initial framing of the inquiry and positionality in relation to me as outsider seeking to co-research with insiders. I then explore the multiple positions we all brought to the process in the context of developing relationships and situating our inquiry.

Developing Relationships and Invitation to Co-inquiry

Attention to the complex nature of collaboration and its interpretation was an important starting point for the lead up to forming the CI group. Following Ann's

departure and Beth beginning her 6 month leave, in addition to patient interviews, phase one took on an important role in providing time and space for introductions and relationship building with respiratory nurses. I became a weekly visitor to the respiratory clinic. During this period, Ciara moved from her CNM role in the ward to stand in as R-CNS. Denise also took up her CNS role at this time. Both Ciara and Denise gained some familiarity with the project through their gate keeping role for patient recruitment in phase one. We developed a friendship through my Wednesday visits to the respiratory clinic. We shared our ups and downs as 'novitiates' in our respective roles: they as acting R-CNS's and me as a researcher. Significantly, they had listened to my concerns about addressing *voice* in research and attending to the stories of illness rather than disease symptoms.

It was less easy to develop relationships with Eadie or Faye since there was no routine mechanism such as a clinic for meeting. The acute care environment in which Faye worked was fast paced with constant re-prioritising and was demanding in nature. For Eadie also, her role was new to the hospital and she was focused on developing her service while waiting for a newly appointed consultant to take up position and lead the palliative care service. It was difficult to promote the inquiry beyond the R-CNS environment in these circumstances.

However, brief chats over coffee with Eadie during phase one provided scope to share concerns about palliative care for patients with COPD. She voiced strong commitment to developing palliative care in non-malignant conditions and working with the respiratory nurses. She was engaged in a hospital wide project that centred on improving end of life care for patients and families. She offered insights into the different worlds inhabited by acute respiratory and palliative care. These became an important theme later in the inquiry and reflected Eadie's interest in engaging in the CI. The idea of the CI was appealing in this regard and in terms of helping her project work with the respiratory nurses. Thus, Eadie and I had opened a communicative space that was focused on dovetailing our shared interests in relation to promoting and developing palliative care beyond malignancy. Recognising that our respective projects complemented each other brought an instrumental quality to our relationship in terms of its value to progressing our individual interests as distinct from co-inquiring.

The First Meetings

Our group was formed over 2 meetings during which I introduced the ideas of action research and specifically co-operative inquiry. Some were familiar with the term action research from their education courses. The days and times for the first and subsequent meetings were chosen to fit around both clinic days and ward routine. I did not record the first 2 meetings to allow the group to form and develop an understanding of the inquiry before formally signing up and completing consent forms. At my suggestion, we did not begin to look at rules for the group until the third meeting. By taking this approach my intention was to make clear the principles of co-inquiring. I wanted to allow opportunity for viewing our inquiry as potentially different from the more task oriented committees associated with clinical practice. I was conscious that we do not enter situations in a vacuum. Rather, we draw on previous frames of reference such as task oriented committees for clinical practice development. By suggesting that we take time to find our feet in the inquiry, I was aiming to challenge these previous frames of reference.

At Faye's suggestion, we agreed to limit the meetings to half hour duration because of work pressures and so as to ensure that people could attend. The idea was that people would be more likely to attend if they knew it was for a short meeting. I was conscious that the suggested time limit might also reflect a view of the inquiry as a disruption to the day's work or yet another committee. The format of the first 2 meetings compared with that of a taskforce or committee set up by management to develop guidelines or improve practice. Our single loop orientation could be contextualised to our framing of clinical practice as inherently hierarchical and, boundary and guideline driven. Thus, management support for the project implied the need to participate. The notion of developing practice implied implications for work practices especially in the ward setting while guideline development would provide a measurable outcome.

When opening up discussion on how we might proceed, our focus turned to issues with guidelines. This focus was away from inquiring into our own understanding and relationship with palliative care and instead, turned towards the practice of others such as doctors. Issues in relation to nursing practice were aired but again these were in relation to difficulties being experienced as a consequence of how palliative care is interpreted or not:

Denise

[We] Need an education programme for staff on palliative care

Geralyn

On what is palliative care?

Denise

And to highlight to the doctors as well, that palliative care doesn't just mean cancer that it's kind of end of life

Helen

I think the BiPap is something as well you know like when to stop the BiPap like we have patients who have literally died when on the BiPap which again like is fierce distressing for family and patient. You literally have patients die while still on [BiPap] [be]cause the doctors continue BiPap you know

Ciara

[I] think as well with the palliative care for COPD cause we are so used to them [patients] coming in and out it's hard to realise like should this person be referred for palliative care

April/2008

At the same time, Eadie stressed the changes that were already taking place in the hospital in respect of palliative care in non-malignancy and possible palliative care interventions including complementary therapies, and improved pharmacological management of the breathlessness and anxiety cycle. Thus a range of suggestions were aired but were predominantly task related. These early discussions were disjointed in that ideas or suggestions were aired tentatively but not taken up for development. Eadie spoke about efforts already in place to improve palliative care through information sessions and the referral process. The focus on medical decision making in relation to BiPap and hesitancy to comment on our nursing practice prompted this journal note following our second meeting:

It is a challenge to keep the focus on nursing practice rather than doctors and allow ourselves to admit that we have much to do ourselves by way of improving care for patients. There was some hesitation when we looked at interval until the next meeting. My heart sank a little when the decision was for monthly meetings. With just 30 mins per session, that seems very little scope for development.

Journal 21st May

In this note, I was struggling with attempting to open up space for freedom to think about the inquiry in different ways and what we might want from it while also fearful that I was in danger of taking control at the very moment when I was trying to open space. I was struggling between framing (Torbert and Cook-Greuter 2004) what I thought we were about and giving space for others to advocate differing views. We seemed to be meeting what others have referred to as the paradox of participation (Ospina *et al.* 2004; Arieli *et al.* 2009).

Framing Our Inquiry

Opening Space

Recent discussions in action research literature have highlighted paradoxes that can surface when seeking to create conditions or space for opening conversations towards mutual understanding (Ospina *et al.* 2008; Arieli *et al.* 2009; Wicks and Reason 2009). Habermas's theory of communicative action provides scope to articulate a dialogue to which many in the world of action research might aspire (Wicks and Reason 2009). Dialogue in this sense corresponds to communicative action in which speech utterances can be tested for their truth claims. In such ideal speech acts, hidden motives are exposed and untested claims are challenged without influence from dominant persons, discourses or ideologies. In reality, everyday communication is distorted by power and hegemony that may be explicit or hidden in language. Ideal speech acts as the medium for communicative action occurring in Lifeworld. In Lifeworld we engage in practical and moral action through our mutual understanding of the values and backgrounds that bind us. In contrast, in 'System', our mutuality is compromised by a dominant techno-rationality and power that underpin our societal structures. By opening a space for lifeworld and communicative action in which truth claims can be tested, the action researcher can confront distorted communication and the impediments to dialogue.

Notwithstanding acknowledged criticisms of Theory of Communicative Action,[18] the distinction between Lifeworld and System in this Habermassian sense provides a useful means of exploring the tensions between efficiency and control oriented actions typical of institutional life on the one hand and on the other

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[18] Theory of Communicative Action rests on the idea of validity of truth claims and distinction between lifeworld and System. However, validity of truth claims may on the surface deny or ignore embedded inequities within a discourse.

hand, mutual understanding and values oriented action. Our focus on need for guideline development in relation to clinical interventions such as BiPap reflected our desires for improved management of and control over decision-making. Our talk was typical of everyday meetings in the clinical arena where problems are quickly identified, responses developed in the guise of protocols or guidelines and evaluated on basis of their implementation. Thus, our focus was on addressing immediate problems without addressing their underlying aetiology particularly in relation to doctor nurse power relations, patients' position in the System and the complex nature of clinical decision-making in advanced disease. In this sense our talk was system oriented and avoided questioning that which lay beneath the issues, reflecting what Argyris has termed single loop learning:

> The overwhelming amount of learning done in an organization is single-loop because it is designed to identify and correct errors so the job gets done and the action remains within stated policy guidelines (Argyris 1982:4)

In other words, our talk reflected our embeddedness in rather than confronting or changing institution practices and our roles therein.

Early Participatory Challenges

Just as Arieli et al (2009) struggled through layered and deeply rooted misunderstandings in their efforts to address participation, I found myself struggling between letting go my participatory ideals and instead, attend fully to the early issues raised in the group. I was conscious that the early suggestions were rooted in traditional divisions between nursing and medicine, and the demands on practice versus those on management. I was aware in-the-moment during and painfully so post meetings, that this struggle was manifest in my advocating speech utterances (Torbert and Cook-Greuter 2004) that were lengthy relative to the contributions of others. These utterances were also my struggle against risking confirmatory evidence that this was another task oriented committee. Memories of previous events in different work settings where the promise of collaboration gave way to co-option or even coercion intersected my own uncertainty about how best to respond to the immediate suggestions for action.

Opportunities to develop relationships with Eadie and Faye prior to the first CI meeting were limited. The absence of Ann and Beth in the run up to the first CI

meeting meant that there was no immediate ownership of what it was we might decide to do or of the rationale for the CI. Rather, I was acutely aware throughout the early meetings that the project was identified as *Geralyn's research* which had management support and so might be construed as requiring input but no ownership. In other words, my invitations to join the CI group may have resembled the more typical establishment of a work-based committee. As Wicks and Reason (2009:247) note, the initiating co-operative inquiry researcher proposes a topic, invites co-researchers to join and then introduces them to the inquiry, 'thus in formality and explicitness mimicking aspects of the 'system''. By way of separating our inquiry from a more traditional view of inquiry or work-based committees, my intention was to make clear the principles of co-inquiring. At issue here is the perceived nature of collaboration initially and its impact on the quality of participation and choices made throughout the inquiry process. Using Cornwall's (1996) typology, it seemed important to move from the risk of perceived co-option if I was viewed as an outsider with management support and a pre-determined inquiry process. Cornwall sees this form of cooption akin to research on rather than with others. In contrast, co-learning or collective action point to reciprocity in the inquiry reflecting research by participants (Cornwall 1996).

Positionality

Among my first priorities then, was to find ways of enhancing reciprocity and freedom to develop our own understanding of respiratory nursing in advanced COPD. As for Ospina et al, (2008) my initial positionality intersected with control, action and voice. Ensuring the group had control over meeting arrangements was an early and easy step in responding to issues of control over the process. In consciously attending to the need to give ownership to the group and to place trust in the process as an emergent one, I voiced no reaction to the 30 minute limit imposed on the meetings. Later, as the process unfolded, the meetings gradually lengthened to over an hour and on occasion to nearly 2 hours. Less simple, however, was finding a balance between the need for laying a foundation towards finding our feet in the CI process, and responding to early calls for action.

I was conscious that Ciara and Denise's suggestions may have reflected their awareness of my anxiety to proceed. Eadie's early suggestions resonated with

her focus on and engagement in the Hospice Friendly Hospital initiative[19]. I was not questioning the importance of this; Ciara's reference to BiPap intervention in the dying process reflected the importance and complexity of end of life care in COPD. Rather, I was conscious that our uncertainty about positioning palliative care in our respiratory practice could lead us towards uncritically accepting advice without any meaningful engagement or questioning. For Eadie, end of life care was founded on the principles of palliative care that is traditionally associated with cancer. We needed to understand these principles in the context of respiratory care. Faye, on the other hand, was neither familiar with my research nor directly involved in Eadie's work. However, as the senior manager on the ward, it was clearly in her interest to monitor suggestions and actions that might have a direct bearing on the ward work.

Thus, it became more evident that each of us brought our own positionality to the collaborative process. By this I mean that we were possibly bringing particular agendas that would influence the form of collaboration and influence we were each seeking to bring to bear on the process. Thus, the issue of voice and action here seemed at one level to reflect, in the traditional sense, our individual voices and sense of contribution and being heard by each other. At this level, I could interrogate my own engagement with others and how individually we responded to one another from moment to moment. At another level, voice and action reflected the meeting of different worlds and how each of these interacted or sought to influence each other.

Positionality in Relation to Roles

The worlds of palliative and respiratory care represent different specialisms with their own distinctive philosophies, expert knowledge and way of working. Eadie's palliative care language held differences in meaning from our more familiar respiratory care language. Her reference to, '*palliative drugs and that kind of thing*' cut through the respiratory care tensions familiar to the rest of us regarding palliative medication and breathlessness in COPD. It seemed to me that our early engagement could potentially polarise Eadie, at one extreme as expert, advising us on strategies and interventions in respect of palliative care. This would position Eadie as outsider consultant. There would be little

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[19] The Hospice Friendly Hospital initiative is a national programme being rolled out at time of writing. It is aims to improve end of life care in acute and community hospitals. See http://www.hospicefriendlyhospitals.net

opportunity for the palliative 'expert or specialist narrative' to engage with everyday context of respiratory care in this instance as 'lay or local narrative' (Scambler 2002). In other words, there would be limited scope for the development of hybrid knowledge bringing together palliative and respiratory knowing. Respiratory practice development would be compromised since the 'expert advice' would not be fully integrated to respiratory practice. At the other extreme, Eadie could be positioned as a helper for advising on or addressing individual patients' palliative needs rather than engaging in wider practice issues that have a consequence for palliative respiratory care. In short, there would be little scope for learning and development of respiratory practice.

Though not as overtly insider/outsider related, from the outset our group featured or identified different configurations of role divisions each of which had a potential bearing on our individual front staging of issues and particular voice. The respective CNM, CNS and researcher/academic roles each reflected different foci from managing a ward environment, to developing specialist clinical practice to theory development and dissemination. A dominance of any one of these roles could impact on the capacity of others to be heard. Put simply, our initial discussions on guideline development drew attention away from Eadie's palliative care concerns while my focus on developing respiratory nursing practice potentially silenced concerns about implications for increasing workload in the ward. Similarly, identity differences could include group members as being at the front line of practice versus my identity as ivory tower researcher; being part of the hospital community versus me as outsider; and all of us as nurses versus doctors. Thus, we brought to the inquiry process insider/outsider elements of different roles. Put another way, our individual outsider/insider status and related positionality resembled more a continually shifting than a pre-determined stable position.

Making Sense of First Meetings

Our initial focus on guidelines and end of life issues resonate with group splitting as experienced by Ospina et al (2004). In short, our initial suggestions focused on splitting our actions as good from those of doctors as 'bad' e.g. BiPap prescribing. In this sense, splitting can be a defence mechanism against questioning our nursing practice. In responding to these early suggestions and their departure from broader palliative care issues such as loss and grief it was tempting move into advocacy mode. While advocacy is one of the 4 parts of

speech that have legitimate value in action inquiry (Torbert and Taylor 2008), my advocacy utterances in these early meetings were not successful in engaging people in conversation. In other words, my behaviour resonated more with the traps encountered by Arieli et al (2009) in which advocating for the processes of inquiry while ignoring calls for action or adequately engaged discussion on why the inquiry process should come first. Ways of addressing these participatory paradoxes include resource sharing, flexibility regarding action before inquiry, testing assumptions, rendering discussable issues such as power, roles, tasks and boundaries (Ospina *et al.* 2004; Ospina *et al.* 2008; Arieli *et al.* 2009).

Participatory paradoxes are embedded in the initial coming together in which the same situation may be defined differently by those in it e.g. a means of imparting information or getting something done, or a time waster. We employ strategies both to control the behaviour of others and to control the opinions that others form about us. Thus, situation definitions carry theoretical notions of how to behave, the extent to which we reveal or lodge our private selves. Strategies are mediated by culture, authority and power. Forming a group in these circumstances is likely to be characterised by uncertainty, pre-occupied issues of identity, power, inclusion and acceptance with little cohesion.

Similar to Tuckman and Jensen's (1977) forming stage in group development, we seemed focused on issues pertaining to our own individual practice concerns. Thus, I was conscious of my reaction to Faye's concerns re workload in which I focused on the CI process rather than fully engaging with her standpoint. Our meeting following KR's death resonated with the storming stage not in the sense of conflict but rather by the emptiness and catharsis followed by growth in which we moved towards focusing on the moral world of nursing. In their review of stages of group development Tuckman and Jensen (1977) refer to studies of nursing students in which the storming stage was less associated with conflict and suggest that factors such as gender and prior cohesion of members as a wider group might influence the storming stage.

Seen in this light, learning to identify our different positions and how they intersected with one another seemed important in early engagement. This brought to the fore our individual insider research roles. The 3 insider researcher challenges proposed by Coghlan and Shani (2008) seemed pertinent to how we could explore more fully the insider elements we brought to the inquiry. These challenges are: preunderstanding, role duality and organizational politics.

Attention to preunderstanding implied exploring our assumption about each of our roles, and practice knowledge and needs. Becoming more aware of elements of role duality for all of us meant revisiting the role boundaries that defined our interaction outside the CI group and their potential impact on both our CI process practice. We also needed to bring to the fore our engagement with potential and eventual political fallout from our engagement in the CI process and development in practice. Attending to political fallout needed to include a focus on our own interaction. In particular we needed to explore the potentially skewed impact on workload for some within the group arising from inquiry actions.

Summary

In summary, the mechanistic nature (Coghlan 2003) of this CI is clear. However, our tentative start and early meetings pointed to the value of an organistic approach to the foundation laying for the inquiry process. The contingency of action research was evident in the impact on the establishment of a co-operative inquiry when unforeseen changes happen. Paradoxes in participation could be identified in our navigation through the complexities of our interrelationship building and situation definitions. Our move into the storming stage of group development was helpful in bringing together shared interests in the actual inquiry focus and process.

Chapter Ten Co-operative Inquiry Themes

Introduction

The purpose of this chapter is to present the themes that emerged from our CI group meetings. As themes emerged they were continuously refined in our conversations over the course of the inquiry. Thus, the themes were not related to any one specific meeting or practice experience and neither was the process of theme development a linear one. Rather, themes emerged through the interplay of experience, observed patterns and analysis in conversation often acknowledging conflicting narratives in the telling of experiences or patterns. The telling of a story about one experience could lead to revisiting a theme that would then lead to revisiting other themes. In this way, the themes were evolving and interconnected. Four themes emerged (Table 10.1).

Table 10.1 Co-operative Inquiry Themes

Theme	Context
Respiratory Palliative Care	Making sense of current and desired COPD
Re/presentation of Patients	Confronting ideologies in nursing practice Instrumentalism
Local Moral World of Nursing	Issues related to our ideal nursing and reality of practice giving rise to the divided self and divided world
Worlds within the World of Nursing	Increased specialization in nursing leading to different identities and roles each with its language and performance base.

The deaths of several patients over the 17 months also informed a continual re-examination of our conceptualisation of palliative care as experiences of interactions with individual patients were recalled, differences in the range of needs from patient to patient were explored and nursing's response was scrutinised. This looking back process emerged in the telling of stories and how interactions and interventions (or non-interventions) in the days, weeks or months previously had impacted on the quality of care for the patient.

Respiratory Palliative Care

Respiratory and specifically COPD palliative care encompassed our acknowledgement of a disease/illness dichotomy in the acute care environment and our sense making of practice. We grappled with a disease oriented approach to care and reflected in our language of blood oxygen saturation and other routine observations. End of life practice issues drew attention to the long illness trajectory leading to that point and the significance of our potential to influence a hospital and discharge related diagnostic event for patients. Three subthemes were generated (Table 10.2).

Table 10.2 Respiratory Palliative Care Sub-themes

Sub-theme	Context
Acute environment and lifeworld	Patients experiencing frequent admissions while the overall decline may be missed over an extended period.
Appreciating diagnostic event	Attending to illness trajectory increased awareness of the impact of hospital care on the experience of a diagnostic event.
Nurse patient relationships	Relationships with patients as built up over time

Acute Environment and lifeworld

We started from the premise that the COPD experience and lifeworld could not be separated. Thus, our awareness of patients' illness meaning was a recurring point of conversation about practice experiences. Patients who had frequent admissions to hospital with acute exacerbations were well known to the 4 respiratory nurses. There was a routine to our experience of advancing COPD that revolved around the patterns and management of acute exacerbations:

Faye

You do you get so used to them coming in and out

Ciara

They're real sick coming in and they're on BiPAp for 24 hours and then they rally and are fine again

CI/May 2008

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Typically, members referred to a bond between them and some of these patients and familiarity in their interaction such as of this patient:

Me
Is she smoking?

Beth
No, she'd tell us I think

Others
Yeah she would
CI/January 2009

Similarly, there were instances described by Beth and Denise in informal meetings of confronting patients about being back smoking or their use of BiPap but being able to do so in a supportive way that was contingent on familiarity with these patients' worlds. Throughout the inquiry process, references were made by Ciara to funerals of patients that she attended. However, this familiarity or knowing the patient was also partial and opportunistic illustrated by Beth in her account of discovering the meaning of loss of a pet for one patient. She was advised by her doctor to give up a much loved pet:

Beth
The bird was her link to her husband like. If she hadn't mentioned it, well I wouldn't have asked her like. [I would have asked] just shortness of breath, cough, sputum you know. It's terrible really… I couldn't believe it. It came up out of nowhere
CI/November 2008

The incident with this patient that Beth described took place in a busy clinic. There were other stories of similar close intimacy and entry into patients' worlds:

Denise
But he had been in for a few weeks and wasn't getting any better and you could see the deterioration you know he was always a very determined kind of man and you could see that he just gave up and it

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was too hard for him to keep going so he was ventilated I think for about 2 days and then he died.

Me

Did you sense he had given up?

Denise

You could see it in his face yeah he just didn't when you were talking to him he didn't have that determination that he always did he didn't feel he was going to get over it—his wife said—she said that he's afraid to let her go home and she'd been with him for I think about 10 days and 10 nights consecutively he wouldn't let her go home

CI/May 2008

Helen

I think she had given up cause she'd been so sick so many times cause it was getting closer and closer each admission was getting closer and closer to the previous one that there was a sense of it was going to happen it was just [a matter of] when

CI/April 2008

Relationships with patients build up over months and years. These relationships can be very close and at one level akin to knowing the person as Liaschenko (1997) describes this in relation to community nursing. But in the acute setting this kind of knowing seemed partial at best and developed opportunistically sometimes in snatched moments. This was illustrated by conversations about family members making daily visits to their parent in hospital over frequent admissions but who sometimes remained strangers to the nurses:

Ciara

We'd have patients in here sometimes and because you are so busy here someone would say to you, so and so's daughter is here and whatever like and you'd be saying [I] don't know the daughter like, I've never met the daughter and the patient would be in here month after month after month…You just don't get the time when you're here especially when they're in acute illness you just don't get the time to speak with the family or even to speak with them

CI/November 2008

Thus, despite these patients becoming increasingly frail, their close family relatives could remain peripheral to the nurse patient relationship. The more distant nurse/carer relationship described by Ciara conflicted with the high dependency on carers for support post discharge.

Appreciating the Diagnostic Event Effect

As our focus turned to supporting patients' increasing frailty and care needs in advanced disease, we drew on the idea of diagnostic event that appeared in the patient interviews. There was discussion about the mixed impact of portable oxygen for example:

> Denise
> This isn't supposed to restrict their lifestyle it's supposed to improve it and like if they are very active then portable oxygen as well so they can actually carry it around and do their normal activities
> Eadie
> But I suppose the more psychological aspect needs to be delved into
> Denise
> Yeah, but you can delve into it to a certain degree in hospital cause you are anticipating them but that may not happen for that individual patient but like if it does happen for the individual patient who do they contact then?
> CI/September 2008

This exchange occurred at the start of the meeting and opened a conversation about addressing support needs of patients who were discharged home for the first time on home oxygen. We were acknowledging the role of the R-CNS to provide education and information prior to discharge home. However, our issue was recognising the life changing event that dependency on home oxygen must be but yet nursing support in the community did not, generally, include respiratory expertise. This conversation led to contrasts drawn between discharge support in palliative care from Eadie's perspective and current practice in respiratory care. Thus, Denise raised the need for developing counselling skills while Eadie and Faye compared and contrasted the content of their respective discharge letters and approaches to GP involvement. For Eadie, discharge letters were 'just diagnosis really' and needed to be supplemented with phone calls to

the GP. For the acute care environment, discharge letters were the main point of contact despite the potentially volatile phases of the COPD illness:

> Denise
> But COPD patients are so unpredictable you know that like one of our patients is now ventilated. She went home a week ago so you'd have to [have] thought she was going home and and she'd be off for a couple of months and we'd see her in outpatients but back out for a week in for a few days and now she's ventilated.

The respective discharge process and supports of palliative care and the acute respiratory environment reflected different philosophies underpinning care practice including type of relationship with GPs. The process that the respiratory nurses described reflected a focus on delivering bio-medical information or disease markers to the GP. In contrast, the palliative care discharge process incorporated a wider range of information exchange between the specialist team and GPs.

The interaction between Eadie and Denise also reflected the tensions for the respiratory nurses between the acute care philosophy with its particular focus on interventions, and palliative care with its 'delving in' focus.

Nurse Patient Relationships

The death of the patient KR prompted a scrutiny on relationships with patients built up over time. The shock of her death conflicted with our knowledge about advanced COPD in general and the gravity of her condition specifically. This was in part explained by being accustomed to repeat admissions that followed set routines in terms of management and stabilisation:

> Faye
> She'd been coming in more and more frequently and at the same time, I suppose we kind of forget that she will she will you know we all knew she'd probably die eventually but you know the timing of it as well…the appropriate time to step in
> Ciara
> You expect them like you know to come in for a few days and like she'll be grand back to her self.

CI/May 2008

Ciara

I think palliative care as well for COPD cause you are so used to them coming in and out it's like hard to realise should this person be referred for palliative care

CI/June 2008

The shock and grief was in part related to the close bond built up with her over the years and especially her final 2 years:

Denise

When she'd come up to the ward everyone would go in and give her a big hug, that's how much she meant to everybody like it made her feel like you know like she didn't like being here but she knew that oh such and such is on and such and such is on tonight. She knew everyone loved her

Beth

They [ward staff] wanted to know her life didn't they like she would be speaking about her life like she hadn't been upstairs for years but she sent her husband up to tidy. She did try to go up herself.

CI/January 2009

The discussion on KR's death in early meetings drew similar examples of relationships with other patients. In some instances the relationship was built over a shorter period of three/four years. Sadness over a death could be mixed with sense of failure:

Denise

Well anyway he passed away….the last couple of [pulmonary rehabilitation] groups…[for] 2 of our groups he was supposed to start [pulmonary rehabilitation] but he ended up in hospital either that day or the day before. He didn't even have the pulmonary rehab so you kind of feel that we kind of failed him a little bit in the sense that you know that if he had had the rehab if he had been fit enough for the surgery [pause] he'd still be here you know that kind of way.

CI/June 2008

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> Denise
>
> If you feel that everything has been done for them it's easier to accept but if you feel that something wasn't done that should have been done then you feel really bad—Like that man. I feel his death was a failure on our part of the system
>
> CI/June 2008

In other instances, over the course of the inquiry, references were made to working with patients to adjust to interventions while giving space for decision-making. Typically, a patient who was prescribed BiPap experienced difficulties adjusting to the device. His final decision to stop using it was made over several conversations with Beth and Denise. There was no sense of failure rather; they saw a successful conclusion in helping him make an informed decision.

In our November 2008 meeting, I began with a summary of where I thought we were at that point in terms of understanding what it means to nurse patients with advanced COPD. My summary included dealing with uncertainty when we move from a disease to an illness perspective, the idea of our role in advanced COPD as bearing witness and issues around our re/presentation of patients. This led to a conversation about relationship building.

> Ciara
>
> It's like when I meet someone or they say Oh I know your mother and it makes them feel at home and they think that we have their circumstances and where they are coming from.
>
> Beth
>
> I suppose if you make an effort to see what life is like. You'd notice in OPD like if you give the time or you make the effort for time they will remember and come back you know you see whereas if it doesn't go that right you know you rush someone you get the feeling the next time that you didn't really give them enough time you know. They do let you know don't they
>
> Denise
>
> You can tell by their expressions that you haven't built up a relationship.
>
> CI/November 2008

However, for the respiratory nurses, this relationship was limited to an extent in its situatedness in the hospital environment:

> Ciara
> I think when they are going home especially when they are in and out all the time I wonder what like are their circumstances at home, Yeah, it would be very interesting to see and like that it would put you on a different kind of relationship you know. They're more or less coming into our home all the time… We have patients who spend a quarter of their life in here. It would be nice for us to see like when they are talking about things.
> CI/November 2008

Despite the emphasis on relationship building, at different meetings we talked about needing the skills to talk with patients about their fears and their deteriorating condition typically:

> Denise
> How do you though I think I'd be embarrassed
> Faye
> And they are so low anyway
> Denise
> They probably don't know how to deal with it themselves so I couldn't aah help or the families come to terms with it.
> CI/May 2008

End of life issues were addressed in pulmonary rehabilitation but by the palliative care consultant rather than the nurses. We continued to grapple with the difficulties for some within the group about making space for conversations with patients about their fears related to their illness.

> Me
> Yeah the point is like we touched on last time and maybe that's one of the problems that we might start to tackle is what are the kind of things that we need to think about or do in order to be able to talk to patients
> Eadie

I think with people they think palliative they think end of the disease trajectory when actually it's along side.. I think with people with COPD it unfortunately comes in at the end of life when it should be coming a little earlier....Aah those patients with COPD that you see earlier their fear is around choking and breathlessness where you know we could easily reduce those anxieties you know.

Denise

Families do you know if they could bring up the issues because they run as far from it all the time as we do so I think it's like between all of us like the patient, family and staff

CI/May 2008

In this exchange Eadie makes clear the link between dealing with the choking fears common among patients in advanced COPD and fears about dying from COPD. This was in contrast to our acute care oriented perception of COPD in which we viewed as separate patients' current distress from future distress. Eadie's palliative worldview, on the other hand, saw management of current distress as integral to addressing what lay ahead for a patient.

The nurse/patient relationships could be longstanding and close given the advanced COPD illness trajectory. However, the value placed on building relationships as Beth described conflicts with the context in which they were often developed in snatched moments in a busy clinic or ward. Despite the close relationships with some patients, our experiences were of hesitancy in responding to patients' fears about choking and dying. These fears became 'the elephant in the room' and remained unarticulated and therefore unaddressed. We needed to re/view our care as taking a palliative approach throughout the illness trajectory. This would mean actively engage with patients' fears as they arise. However, our default approach was not to explore fears.

Patient Re/presentation

Acknowledging a disease/illness dichotomy in our relationship with patients drew attention to different ways we re/presented patients. In our documentation and referral conversations, we addressed biomedical markers and were reductionist or disease oriented in our talk. This was at odds with our illness knowledge of a patient. Attending to these conflicting re/presentations drew attention to our advocacy interventions. There were 2 sub-themes (Table 10.3).

Table 10.3 Patient Re/presentation Sub-theme

Sub-theme	Context
Documenting knowing the person	Reflecting patient relationships and illness experiences in documentation.
Advocacy	Attending to how is patient is re/presented by HCPs in a given moment.

Documenting Knowing the Person

Several practice-based experiences that were aired in the group were related to what we do with our *knowing the person* knowledge. I brought this term into our conversations as a way of naming our stories that centred on patients' lifeworld and the accounts narrated in the patient interviews in phase one. Some within our group were familiar with the Joan Liaschenko's (1997) *knowing the case, knowing the patient and knowing the person* distinctions in nursing. Though, we increasingly saw the centrality of knowing the person to developing the quality of our care, this was also knowledge that could not be articulated in formalised accounts. In one example, a patient whose distress about loss of a pet as a consequence of her illness was particularly intense:

> Denise
>
> If you tell that to someone outside of COPD they'd laugh. They just wouldn't get it
>
> Beth
>
> Well I didn't document it. There's nowhere you could put it
>
> Denise
>
> You'd be embarrassed to document it
>
> Beth
>
> Yeah you'd be thinking how can I put this down in a medical way?
>
> Me
>
> That's the point who's telling us we have to write in a particular way
>
> Denise
>
> Who's going to act on that?
>
> Beth
>
> But a big thing was that Dr X listened to her and acknowledged the loss
>
> CI/January 2009

There was a conflict between the knowledge that we see as integral to our care and that which we view as appropriate for documentation. The consultant and nurses alike acknowledged the patient's loss and its link with her illness but made no record of it in the patient notes. Knowledge about the patient was limited to her diagnosis, prescribed medication and ongoing monitoring typical of acute care management. Knowing-the-person knowledge appeared subversive and passed through word of mouth. The patient was re/presented in a 'medically appropriate manner' in her official notes. She was severed from her lifeworld and illness sense-making. I was reminded of the *Amber Spyglass,* the final work from the *His Dark Materials* trilogy (Pullman 2005), in which the children were severed from their daemons or souls.

Subsequently, there were instances in sub-group meetings, when we were discussing possible strategies for documenting patients' illness experience, we considered various instruments ranging from the SGRQ, HADS, BORG scale or a devised questionnaire. For Beth and Denise, it was important to use instruments to 'appear more professional' in the way we work. Though drawn to the patients' illness experiences and their sense making of their illness, we seemed to be actively seeking to 're/present' these worlds in a manner in harmony with reductionism. Our re/presentation of patients seemed linked with our re/presentation of the CNS role and performance within the respiratory care environment. As we developed our roles we looked to developing credibility through aligning our performances with expectations of others.

Advocacy

We were also able to draw on instances of a conscious stepping back from a situation in order to examine how a patient is understood by the greater respiratory team. Faye's act of stepping back involved attending to the ongoing presentation of the patient in terms of evolving bio-medical problems.

> Faye
>
> You have to try and you know figure out where the patient is coming from and what they want you know maybe they've reached the end of the line they can take no more so you know its very hard if everyone around them is pushing them pushing everything like and they really feel like they have reached the end of the line themselves and they don't maybe they just feel they've got to the stage they don't want

anything else done to them like it's easier to die like than keep going so you know the way. Sometimes it's hard when the doctors come in and they see the patients you know the way and they keep adding something else or doing something else you know. Someone has to stand back and maybe make a decision like stop or just to look at what are we doing or how it's affecting the patient you know. I think with the doctors, that's the way they think you know they just want the quick fix like then the next problem sometimes they don't look at the whole picture but when you see the patient every day you kind of you're more inclined to look at the whole picture. You see the families and how they're feeling you know what they're expecting like what they're going through as well like and at the same time you know looking at relatives maybe struggling like or just you know reaching the end of the line but it's- it's kind of I suppose it's hard to take it all in until everyone comes I suppose you know you need to get the doctors in as well kind of or try to you know be the advocate for the patient yourself maybe. But it's great since [Eadie] came on board like – it's been a huge help to us on the ward

CI/June 2008

Faye's stepping back in her account looked to bridge competing philosophies of acute and palliative care where her understanding of the patient's needs was at odds with the ongoing interventions 'being done to him'. She did not articulate what informed her knowledge of the patient having reached 'the end of the line' beyond her relationship with him over the course of his recent admission. In a subsequent meeting, we explored our reasoning for suggesting a palliative care referral. Poor response to treatment interventions and physical distress were primary drivers. However, other factors were also important:

Faye

I suppose if they were fairly withdrawn in themselves you know it's hard to describe but you kind of generally know or you'd have a good idea when you don't feel somebody is going anywhere or they are not turning a corner like not getting better you know it's very hard to put your finger on it but.. it's just with experience you might feel they are not going to get better and maybe someone could make things a little easier for them'

CI/July 2008

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However suggesting palliative care involvement to the doctors was a delicate matter and frequently rejected. For Eadie, this meant being caught between wanting to support the nurses in helping their patients but needing to wait for an 'official' referral:

> Eadie
> They don't feel there's a need yet although the patient is at end of life
> and you can see that they are not being settled
> CI/June 2008

Some referrals were taking place and though appropriate in terms of the need for specialist palliative care, for Eadie, they seemed sometimes too late:

> Eadie
> From cases I have patients that I'm involved with in end stage COPD
> that they are very much aah specialist because it's more like they are
> in terminal breathlessness…. A situation last week we were involved in
> but my feelings for that [are] that we were involved too late in that
> whole situation cause I met someone that was quite distressed and I
> hadn't time to build up a relationship with the patient
> CI/August 2008

Nurses often saw the need for referral to palliative care at an earlier stage than was the case for doctors. This was in part a consequence of interpreting palliative care differently. Nurses looked to palliative care for help with anxiety, adjustment and opening discussions about dying in addition to the physical symptoms of advanced COPD. For the respiratory nurses, the severe breathlessness and anxiety cycle experienced by some patients was a frequent reason for referral. For doctors, palliative care was conflated with end of life. Thus, Ciara referred to her learning to present to a consultant an argument for referral, sometimes with success while also having to think about how to make her case:

> Ciara
> No but I put a fairly good argument forward like that she really
> wanted to go home and you know that if we could maybe make her
> more comfortable and would we think of palliative care

Me

Do you feel there are some cracks happening

Ciara

Yeah well I was surprised

Ciara

there was another lady that I would really like them [palliative care] to see you know there are some days when she is really short of breath just to give her a little bit of something

CI/July 2009

When patients were not at end of life such as the 'other lady' in the above quote making a case for referral was difficult. Identifying need for specialist palliative care referral was made more complex when justification was difficult to articulate or influenced by perception of *handing over* patients who are not yet at end of life. Multi-disciplinary team interaction also influences palliative care referral with evidence of the doctor/nurse game being played out. Late referrals suggest lack of awareness of the importance of relationship building in palliative care.

Local Moral World of Nursing

In our CI, we articulated the gap between our (and society's) ideal nursing selves in relation to an ethical framework and the moral experience of living with compromises and harsh reality of care delivery in the current Irish healthcare environment. Our idealized nursing care gives way to care practices and compromises driven by pressures of staffing levels, time pressures, ward routines, bed shortages, need to discharge patients quickly with little notice etc. In other words our world was divided. At the same time, we confronted tendencies to attribute reticence about conversing with patients about their fears to work pressures. Three sub-themes emerged (Table 10.4)

Table 10.4 Local Moral World of Nursing Sub-theme

Sub-theme	Context
Living with compromise	Reflecting little hope of shift in the context and culture of everyday practice.
Reductionism	Dominance of medical reductionism that silenced other world views in official practice discourse.
Instrumentalism/strategic action	System-oriented practice impeding efforts to address illness needs.

Living with compromise

At different points over the course of the CI process, we explored experiences of care practices driven by pressures of staffing levels, time pressures, ward routines, bed shortages; need to discharge patients quickly with little notice etc. Ciara's earlier reference to not knowing relatives or not getting a chance to develop a relationship with her patients reflected this local moral world of care. Denise expressed frustration at not getting to see all patients who are discharged home on oxygen

> Denise
> If I don't get to see them then I don't know what's going on or what way they are feeling
> CI/September 2008

There were instances mentioned where members believed organizational culture had impeded the delivery of palliative care at an appropriate time resulting in increased distress fro patients:

> Eadie
> I am probably getting in a little too late unfortunately
> Faye
> It's a pity you weren't involved but I suppose it's not always [possible]
> Eadie
> It's not
> Faye
> I don't know whether the consultant would have agreed but when you look back it should have –I felt we could have done it earlier you know even though I didn't think [at the time]
> Eadie
> Looking back he was distressed and you look at the notes---and you can see that someone was unwell and yet you know that's going back quite a few weeks before I came into see him.

Ideas about addressing the discharge process were rejected because of poor expectations for changing nursing practice in relation to documenting patients' fears and illness experience. Implicit in these accounts was the moral experience of living with compromises. In unrecorded sub-group meetings the reality was frequently raised of nurses feeling under pressure from colleagues to move

through the clinic more quickly and being unable to respond to patients' distress. Recording entries in patients' charts highlighting R-CNS concerns regarding patients' distress were ignored. Examples were aired of being aware of patients' wish to speak about their fear but failing to meet this wish or diverting conversations towards safer territory. However, there were also instances described earlier of uncertainty about opening conversations with patients and responding to their fears.

Barriers to engaging with patients' illness experiences and distress seemed evident in the local moral world of nursing. Organizational and team culture appeared as barriers. However, reasoned justifications for claims about barriers may also mask our individual uncertainty about engaging with patients' lifeworld and fears. Palliative care philosophy is different to the philosophy underpinning acute respiratory care in its ease with responding to patients' fears and distress whether that is physical or psychosocial. Acknowledging uncertainty about our care practice allowed us to begin to engage more critically with the tensions between idealized nursing selves and the local moral world of everyday care.

Reductionism

The respiratory nurses' engagement with the illness experience meant confronting the hegemony of medical reductionism in which illness experience is reduced to bio-medical markers or disease focused management. Medical reductionist hegemony meant the silencing of other forms of knowledge notably illness experience. As a result there was conflict between disease management on the one hand and on the other, the knowledge about the illness experiences of individual patients that was built up through relationships developed over long periods. The group identified this knowledge as that in the nursing domain. However, Beth and Denise also made reference to a consultant's interest in the illness experience. This interest did not translate to movement away from the reductionist depiction of disease status in medical notes. The silencing effect on knowledge about illness experience appeared in Beth and Denise's account of being unable to document a patient's grief over the loss of a pet referred to earlier. Illness knowledge surfaced primarily in informal conversation and as a consequence, did not have legitimacy in cross disciplinary interaction or medical decision-making.

Following the death of the patient KR, the group members shared their concerns about how her fears and illness experience had been addressed. Individually, all believed that she might have wished for more open conversation about her dying process but this was not articulated in the wider group or respiratory team and in a manner that would ultimately facilitate decision-making. Though their knowledge of her illness experience had developed over their long relationship with her and her husband, decision-making in the final days was informed more by a bio-medical model approach to care rendering invisible her own illness meaning-making. This conflict between knowledge of a patient's illness meaning making and the bio-medical markers of disease was also illustrated in an experience that Ciara brought to the group. In this, she was caring for a patient who had previously been admitted and had ultimately been transferred to intensive care for ventilation. On this admission, the patient and her husband had made clear her wish not to go to intensive care and their belief that her high anxiety was in part, driven by her previous experience was a contributing factor to the extreme breathlessness she experienced. Ciara's own assessment of the patient and knowledge about the previous admission concurred with the link to anxiety. However, Ciara was unsuccessful in having this knowledge heard by the consultant and believed that they had failed the patient. In short, knowledge about patients' individual illness experiences and meaning-making while acknowledged as central to understanding patients' needs was viewed as informal knowledge and consequently was not easily brought into decision-making.

Attending to the interplay of lifeworld, illness meaning-making and symptom management brought to the surface issues regarding measurement and quality assessment. For Beth and Denise this posed particular problems in identifying measurable criteria against which the R-CNS activities could be measured. In one subgroup meeting we brainstormed possible strategies for developing the R-CNS role in addressing advanced COPD care needs. These included providing additional appointments for patients outside of clinical times to facilitate longer consultations with those in need of support similar to the format for the P-CNS's consultations. We also proposed developing documentation that would inform a more illness focused patient assessment. However, these ideas were juxtaposed with the need to have assessment instruments that were acceptable to the medical team. The performance in relation to the CNS role was aligned conforming to the norms expected by the medical team and management.

> Tools seem to be the preferred way of justifying the kinds of conversations [Beth and Denise] are having with their patients but which they currently have no way of 'legitimizing' at the moment. We will have to move very slowly here to avoid the tools becoming a replacement for the conversations.
>
> Journal entry 20th February 2009

The instruments we were exploring for moving consultations away from the standard assessment list of oxygen saturation, shortness of breath, cough sputum etc included quality of life questionnaires. However, we were also concerned about potentially replacing one reductionist approach to assessment with another in our efforts to work within the dominant way of viewing the world of care delivery.

Instrumentalism/Strategic Action

For the purposes here, instrumentalism or strategic action refers to goal orientation rather than understanding. Instrumental reasoning that underpins this action is the subjugation of response to illness concerns, to the apparently disconnected goals of institutionalisation/rationalisation. For Beth and Dense, instrumental reasoning in this sense created tensions with other outpatient staff when patient consultations were seen as taking too much time. This placed further difficulty for the R-CNS's in trying to defend and develop their specialist role particularly in relation to incorporating palliative care levels 1 and 2. A point of frustration was the difference in expectations of the organization between the palliative care and the respiratory clinic. For the former, one hour consultations were the norm. For patients in end stage COPD who were attending the respiratory clinic, their consultation time was no different to that of someone with asthma. In this way, Beth and Denise faced the choice of either focusing on bio-medical markers for monitoring their patients while not acknowledging their illness and lifeworld, or encounter tensions with other staff over clinic times.

For the ward-based nurses, instrumental reasoning permeated practice with a focus on patient turnover, absence of multi-disciplinary team meetings and limited scope for family review meetings. Patient discharge issues arose typically when home oxygen or BiPap was prescribed shortly before discharge giving little scope to support the patient. Though these issues could lead to readmission, strategies to address them were not explored. Denise's home visit to a patient

recently discharged revealed significant anxiety and difficulty adjusting to home oxygen. There was consensus within the group that her visit had prevented the patient's readmission by addressing his anxiety and difficulties.

Worlds within the World of Nursing

Meetings drew attention to the impact of increased specialization in nursing on how we identified our individual roles and relationships with each other. Our respective languages of acute respiratory and palliative were different reflecting different approaches to care and relationships with patients, carers and other HCPs. Engaging with different world views arising from our respective disciplinary languages brought fresh insights to our practice. Three sub-themes emerged (Table 10.5)

Table 10.5 Worlds within the World of Nursing Sub-theme

Sub-theme	Context
Discovery	Discovering different worldviews within our local nursing world.
Crossing rules and boundaries	Confronting formal cross discipline and role boundaries within a hierarchical environment.
Redefining boundaries	Negotiating conflict zones across disciplinary related worldviews.

Discovery

The CI process opened up a world of specialism wherein we were 'discovering' the different worlds within nursing. In our evaluative meeting in September 2009, gaining insights into each other's worlds was one of the strengths of our inquiry cited by all of us. Eadie's world of specialist palliative care was different to the world of respiratory care. Differences between the acute and palliative care philosophies emerged throughout the inquiry process. Her approach to discharge planning and GP interaction described earlier was in contrast to the diagnostic focused discharge process in acute respiratory care. Her focus on confronting patients' fears and concerns in the now was integral to and informed by end of life care in the future. In contrast, in the acute care arena, we were seeing concerns raised 'in-the-moment' more as discrete events. Faye and Ciara's world was that of managing a busy ward negotiating with staff and the diverse groups involved in patient care. They faced moment to moment changes in the

environment. Acute and palliative care remained separate even towards the end of the CI process despite our espoused merging approach:

> Beth
> We are much better at contacting patients but probably not to the level we want. You always see the gap 'God I didn't contact her or that man died at home' you know the way with palliative care it's difficult to combine both
> CI/July 2009

The insights gained from attending to our different worlds extended beyond the obvious differences in roles. Rather, there were differences in our language and views of the world. Faye and Ciara's patients were acutely ill or recovering. Faye referred to patients 'turning the corner' or 'reaching the end of the line' reflected her acute illness focus. Ciara's earlier reference to the ward as 'our home' reflected her awareness of the ward environment for inpatients. In contrast, Eadie's focus on a more intense engagement with patient, family, GPs and homecare teams was on bridging hospital and home. Eadie used phrases such as 'being with them in their kind of journey' (CI/July 2008), and 'issues going on for them [patients]' CI/June 2008. Beth and Denise sought contact with patients post discharge and their clinic roles focused on the patient's home-based illness management. Thus, our different roles and work-based performances gave us our particular world views and language. Our different worlds presented different challenges and sense-making of respiratory nursing care.

Crossing rules and boundaries

The boundaries between the worlds of palliative and acute care; and between ward-based and specialist care were negotiated through formal hierarchical referral processes. Referral of respiratory patients required a formal request for consultation from the respiratory to the palliative care consultant. Only when the palliative care consultant saw the patient could Eadie become formally involved. We recognised that nurses saw a need for earlier referral than the medical team:

> Eadie
> But it is always the nurse who initiates. Sometimes I would come across like the nurses would let me know about patients that have palliative care needs and then they would have aah asked quite

frequently about referring and when they're not getting anywhere and the patient is symptomatic I'll like I will briefly go through the notes and see that they are like but I can't go and see the patient
CI/June 2008

Getting agreement on need for referral was a recurrent issue and a point of frustration:

Eadie
I find on the wards that like it is the nurses who get the referrals. Like one patient it took 2 weeks for the girls to [get a referral] it did take a lot of chasing.
CI/July 2009

In response to these difficulties, nurses sought advice from Eadie though the impact on direct patient care was limited because she could not attend the patient before a formal referral. This informal nurse to nurse approach helped confirm the nurses' perceived need for referral and scope for Eadie to develop awareness of the palliative care role in advanced COPD. Different strategies at informal level provided nursing support in this way while also encouraging nurses to request palliative care support. Denise made entries in patients' charts referring to discussion with the P-CNS:

Denise
I thought it added more strength mentioning that you discussed with the CNS because of your experience
CI/July 2009

However, while these informal strategies were facilitating the crossing of boundaries between the 2 worlds, they were also creating additional problems for Eadie in our final meeting:

Eadie
I've found it quite helpful and learning about the respiratory point of view you know it's nice to bounce things off each other but the best thing would be to be actually involved with the patients' care but you don't get to you know the odd time I might pop my head in and introduce myself as Eadie cause I'm not actually involved but I'd like to actually build up the relationship you know.

Thus, the informal approach was drawing her towards a nurse to nurse advisory role and severely curtailing her actual role P-CNS and adding to the frustration of being called in too late. On the other hand, for the respiratory nurses Eadie's support was integral to their continuing efforts to increase the links between the respiratory and palliative care. Small successes were sometimes surprising and signals of opening boundaries:

> Ciara
> We have a lady she's in end stage and she's in and out a lot and just not coping very well and she gets really short of breath and she spends a week or so in. [There's] good family support. And she came in and I asked the consultant about palliative care who agreed. I was very surprised. And Dr X came up next morning and started her on a little bit of [medication] and felt the breathing was really problematic for her and felt that if her breathing was a bit better she could go home but that the family did not have anything to offer except more nebs so the fact that she had a little medication helped. She [patient] felt better with the oromorph and it was great.
> CI/July 2009

Ciara attributed her success in achieving a referral for this patient to being able to formulate her argument as a consequence of her own growing ease and understanding of the role of palliative care. She contextualised her success against a background of a continuing struggle to find ways of presenting a case for palliative referrals for specific patients:

> Ciara
> there was another lady that I would really like then [palliative care] to see you know there are some days when she is really short of breath just to give her a little bit of something
> CI/July 2009

In these instances, the perceived need for a palliative referral was built on the link between severe breathlessness and anxiety cycle, an issue that is familiar to both specialist respiratory and palliative care.

Redefining boundaries

The work of the group in seeking to open the boundaries between palliative and respiratory care increasingly created tensions for Eadie in balancing her ongoing support with the need for greater awareness among nurses of the distinctions between the different levels of palliative care. There was widespread confusion about the 3 levels. As a result, Eadie was experiencing requests for support in relation to level one.

> Eadie
>
> They are actually providing level 1 and 2 you know the challenge is to get in level 3. At the beginning I think they did not see they were providing level 1 and 2. Even on the ward they are providing levels 1 and 2
>
> CI/September 2009

While level one reflects an awareness of a palliative approach to care encompassing the way nurses address psycho-social needs, tensions continued within acute care as to how nurses attend to patients' broader needs in their environment. The idea of level one palliative care was potentially fuelling a perception that talking with patients about their fears and illness concerns belonged to the domain of expert practice in this case palliative care. Reticence among nurses towards engaging with patients about their fears and illness experiences may be translated into need to seek referral for P-CNS support. Put another way, referral to the P-CNS may be thoughtful justification for reticence to engage with patients or dealing with the pressures of acute care.

Practising level 1 or 2 palliative care at the R-CNS level left Beth and Denise vulnerable to criticism about their clinical management. Beth compared their 33 patients in a clinic with the 5 patients for the palliative care.

> Beth
>
> People will say why is your clinic staying so long and initially I'd wonder gosh is it was inefficiency whereas now I'd just try to like explain that these patients have different needs than surgical patients. You know we possibly need more education needs for staff members because they don't understand the needs of these patients. I can see where they are coming from but they don't understand the needs they

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think that these doctors are not efficient. So I think what that's bringing up is need for increased awareness of PC and chronic illness

CI/September 2009

In our sub-group we proposed to respond to the conflict between giving patients time while getting through a busy clinic by identifying those in need of longer consultations to return later in the week to meet with Beth or Denise. This would require setting aside 2 hours a week as a trial period. However, there was concern among senior managers about the practicality of this and the risk of 'opening a can of worms'. Embedding a level one palliative care approach within the world of respiratory care requires greater attention to engagement with patients' illness experience and fears, and competing philosophies of care. Paradoxically, developing their practice in this way increased Beth and Denise's vulnerability to criticisms from colleagues and management about time management since a level one approach was not embedded within the organization.

Chapter Eleven Palliative Care in COPD

Introduction

Illness and suffering permeated through the findings from both phases of this project. The WHO definition for palliative care includes suffering though does not define the term[20]. Nevertheless, it is clear from the definition statement that the palliative care seeks to address illness experience attending to its physical, psychosocial and spiritual aspects. Notwithstanding their critique of the WHO palliative care definition, Randall and Downie (2006:225) make explicit the need to address patients' views about their values and goals. The definitions seem in agreement that palliative care connects with an understanding of illness experience: how patients engage with and make judgements about how best to cope with or endure the distress and problems in daily living. Moreover, at the core of cancer illness accounts of Arthur Frank (2002a) and Reynolds Price (2003) among others; and chronic illness accounts (Strauss *et al.* 1984; Ellis 1995; Charmaz 1999) is how those affected including carers, perceive, live with and respond to their range of symptoms and disability. In palliative COPD terms, the integration of palliative care principles into basic nursing care (Department of Health & Children 2001; Health Service Executive and Irish Hospice Foundation 2008a) necessitates engagement with patients' illness experiences in acute care. The purpose of this chapter is to propose broad definition statement for palliative COPD care and its implications for all 3 levels of palliative care delivery in the acute care context.

While the terms illness and disease are often used interchangeably in palliative care journals as happens in the wider healthcare literature, the distinction is implicit in palliative care philosophy and acknowledged in research methodology (Anonymous 2006). In this project, participants in both phases distinguished illness experiences from disease oriented care. In this chapter, I will make explicit these distinctions and the importance of suffering as the basis for how we might construe palliative COPD care. In how we might address our understanding of palliative COPD care, I will explore the tensions that are inherent in our local moral world of nursing. I will draw on the ideas of Mikhail Bakhtin to illustrate the importance of different speechness in understanding the challenges to

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[20] www.cancer**care**.on.ca/pdf/GTA2014Chapter12.pdf Accessed 16th September 2008

addressing palliative COPD care. In particular, Bakhtin's idea of heteroglot seems useful in understanding how it is that while policy and evidence support palliative COPD care as integral to respiratory nursing, their implementation remains illusive.

Health Related Quality of Life

Hospital Admission as Indicator

The inclusion criteria for inviting patients to participate in this project were broad relative to the norms for assessment of COPD status. Participants were not assessed according to their FEV_1 or pulmonary function status and so could not be recruited on the basis of the GOLD criteria for stage 111 or 1V (Global Initiative for Chronic Obstructive Disease 2008). By focussing on a history of emergency admissions for treatment of acute exacerbation, I was attending to evidence of deteriorating illness and the associated risks of mortality. Despite this broad inclusion criteria, in all but one instance, the patients who participated in this study appeared to have advanced disease based on MRC and HRQoL. Using the GOLD criteria (Global Initiative for Chronic Obstructive Disease 2008) for staging COPD severity, Ståhl et al (2005) reported a statistically significant difference in the SGRQ scores between the severity groups (p = 0.0005):

> Stage I: 25,
> Stage II: 32,
> Stage III: 36,
> Stage IV: 53

This would imply that the average total SGRQ score of 62 falls well above the stage IV score reported by Ståhl et al (2005). Of the 26 participants, 19 (76%) had total SGRQ scores above 53 while 3 (12%) had scores reflecting stage III. In short, 88% of participants reported poor quality of life reflecting moderately severe and severe COPD as categorised by the GOLD guidelines.

HRQoL and Anxiety and Depression Relationship

The findings here concord with those of Gudmundsson et al (2006a) in their review of anxiety and depression before discharge from hospital following treatment for acute exacerbation. Additionally, they found a greater effect (12 units) of anxiety and depression on SGRQ scores than is considered clinically significant for medication impact (4 units). Participants in phase one of our project reported anxiety and depression that continued in between hospital

admissions. Contrary to suggestions (Gudmundsson et al 2006a), anxiety and depression symptoms for our participants did not appear to subside following discharge. It is possible that for those experiencing frequent admissions, regular courses of high doses of steroid medication long associated with mood changes, may contribute to low mood. However, where other studies examined patients during or immediately post exacerbations, the assumption that anxiety and depression should ease is speculative. In the integrative analysis shown earlier, ongoing and painful confrontations with an ever contracting world and diminishment of self seemed closely linked with HADS scores suggestive of anxiety and depression. It seems unsafe to speculate therefore that patients experience any significant relief from anxiety and depression symptoms post acute exacerbation in advanced COPD.

Disease and Illness Trajectories

Experience of Illness as Suffering

The integrative analysis challenged any notion of anxiety and depression in COPD as endpoints in themselves. Rather, behind the high HADS scores, narratives illustrated both how advanced COPD permeates all aspects of one's life and the importance of understanding this in acknowledging the suffering in a palliative care context. The profound sense of loss and diminishment of self was graphically illustrated by participant 27 when she described her first morning at home following her discharge from hospital. She had come home to a newly medicalised bedroom complete with hospital bed, oxygen and BiPap equipment. That alone, represented a dramatic diagnostic event with loss of a fundamental aspect of her previous life and her personhood that is to say her physical, social, emotional and whole sense of self. However, added to that, she found her primary immediate concern was how she was going to make her bed. In her account, coming to realise what was her immediate concern, how to make her bed, represented a diminished sense of self and closure of a previous life. Her grief and anger as she described this experience were palpable and would remain unknown to the respiratory nurses. On the contrary, from a disease management perspective, the changes were put in place by the team to improve her symptom control and self efficacy. Follow up OPD care in relation to the changes put in place would typically focus on oxygen saturation and BiPap readings.

As participants faced loss and diminished sense of self, diagnostic events were meaningful to the extent to which they impacted on lifeworld and contracting

worlds furthering their loss. Events such as no longer playing with grandchildren, participating in shopping or waiting for someone to carry a bag of turf, were reminders to participants and family about growing disability and loss of previous roles. Illness experience was thus borne out of a strangling of sense of self and identity with previous roles. Family and social interactions were framed against this background with participants describing interactions with others that were characterised by foregrounding increased disability. Typically, when Participant 7 referred to trying to help in the kitchen, his wife commented that he seldom managed to finish tasks such as washing dishes.   Thus, expectations in relation to interactions with others were negative, fuelling loss of sense of self and conflict between wishing to withdraw and wanting to engage with others and everyday activities. Where diminished sense of self and conflict resonates with the idea of suffering described earlier, the illness experiences challenge the accepted representation of COPD trajectory as a downward slope marked by dips reflecting acute exacerbations. Based on these findings, the COPD illness trajectory is a more chaotic one marked by dips of varying degrees and width.

COPD and Personhood

Participants' accounts relayed different dimensions to conflict with self and that appeared to contribute to anxiety and depression.   In COPD terms, acknowledging responsibility for the condition was an obvious source of ongoing inner conflict. The tensions arising from contracting worlds resulted in conflict between desire to engage with life and social interaction and desire to withdraw. Conflict in this sense was often played out in tensions with family relating to engaging in everyday activities as illustrated by participants 1 and 9. However, the tensions also contributed further to conflict with self in that they reinforced the loss of place and role within the family.   A husband is encouraged to participate in shopping trips but feels diminished by his inability to carry purchases; a wife/sibling is encouraged to participate in family events but feels diminished by her passive rather than an active role in these same events. Since breathlessness permeates all activities, this sense of diminished self is ever present in accounts such as those related to getting up in the morning and supports Cassell's (1991) contention that the body is a constant source of humiliation.

Living with severe breathlessness meant always distrusting one's body since any activity or event could result in a frightening attack such that life meant living in a state of continued conflict with self. Episodes of severe breathlessness though frequent were associated with an all consuming fear of losing breath. Thus, participants on the one hand referred to their successful management of these episodes while on the other hand spoke of being in constant fear of them. A feature of the interviews was the struggle to articulate both the sensation of losing breath and the conflict with self. Phrases such as 'it comes up on me' or 'it closes in' were common but we struggled to name 'it' supporting Iain Wilkinson's (2005) contention that researchers continue to debate the adequacy of language to conceptualise human suffering.

Denial or Silencing of Suffering

Participants mediate between a western bio-medical focus or disease oriented world view and their illness experience that extends through all aspects of their life and engagement with the world. Formal healthcare delivery does not engage with the illness experience, rather participants described a process of negotiating with health care that had its own rules of engagement. Rules of engagement included responding to HCPs' questions in OPD that focused on specific symptoms and management of acute exacerbations as discrete events rather than merged into the individual's illness trajectory. Markers of deterioration and stabilisation are bio-medical rather than day to day experiences of evidence of illness progression. At the end of an interview with Participant 8, I returned to her comment about believing she would die in the following months. She had mentioned trying to open a conversation with her husband about her illness. Though fearful of what lay ahead, she had not raised her sense of imminent death or fears with either the hospital team or her GP nor did she believe there was an opening to do so in her interactions with HCPs. She died 6 months later. Her reticence about raising her fears reflected a general low expectation among participants in relation to HCPs' engagement with illness experiences and by implication any recognition of the impact on loss of self and conflict.

Denial of personhood from the clinical encounter actively contributes to the patient's suffering. Those dimensions of personhood that cannot be readily objectified in diseased focused acute care were unacknowledged and so suffering could not be fully acknowledged. Accounts of interactions with HCPs pointed to denial of personhood particularly during routine visits to the extent that some

questioned the purpose of the clinic. In contrast, in the throes of severe breathlessness during acute exacerbations, the task and disease orientation of A/E care did not deny personhood since both the needs of the patient and responses of HCPs were usually in harmony. However there were also examples of denial of personhood in A/E when 2 participants relayed experiences of not being taken seriously by HCPs. In both instances denial of personhood included rejection or dismissal of the fear and panic that accompanied acute severe breathlessness. Though these events had taken place some years before, both participants spoke with palpable anger in the retelling. In short, not taking seriously an individual's perception of worsening already severe breathlessness was to leave unacknowledged the fear and panic of losing breath.

In the A/E context rejection was particularly felt since A/E was the 'last port of call' in the event of worsening breathlessness. Apart from the felt need for additional treatment, the A/E experiences were bound up in images of self as acting responsibly that is to say managing treatment of symptoms and medication, and only attending A/E when absolutely necessary. All participants made a point of journeying to A/E only as a last resort. Similarly, several spoke of their awareness of bed shortages and working to recover quickly while in hospital. Thus, the felt rejection in the hospital and A/E contexts discredited this image of self as responsible patient. The valued attribute of being responsible and self managing illness was called into question and replaced by sense of being viewed as a burden to A/E, wards and HCPs.

In appearing to reject participants' justification for attending A/E or bed occupancy, HCPs were discrediting participants' ability to act responsibly and self manage their illness. Participants, in return felt alienated from HCPs and having to battle against being perceived as a failure in terms of capacity to self manage symptoms. Participants were demoralised by both COPD, and engagement with the System and HCPs. Demoralization in this sense is a consequence of a construct of suffering that is played out in acute care where illness is reduced to biomedical markers. The focus of A/E-based HCPs on what resources by way of home oxygen and medication were available to Participant 7 at home overlooked the reality of his previous experiences of acute exacerbations and illness experience. In short, the felt rejection compounded suffering and brought into sharp relief the active role that HCPs placed in patients' suffering.

Responding to suffering experienced by participants requires engagement with or recognition of their disrupted lives. From the participant interviews, palliative care in COPD might be understood as minimizing the breathlessness experiences and engaging with illness response to a contracting world through acknowledging and healing the fractures and threats to one's integrity or whole. Integrity or whole in this sense refers to personhood: the physical, emotional and the social dimensions of self. Thus the individual illness experience rather than disease needs to be the focus in care planning with efforts to counter a continually contracting world or self conflict.

Responding to Other

The participants' accounts lent support to international evidence that engagement with acute care services significantly increases in advanced COPD (Kinnunen *et al*. 2007). Participants who were experiencing severe breathlessness and poor quality of life had in excess of 2 hospital admissions in the previous 2 years and were regular attenders to OPD. In addition, many were using home oxygen. In other words, these participants had developed relationships with HCPs that stood on the boundary between the knowing the case/patient relationship associated with acute care and that of knowing the patient as person associated more with ongoing or long term care (Liaschenko 1997). Their relationships with HCPs and the acute care environment invited a response to their illness experience. Such invitations were made in different contexts and often at inopportune times such as during a clinic visit. These were inopportune times simply because the respiratory nurses were torn between remaining disease focused in their assessment and clinic schedule or responding to patients' need for illness focus with consequences for the clinic duration.

Nonetheless, we shared experiences of moving into a communicative space wherein there was an acknowledgement and reaching towards *Other*. *Other* in this sense represented the move towards *knowing the patient as person* with his/her own unique illness experience and shared meaning making. When a patient opened a conversation with Beth about loss of a pet they entered together this communicative space. Moving towards *Other* also represented consciously entering into a communicative space with patients with whom relationships were established. Faye's reference to watching patients turning (or not) *the corner* was easily recognised by all of us in the group and so too was Denise's retelling of her care and watch over a dying patient: 'you could see that he just gave up'. It

was Eadie who recognised these accounts as journeying with the patient and integral to a palliative care approach. In short, coming to know the patient as person seemed the basis for journeying with the patient over time. However, moving into a communicative space that enabled relationships with patients to move beyond being disease focused was not intrinsic to the OPD clinic routines or the busy high dependency environment in which the ward-based respiratory nurses worked.

Palliative care in COPD should seek to minimize breathlessness and other symptoms, and acknowledge and respond to the patients' suffering by recognizing the uniqueness of and responsibility to the *Other*. The antithesis of this palliative care view is failure to minimize breathlessness by failing to acknowledge the interplay of breathlessness and suffering. Failing to acknowledge *Other* in this sense is to deny the uniqueness of the *Other* or to subsume the *Other* through the conversion of illness experiences into disease pathophysiology.

In summary, the patient interviews point to the importance of recognising and responding to illness narrative in COPD palliative care. This is not to deny the importance of a more reductionist or disease oriented response when immediate stabilization of symptoms is needed. Rather, the distinctiveness of and interplay between disease and illness discourses need to be recognized as central to our understanding of palliative COPD care. How that interplay can be played out was articulated by Participant 25 in his description of a deepening partnership with consultant and nurses. Their partnership was expressed in a shared assessment of his health state rather than relying exclusively on biomedical markers and recognising importance of self image. Later, during the project period, this participant was prescribed BiPap for home use. Following a trial period and several lengthy discussions with Beth and Denise, he decided to discontinue.

Co-operative Inquiry

Divided World and Divided Self

Relationship with *Other* gave form to the CI both in terms of patient care and reaching across discipline and specialist practice boundaries. On patient care, our initial focus was on issues pertaining to gaining control or certainty through symptom management or risk assessment and guideline development. This

quickly gave way to uncertainty that arises when routine every day practice and interaction with patients are challenged by a sense of inadequacy in the face of patient suffering and powerlessness. Confronting difference among ourselves in our differing roles gave insights to different worlds within healthcare and relationships within and between disciplines. Factors mediating relationship with *other* highlighted the tensions being played out in everyday practice between the ideal and the harsh reality of nursing.

Local Moral World of Respiratory Care

In our CI, we articulated the gap between our (and society's) ideal nursing selves in relation to an ethical framework and the moral experience of living with compromises and harsh reality of care delivery in the current Irish healthcare environment. Our idealized nursing care gives way to care practices and compromises driven by pressures of staffing levels, time pressures, ward routines, bed shortages, need to discharge patients quickly with little notice etc. In essence, practice becomes subsumed by efficiency and control requirements of System in the Habermassian sense (Outhwaite 1996; Cooke 1997). Despite the rhetoric of individualised nursing care and patient centred care, the contrast between the culturally accepted pace of the palliative care clinic compared with that of the COPD clinic illustrated a divided world. However ill patients appeared with COPD, the time deemed appropriate for them in the clinic setting was unequal to that deemed appropriate for patients dying from cancer. For Eadie, a palliative care clinic usually involved seeing 5 patients. In marked contrast, in a respiratory clinic that involved a mostly COPD focus, Beth and Denise saw 25 patients. The clinic frequently over ran leaving patients waiting, and the team under pressure and open to criticism for not running to time.

Divided Worlds

The nature of advanced COPD was such that nurses built up close relationships over years during frequent admissions; sometimes extended hospital stays and follow-up care. The shock and grief experienced by the respiratory nurses when a long known patient died was a recurring theme. Charon (2006) saw the patient/doctor relationships as far more troubled than those of patient/nurse or other allied healthcare professionals. While the CI group also saw their relationships with patients as being different, the patient interviews and stories explored in the CI meetings pointed to the patient/nurse relationship as situated

on a boundary between that of knowing the case or patient (Liaschenko 1997) and knowing the person. Knowing the case/patient accounts signified episodes in which interventions were focused on biological rather than illness markers. In short, the divides identified by Charon (2006:22) relating to mortality, contexts of illness, beliefs about disease causality and emotions of shame and blame were also evident in our explorations of incidents and the patient interviews.

Participant 8 believed she was dying and was deteriorating rapidly, yet had no such indication from the healthcare team. Despite his disciplined exercise routine and self management, Participant 25 believed he was ready 'to go' and made an informed decision to discontinue his BiPap. However, he had not had a conversation about dying with the healthcare team. The illness contexts divides were starkly illustrated in the healthcare focus on exacerbations as discrete events with patients admitted, stabilised and discharged. In contrast, for patients, exacerbations featured as part of their continuing illness and sometimes as diagnostic events in terms of their impact on contracting worlds. There were clear divides in relation to COPD causality in which smoking remains the primary explanation for COPD within healthcare. For participants, COPD was part of their life history. Furthermore, for participants, diagnostic events were an integral part of causality in that they were bound up in the whole COPD story. The emotions of fear, shame and blame underpinned the suffering experienced by participants but were not acknowledged in disease focused care. These divides reflected that which separated participants from those in healthcare.

Divided Selves

Similarly, the demands of the acute care environment appeared to overshadow attempts to pre-empt the worst effects of a diagnostic event and contracting world. Though the instrumentalism or means-end of the patient discharge process was acknowledged and similar to that articulated by Wells (1995), the group believed that they were powerless to change the discharge practice. This was despite recognition of the links between support through the discharge process and contracting world. Encountering everyday issues such as patients' wish to speak about their fear but failing to meet this wish or diverting conversations towards safer territory, illustrated the divided world and self in everyday practice. Thoughtful justifications for such actions merged with the practical self in 'our local moral world' (Kleinman 2006:219). Inability to sit with distressed patients was explained as evidence of System limitations reflecting

reasoned justifications. These, however plausible, may be based more on passion or reactive selves against fear of exposure to uncertainty when facing the suffering of another. At other times and especially in the aftermath of KR's death, this inability was articulated in terms of not knowing how to respond to a patient's suffering, existential distress, fear of the future or simply need to talk about their lives. In this sense, passion-laden or reactive selves surfaced when, as Charon (2006) suggests of doctors, our uncertainty and call to respond to the suffering of another invited us to confront our own suffering. For Kleinman (2006) *our* suffering emerges from our divided worlds and divided selves.

The Heteroglot in COPD Acute Care

Knowledge built up from knowing the person relationships fell within our idealised sense of nursing and care delivery in chronic illness (Lubkin and Larsen 2006). However, this knowledge was external to the official disease centred care approach and resulted in tensions between the 'official' re/presentation of patients in bio-medical terms and an unofficial suppressed dialogue with patients. In our CI meetings, we confronted what we saw as re/presentation that allows System oriented decision-making and control in discharge planning, ward-based routines and processing patients through OPD. Denise's home visit illustrated the impact of a severe exacerbation on a patient in terms of his lifeworld. His fear of discharge, discharge experience and difficulties adjusting to a new life on home oxygen marked a significant a diagnostic event. The CI group members involved in his care were conscious of this possibility and consequently decided on a home visit as an action cycle in our inquiry. Nonetheless, our learning from the visit illustrated the degree to which this diagnostic event had not been acknowledged never mind tackled. Following the visit, Denise was clear in her belief that this patient would have required a further admission as a consequence of his distress from the exacerbation. In short, the visit revealed the interplay between disease and suffering.

Significantly, at different times CI group members referred to doctors also engaging with patients' illness narratives but maintaining the official bio-medical discourse in documentation and clinical decision-making. In short, the bio-medical approach was shorthand for a System-wide selective silencing of illness narratives. The silencing is selective because illness narratives are deemed central to palliative care delivery as Eadie illustrated in comparing her approach with that of the respiratory team to care and discharge planning. Nevertheless,

the relationships built up with patients generated an informal or unofficial illness oriented care approach that was articulated within the CI group and captured in Faye's long comment on interrupting treatment decision-making.

Conflicting Narrative

In our CI, we recognised illness, disease and management narratives and the conflict inherent among them in our conversations. Engagement with disease and management narratives was reductionist and System oriented and therefore centripetal in Bakhtinian terms. Engagement with illness narratives reflected resistance to System and was therefore centrifugal in direction. We saw that this conflict between disease as centripetal and illness as centrifugal narratives was more complex than a simple ideological clash between nurses and doctors. Firstly, nurses in acute care mostly worked to a disease narrative. Indeed, patients, in their interviews, recognised this and accepted it in certain circumstances such as in A/E. Secondly, in both the CI group and in patient interviews, there were several references to consultants engaging with patients' own illness stories. Thirdly, that neither the consultants nor nurses could find a way of documenting the illness narratives suggests an underground bubbling illness narrative in conflict with the official disease one. Similarly, there appeared a conflict between both disease and managerial narratives. Accepted length of bed stay, bed management, appointment-systems conflicted with medical teams' decision-making. A co-operative inquiry involving doctors might have explored that conflict more fully. However, Charon (2006) and Frank (2002b) detail the complex and difficult relationships between administration and delivery of medical care so that 'doctors seem divided from their patients and themselves' (Charon 2006:7). The differences in language between the world of medical administration and that of medical care are illustrated by Little (2005) in his eloquent example of clinicians and administrators failing to agree on outcomes because of disagreement over the meaning of the word.

The hospital notes of a patient with COPD in Bakhtinian terms might be imagined as a book residing in the shelves of Hogworth's Library (Rowling 2004) that upon opening erupts into a cacophony of different voices in dialogue. This polyphony or multi-voice-ness would reflect voices interacting on an equal basis. However, drawing on an example of hospice team conferences, Poirier (2002) describes how the rhetoric of multi-vocality can reflect more the heteroglot of team conferences working to strict hierarchy and inequity. Understanding the clash

between disease and illness narratives as heteroglot gave meaning to the responses and actions of the CI group members. Ciara's pre-planned approach to a consultant to request a palliative care referral, Faye's interventions when a patient appeared to withdraw, and Beth and Denise's interventions in the clinics all pointed to a striving to influence by working around the more dominant disease narrative. There was recognition that working 'around' obstacles was more likely to generate solutions than seeking some kind of reasoned debate in a Habermassian sense. Significantly, understanding the conflict as narrative-based rather than professionally-based (notwithstanding the importance of disease narrative in medicine and doctor identity) allowed an interrogation of conflicting narratives within respiratory nursing and between respiratory and palliative care.

In the Bakhtinian sense, human consciousness is formed through dialogue with self as inner dialogue and with others through a multitude of voices expressing opinions, ideas, beliefs etc. Dialogue is not finalised but rather is continually becoming since it is dynamic and context dependence; dialogue is polyphonic. In a Bakhtinian sense therefore, our exploration of palliative COPD palliative nursing was polyphonic. Our own expressed views of care delivery: the gaps between ideal care and the everyday reality; our views and beliefs concerning interaction with patients, doctors and others; were a dialogue polyphony. The conflicting narratives are thus both internal for each of us and external as expressed and experienced rather than imposed upon us. Our exploration of our worlds within the world of nursing reflected an attending to voices that had previously not been fully acknowledged. In other words, these voices were already present but not heard over other voices that homogenised nursing. Our internal voices reflecting divided worlds and divided selves could be silenced by attending to the voices of disease narrative and reductionism. Pausing to make sense of our COPD care through the CI group, brought forth those more silent voices giving expression to our uncertainty about care, and grief for patients who had died.

Understanding Palliative COPD Care

Palliative COPD nursing becomes care that assumes a cacophony of voices that include centripetal oriented disease and managerial, and centrifugal oriented illness narratives while aiming towards giving space for the latter to be heard and entering into a dialogue with each. The open-endedness of the dialogue is underlined. In essence, palliative COPD care centres on responsive

understanding to illness and disease narratives that flow through each individual patient's illness trajectory.

Embedding Principles of Palliative Care into COPD Care

Put another way, palliative care for patients with COPD cannot be addressed unless engagement with their illness experience is brought to the front stage of hospital care. However, to do this, the current position of illness narratives in the COPD heteroglot needs to be brought into question. In particular, the tensions between a palliative care philosophy and disease centred specialist practice of respiratory care need to be acknowledged and explored by the respiratory team. From the experiences of this inquiry, concerns appear well founded that 'palliative care could default into a series of competencies directed only at technical control of symptoms' (Royal College of Physicians of London. 2007:1).

For Eadie, her help was increasingly sought for what she described as level one palliative care when respiratory nurses believed they were not competent to talk with patients about illness concerns and suffering. At the other end of the scale, specialist palliative care was increasingly sought for management of severe intractable symptoms notably breathlessness. While there was no question as to the appropriateness of specialist palliative care referrals in such instances, that they were possibly sought in the absence of an overt overall palliative approach to care lends credence to the concerns regarding technical control of symptoms. In Bakhtinian terms, this reflects the pull of centripetal forces towards a reductionist approach to care where technolization of palliative COPD care includes reducing or monologising illness narratives to a series of discrete needs such as counselling or pain relief.

Responsive Understanding to Illness and Disease Narratives

Recent reports have supported the idea of embedding the basic principles of palliative care in routine practice (Department of Health & Children 2001; Health Service Executive and Irish Hospice Foundation 2008a). In essence '[t]he palliative care approach should be a core skill of every clinician at hospital and community level' (Health Service Executive and Irish Hospice Foundation 2008a:XII). To this end, HCPs 'should be responsive to help people adapt to their illness, take a realistic approach to defined goals and take its pace from the individual' (Health Service Executive and Irish Hospice Foundation 2008a:38). At

first blush, then, the core principles of palliative care at level one appear no different from those of chronic illness care (Lubkin and Larsen 2006). Where meetings centred on minimizing the impact of diagnostic events, reviewing support for patients pre and post discharge or addressing anxiety, the group's cited barriers to developing practice included time and work pressures, uncertainty about support from management and the medical team, perceived need for counselling or communication skills. In the local moral world of nursing, the issues confronting respiratory nurses reflected more the challenges of responding to illness care needs in the acute environment. To this end, the process of integrating basic principles of palliative care was bound up in our engagement in the local moral world and attending to the heteroglot of acute care.

Level One Palliative COPD Care

For A/E and ward-based nurses, disease narratives are likely to always dominate over illness narratives. Notwithstanding the focus on management of acute exacerbation, stabilizing breathlessness and other symptoms, the routines and narratives of admission and discharge processes, measures to minimize bed stays and pace of ward collectively work act as centripetal forces to disease narrative dominance. Technical control of the pathophysiological markers of advanced COPD and management of finite healthcare resources remain a central plank of acute care. Thus, acknowledging these while consciously attending to illness narratives provide the basis for level one palliative care in the wards.

In his suggested method for caring for people with chronic illness, Kleinman (1988) turns to what he calls a mini-ethnography in which the clinician attends the story of the other and interprets this in the light of major themes including those related to the social, political, psychological and economic. As an outsider, the ethnographer can challenge common-sense understandings while also revealing underlying socio-political factors influencing illness meaning making while also challenging 'conceptual commitments and professional biases' through self criticism and dialogue with other (Kleinman 1988:232). While Kleinman directs his mini-ethnographic method at the physician, it is about establishing an open collaborative relationship with a patient in which disease and illness narratives are brought together through dialogue. As such, the method is relevant to the nurse involved in care delivery. In bringing this mini-ethnographic approach into advanced COPD care, the respiratory nurse brings to the fore the

patient's illness experience. The process of undertaking this mini-ethnography is drawn out over time rather than compressed into a single encounter. The process includes 1) reconstructing the individual patient' illness narrative; 2) seeking a life history; 3) establish explanatory models; 4) negotiation; 5) remoralization. These different stages are continually cycling and reflect an on-going conversation or dialogue between nurse and patient.

Reconstructing illness Narrative

Drawing on his 4 types of illness meanings, Kleinman thus suggests exploring the illness account through symptoms and what they mean to the patient e.g. fear/breathlessness cycles; cultural influences on meaning making e.g. smoking related disorder and links to ways of working; personal and interpersonal significance; and explanatory models. Significantly, the 'clinician comes to recognize that the narration of the illness, in part, creates the experience because of the special concerns-cognitive, affective, moral-that patients bring to their encounters with the events and career of chronic illness' (Kleinman 1988:233).

Seeking a Life History

A brief life history brings personal context of illness to bear on the illness account including the diagnostic events that have taken place along the trajectory. In particular, the presence of anxiety and depression as emotional reactions to illness effects can be revealed as in the patient interviews and Denise's post discharge visit and interviews with patients.

Explanatory Models

Kleinman's explanatory model question: *What do you think is wrong?* resonates with one of Charon's suggested opening questions during a patient consultation: *Tell me what you think I should know about your illness*. These and their follow-up questions invite the patient to describe his/her ideas about cause/effect, vulnerability, management and care issues. The patient interviews revealed the importance of explanatory models to the point where deaths of family members from COPD or hardship in early life framed their current expectations and emotional response to illness. However, for Kleinman and Charon, explanatory models are continually developing and frequently conflicting in sense-making through the emotional chaos of illness effects. The explanatory model of the clinician is also relevant both in terms of its relationship with that of the patient and how it is presented. Thus the explanatory models are never complete but

rather are rooted in the sense-making dialogue between clinician and patient. In Bakhtinian terms explanatory models are polyphonic in the inner dialogues of both clinician and patient and in their utterances. Just as Kleinman refers to the inchoate nature of explanatory models, recognising the polyphonic nature of the models helps avoid monologising them to fit with a particular view.

Negotiation

Kleinman (1988:242) distinguishes genuine negotiation from 'a grudging pseudomutuality' in which the former focuses on negotiating the professional and lay explanatory models with the patient 'as a colleague involved in care as collaboration'. In Bakhtinian terms, this positions the HCP as characters in the patient's illness narrative rather than as authors. In other words, negotiation recognises the patient as living a life of illness. Central to this negotiation is acknowledgement of uncertainty and open endedness of both explanatory models. Negotiation also includes on-going critical reflection and interrogation about the underlying personal and professional factors such as tacit moral judgements, influencing one's explanatory model.

Remoralization

For Kleinman, the relationship between practitioner and patient is a moral one in which the former bears witness to the suffering of the latter. The relationship is also a psychotherapeutic one in which the practitioner attends to the psychosocial needs of the patient through bearing witness, practical problem solving responding to loss and grief. By remoralization, Kleinman seeks to enable the patient to come to terms with his/her current position. Remoralization in this sense resonates with the idea of responsive understanding wherein the practitioner demonstrates both her state of bearing witness not as a passive observer but as one actively engaged in the sense-making and problem-solving process.

Mini-ethnographic method at Level One

A strength of Kleinman's approach is his emphasis on its development over time. As such it potentially offers a way of framing the development of the nurse/patient relationships built up between ward-based nurses and patients. Where Ciara and Faye both described their knowledge of patients who were experiencing repeated admissions, articulating this in terms of Kleinman's mini-ethnography would enable a more questioning approach to the nature of the

developing relationships and subsequent ease about them such as when a patient dies. In short the method facilitates a responsive understanding to patients' individual illness narratives enabling nurses to actively confront the uncertainty described by the respiratory nurses when meeting the fear of patients in advanced COPD.

Level Two Palliative COPD Care

The R-CNS's, are well positioned to engage more fully with Kleinman's method through negotiating explanatory models and a responsive understanding to patients' individual illness narratives. The post discharge visit undertaken by Denise represented a watershed in bringing the illness narrative to the fore in discharge care planning and follow-up. Focus on the impact of an acute exacerbation and subsequent management as diagnostic events enable the R-CNS to engage more fully in the interaction between symptom and treatment meaning making, and contracting world. In Bakhtinian terms, this interaction reflects responding to the call of the *Other* and enabling expression of the inner dialogue that is shaping a patient's illness narrative. Illness support activities identified by the group thus included follow up phone calls and home visits post discharge, establishment of support clinics for patients identified during clinics as needing longer consultations, use of texting and regular phone conversations for 'touching base' with patients and pre-empting worrying symptoms.

Level Three Palliative COPD Care

Specialist palliative care support was increasingly sought by the medical teams over the course of the inquiry. While this may well be attributed to nurses suggesting or requesting patient referral, there is also increasing attention in the respiratory literature to palliative COPD care. Palliative care is the subject of a specialist symposium or concurrent sessions at the European Respiratory Society's annual conference in recent years. Awareness of palliative care is thus increasing across the respiratory team notwithstanding continuing concerns about management of referral and medication related complications. However, for the CI group, Eadie's role was a powerful force in raising the palliative care agenda at ward and R-CNS levels.

As the inquiry unfolded a mismatch emerged in our different understandings of engaging with the principles of level one palliative care. Though Eadie contested

that at ward and CNS level, many nurses were addressing the principles of palliative care, others in the group did not share her view. At issue here was both our understanding of what constituted palliative care principles and the centrifugal force or unofficial nature of our illness care language. In other words, though Eadie had observed respiratory nurses attending to illness narratives, in the heteroglot of COPD care, this work was less official and therefore not part of the nursing/medical team/management interaction. Significantly, clinical decision-making, for the most part did not include this work since it was not acknowledged. Responding to patients' fears, uncertainties and grief generated uncertainty in the local moral world of nursing with the respiratory nurses feeling trapped between the idealised rhetoric of care and the dominance of disease and reductionist narratives. Where Eadie linked engagement with patients' illness experiences as a fundamental part of level one palliative care, others saw their perceived inability or reticence to respond to patients' anxiety or communication needs as indicative of the need for specialist palliative care. Eadie's increasing presence on the ward and continuing promotion of a palliative care approach was viewed by both Faye and Christine as essential on 2 counts. Firstly, Eadie was on hand to respond to immediate concerns of ward-based nurses in relation to patient issues and nurse/patient interaction. Secondly, Eadie's increased visibility prompted conversations about palliative care and articulation of patient needs as palliative.

From Eadie's perspective, her presence on the ward also brought a participant observer dimension to her role wherein she was able to identify patients with possible palliative care needs that were not articulated as such by the respiratory team. This was important from 2 counts. Firstly, she was able to highlight possible unmet needs with the nursing and medical team. Secondly, where the ward-based nurses were struggling to promote palliative care needs for individual patients with the medical team, Eadie provided encouragement and support. Thus her role, unofficial though it was, became both advisory and facilitative similar to that described by Pitcher and Davis (2001). The unofficial nature of this role however, meant Eadie was limited to the extent she could proactively encourage and embed the principles of palliative care into ward-based nursing practice. Rather, she continually sought openings to promote the principles of palliative care and interrupt the dominant disease narrative in decision-making. To this extent, there was a subversive element to the collaboration between the respiratory nurses and Eadie.

Eadie's unofficial role as observer and collaborator resonated with Kleinman's mini-ethnography approach to patient care. In Eadie's case, her's was the professional palliative care voice engaging with the 'lay' voice of the respiratory team Their ensuing dialogue that took place within the CI group and at ward level was essentially seeking to reconstruct the meaning of COPD care though attending to 1) symptom management; 2) cultural influences on meaning making including acute care and team-based culture; 3) personal and interpersonal significance including relationships with patients; and explanatory modes of care approaches including disease and illness-oriented approaches to care. In short, Eadie's engagement with the respiratory staff was centred on negotiating through the palliative and acute respiratory care worlds wherein the knowledge and experience of both worlds was acknowledged and meaning from each was a negotiated one. Significantly, Eadie's response was one of bearing witness to the difficulties for the ward-based nurses in engaging with uncertainty and struggle to bring an illness narrative into the acute care environment.

illness narratives represented a centrifugal force in COPD care discourse but a centripetal discourse in palliative care. Thus to render 'official' a patient's illness care needs meant looking towards palliative care. However, for the CI group, tensions emerged between trying to give voice to and embed the principles of palliative care in respiratory nursing practice on the one hand and on the other, working around the dominant respiratory language by 'handing over' a palliative care issue to Eadie. The latter approach was the more expedient. However, this also served to endorse without question the dominant disease narrative in acute respiratory care and prevented dialogue between disease and illness narratives. For Eadie, this slowed down efforts to increase visibility of palliative care in acute respiratory care since there was less scope to embed both illness narrative and palliative care principles in nursing practice. In short, in order to bring illness narratives into 'officialdom' in respiratory languages in any polyphonic sense, the respiratory nurses needed to normalise and take responsibility for bringing level one palliative care into nursing care at ward and clinic levels.

Eadie's presence on the ward and engagement with respiratory nurses was viewed by all within the CI group as serving to both increase awareness of palliative care in COPD and build confidence among nurses in responding to illness narratives and thereby addressing level one palliative care. The commentary in some palliative care writing (Addington-Hall and Higginson 2001b) points to concerns among specialist palliative care of becoming swamped if

services are extended to non-malignancy. The issues from Eadie's experience in the group were less to do with being swamped and more about trying to raise the palliative care agenda at levels 1 and 2 in order to both increase patient exposure to the principles of palliative care. Paradoxically, this should ultimately reduce the number of referrals since greater engagement with illness narratives should enable more informed decision-making about end of life care as a consequence of a more developed relationship between patient and HCPs (Kleinman 1988; Charon 2006; Roberts *et al.* 2008).

Summary

For patients with advanced COPD, life is COPD. To live a COPD life means living through the interplay of breathlessness and one's hold on and engagement with life. Palliative COPD care might thus be understood as centring on a responsive understanding to illness and disease narratives that flow through each individual patient's illness trajectory.   The aims of palliative COPD care in terms of minimizing breathlessness and other symptoms work in concert with the broader definitions for palliative care (World Health Organization 2002; Randall and Downie 2006). However the distinctiveness of and interplay between disease and illness discourses need to be acknowledged. The open-endedness of the dialogue between disease and illness narratives is integral to Palliative COPD care.

As things stand, the local moral world of nursing reflects disease and illness narratives in an unequal conflict in the acute care heteroglot. Embedding the principles of palliative care in respiratory nursing involves an awareness of and engagement with this conflict. Failure to recognise the heteroglot is more likely to confirm concerns (Randall and Downie 2006; Royal College of Physicians of London. 2007) of a creeping technological approach to palliative care without addressing the suffering of patients. A broad mini-ethnographic model at the level of the nurse/patient relationship and the wider local moral world of nursing is suggested as a counter to the dominance of disease narratives. This model provides a broad framework for developing COPD palliative nursing care.

Chapter Twelve Attending to Other in Co-operative Inquiry

Introduction

This project was underpinned by an understanding of action research as 'rooted in participation' that 'is a key tenet of political practice' (Reason and Bradbury 2007b:8). Significantly, 'participation in inquiry means that we stop working with people as 'subjects'' (Reason and Bradbury 2007b:9). The initial project design was built on the idea of 'bringing different voices to the table' in this co-operative inquiry while focused on developing nursing practice. However, as we began to collect these 'voices', questions emerged. How, for example, does one reconcile the participation principles of CI, as an attitude of inquiry, with a multi-phased project that draws on traditional data collection methods or what Chandler and Torbert (2003) refer to studies in the past from the perspective of the third person voice? What constitutes a voice? How does participation 'sit' with the practical and ethical constraints of action research within a hospital environment?

Phase one was initially positioned within the boundaries of a mixed methods design that would inform the 2nd phase. In this sense, the overall project drew on the idea of action research with phase one as a discrete cycle informing phase 2. However, we were also confronted with conflicting voices since our attempts to engage local managers and the wider respiratory team were, in part, contingent on objectification or hard data favoured in management and medicine discourse. In Bakhtinian terms, we were already moving towards finalising or monologising the voice of *Other* where *Other* reflects the lived experience of COPD. In this chapter I will explore the contributions of the idea of Bildung with its focus on looking to *Other* and from there Bakhtin's dialogism, to approaching the patient interviews as an open-ended dialogue that continued into phase 2. In so doing, I brought into phase one the questions asked by Marshall and Reason (2007), and Chandler and Torbert (2003) about the quality of the inquiry process. In the final section, I will address the co-operative inquiry process as one that centred on the idea of attitude of inquiry and dialogue in Bakhtinian terms. Ultimately, and drawing further on Bakhtin's dialogism, the quality of this inquiry might also be judged in terms of its open-endedness in which the reader and inquiry continue to dialogue and attune to different voices therein. I finish with how the defining

features of a CI which I outlined in Chapter 6, interfaced with the project and will address the limited actions that emerged from the group.

Bildung and Inquiry

The idea of Bildung brought to this inquiry a focus on self and *Other* thus offering a way of engaging with the world of healthcare in which multiple and often competing discourses and worldviews collide in a melting pot. While recognising that some are more dominant and often silence other worldviews, developing practice seems contingent on engaging with all rather than alienating any one of them. In other words, developing practice invites us to hear the more silent voices (such as those with chronic illnesses) while also hearing those that are more dominant. Taking these worldviews as *other*, Bildung offers a way of engagement that seeks to converse with all but with a focus on development of self through this engagement. Rorty's (1980:360) 'edification' as an anglo-american term for Bildung looks towards 'finding new, better, more interesting, more fruitful ways of speaking'. In this sense, objectivity is simply one of several ways of describing ourselves. Engagement with patients' accounts of their illness experiences, the divided world and divided self nursing experiences and worlds within the world of nursing generated different ways of describing our nursing selves.

First Phase

Bildung in its modern meaning, has also come to imply something inward and reflecting autonomy of the individual. This is a process of engagement that stands apart from dominant normalisation processes and hegemony. Edification or edifying discourse (Rorty 1980) is meant to remove us from our comfort zones by the power of strangeness that brings us to new places or become new beings. The point here is to consciously attend to the divergent languages, values, desires and ways of knowing that surface while engaging in inquiry. Participants in the first phase chose to respond to closed questions through the telling of their stories. Their responses also gave the data needed for the assessment of health status. The use of health status measurement instruments become one element of a patient's narrative (Kleinman 1988). But, by their stories, they brought to the inquiry a new understanding of the meaning of living with chronic respiratory illness while also asserting their own world view on the inquiry process. Their stories resonated with the view expressed by some theorists that severe chronic

illness and life become one and is a unique experience to each individual (Kleinman 1988; Frank 1997; Charon 2006).

The 'voice' of the patient becomes a rich interaction of narratives rather than a single unified voice that must be somehow represented in an inquiry. Bildung, then, invites the recognition of and engagement with multiple voices or narratives and perspectives. Since these voices are fluid, dialogue is always open both in terms of a continual flow and also recognising that its purpose is flow rather than achieving a final point or closure. The central idea of Bildung and Bakhtin's dialogism is that of moving towards *Other* and then return to self or that which is familiar. There is no end point but rather there is what Bakhtin refers to as unfinalizability. In Bakhtinian terms, the 'voice' of the patient reflected more a collection of continually becoming narratives in both an inner dialogue and one with the world. *Voice* becomes permeated by the sedimentations, registers[21] and orientations of language that surround an individual patient.

Viewed in this way, Kleinman's (1988) illness meaning making through symptom, culture, lifeworld and explanatory model takes on a Baktinian gloss. We draw on the language of others in our illness meaning making. Bakhtin referred to ideological becoming as the process 'of selectively assimilating the words of others' (Bakhtin *et al.* 1981:341). In other words we engage in a process of selectively assimilating the words of others such that the coherence of our individual accounts is the result of selecting out or selecting among my assimilation of others' speech. The illness accounts here told of symptoms framing day to day living, shattered hopes, losses and sense of self. In their telling, they gave shape to experiences and meaning in the interaction between the 'teller' and me as audience. In other words, the telling of experiences formed a larger story about living with COPD that, in the process of telling became accessible to the sufferer. In this way the 'teller' as patient became both reader/listener and author/narrator.

Participants' assertion of their stories in response to the interview questions challenged any representation of their voice as one. The commonality of symptoms and their impact on activities of daily living was countered by participants' individual and unique illness experiences. They demanded and went on to particularise the closed questions to their individual contexts. As an action

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[21] Register in this meaning refers to the variety or form of languages used such as adherence to a particular style.

researcher, my textual representation of participation as one in which there is overt formalised participation was challenged. These participants sought a more subtle and dynamic form of participation drawing on their home and hospital experiences to contextualise their illness and pressing needs in terms of maintaining their personal integrity in a system that views COPD as an excessive burden on resources. By exerting control over the interviews and their responses through their stories, they turned interviews into conversations fully acknowledging me as a nurse with 'insider knowledge' about how the system works, and respiratory and nursing skills but also ignorant of living a life with COPD within and beyond the hospital environment.   In short, participants challenged the inquiry process and its participatory elements to engage with the messiness and complexity of care needs, and any notion of '*the voice of the patient'* as one common voice.

Participants by their responses, challenged not just the closed questions of health status measurement instruments, but also the distinction made by the mixed methods approach in phase one. Their expressed meaningfulness of symptom, impact and activity domains of the health status measurement instrument was of greater importance than was their scoring. In their stories, they sought to open a conversation about their illness and suffering thus challenging any distinction between action and inquiry. Rather, their conversations demanded a real time inquiry or 'presence in the present' (Chandler and Torbert 2003:136) in attendance to territories of experience during interviews and responding to them through attending to the overall inquiry. In other words:

> What counts as timely action in a given setting depends not only on past oriented norms and on attention in the present, but also on the personal intentions and collective visions of the future (Chandler and Torbert 2003:138).

Participants' responses to the methods and kind of data being sought invited a conversation about their experiences in which they continued to make sense of their illness and life with COPD and ways of improving their care experience. In short, the invitations were dependent on the idea of attitude of inquiry, that is to say attending 'to the processes through which the researcher constructs things' (Marshall and Reason 2007:370). Interviews thus became more focused on the idea of a joint production of meaning-making as stories rather than a demarcation of structured and semi-structured responses.   In addition, the

process brought to the fore engagement with the ideas of epistemic and political participation (Heron 1996; Heron and Reason 2001; Reason 2003a; Reason and Bradbury 2007a):

1. epistemic since by their accounts, participants sought to assert their individual and unique experiences and expressed needs towards generating news ways of understanding their care needs;

2. political since participants asserted a joint ownership of the interview process.

In summary, accounts opened up conversations about illness experiences in the everyday routines, of interactions with carers, family, HCPs, health service, sales assistants etc. The use of health status measurement instruments become one element of a patient's narrative (Kleinman 1988). In the patients' stories, the idea of narratives (Kleinman 1988; Charon 2006) brings into question the idea of addressing 'the voice' of the patient as if patients' experiences are one rather than different or unique experiences.

Phase Two: Co-operative Inquiry

The idea of *Other* underscored the Co-operative inquiry. A focus on illness rather than disease needs as highlighted in phase one brought to the fore the need to look beyond familiar disease management approaches and routines of practice. Through the lens of Bildung, the co-operative inquirer could be said to be engaged in self education that develops from her embeddedness in the world and in, for instance, the world of healthcare. The inquirer begins from an understanding of the centrality of culture and context to her inquiry. Disciplinary knowledge cannot operate in isolation from its past and current relations with the world. The nurse CI inquirer is situated in a world of healthcare that has developed ideas such as 'sick role' cure/death divides, belief models, nurse/doctor relationships, risk management etc. In Bildung, we recognise current healthcare practice as coming from a tradition that has been both absorbed and moved on from but never forgetting these ideas. Through the Bildung lens the co-operative inquirer recognises this history or tradition not as something past and dead but rather as active in the context of her self-understanding of competing narratives across rather than between disciplines. It is with this understanding that she engages in her questioning of those problems she seeks to address and understand in the here and now.

The patient participant interviews and focus on the life of KR whose death framed early meetings, brought to the fore differences and contradictions between the language of our everyday disease management and that of our engagement with the lived experiences of patients. Bakhtin's description of language fitted these emerging differences:

> Actual social life and historical becoming creates within an abstractly unitary national language a multitude of concrete worlds, a multitude of bounded verbal-ideological and social belief systems (Bakhtin *et al.* 1981:288).

As we moved towards grappling with our local moral world of nursing and began to identify conflicting narratives that underscored our everyday practice, we began to recognise *Other* within our own individual speech. In other words recognising the heteroglot of our own everyday world of practice invited greater attentiveness to our individual responsiveness to different discourses such as those of bio-medicine, management, discharge planning etc. In coming to recognize these as competing narratives (Charon 2006) we were better able to observe our interaction and consciously engage with different perspectives. We were recognizing in a different way what Bakhtin refers to as our 'professional stratification of language' (Bakhtin *et al.* 1981:289). In other words, professional groups have each their own language with its own intended meanings and value base. Presumably, he would have extended the professional stratification of language to disciplinary stratification in the modern world of specialist practice.

Our different worlds within nursing revealed different ways of speaking that underpinned the strangeness or *otherness* of our different speech most notably, Eadie's term *journeying with the patient* was at odds with the acute care language of the respiratory nurses. Significantly, at feedback meetings following circulation of drafts of my findings and discussion chapters, Eadie spoke of her new insights into the world of respiratory care while Denise spoke of her recognition that the challenges to addressing illness narratives of patients were similar for doctors and nurses. In both examples there was a reaching toward *Other* and back to self. In Eadie's case, *other* was the acute respiratory care world. For Denise, *other* was a recognition of a different way of seeing within her world of respiratory care. In this way, the essence of our making sense of our experiences of advanced COPD care was firstly being able to recognize *Other* within our familiar world such as illness in contra distinction to disease narratives

or potentially different ways of viewing professional boundaries. Secondly, we needed to explore *Other* in order to develop new understanding. For Faye and Ciara, the strength of their CI experience was not dramatic changes in practice or even a significant rise in number of referrals to palliative care but rather recognising palliative care needs and developing relationships with the world of palliative care. In short, recognising *Other* in the idea of and engagement with illness needs rather than disease management, represented a platform for exploring ways of responding to a different worldview of acute care.

Bakhtin and Co-operative Inquiry

For Bakhtin, self is formed through dialogue, that is to say beginning with our names we learn about the external world through the words of other. From this he argues that there is no choice but to enter dialogue that implies our living always on the boundaries between self and Other or own consciousness and other consciousness. There is a tension then, between self and non-self sufficiency and it is from this tension that Bakhtin warns against one consciousness fusing with that of *Other*. Dialogue requires difference; to 'finalize' *Other* or merge with another consciousness means to speak *about* rather than *with Other*:

> The way in which I create myself is by means of quest: I go out to the *Other* in order to come back with self. I "live into" another's consciousness: I see the world through the other's eyes. But I must never completely meld with that version of things, for the more successfully I do, the more I will fall prey to the limitation of the other's horizon (Clark and Holquist 1984:78).

This is a crucial point in Bakhtin's dialogism. We live on the boundary with others; in dialogue we see ourselves through the eyes of others but we are not determined by others (Frank 2004). Thus in reaching out to *Other* I seek to broaden my horizon; in returning to self I seek to avoid 'exchanging my own limitations for those of someone else' (Frank 2004:47). Thus, dialogue is in constant flow and openness to *Other*. Dialogue is diminished when we finalize *Other*.

Bakhtin's dialogism seems relevant to our grappling with illness narratives and moving out from our disease orientation within the group. In the words of Author Frank:

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> [T]he moral demand of dialogue with people is more than recognizing their inherent dignity and defending their rights; it's being willing to count their voice as much as yours (2004:44).

Many of the accounts from practice that were aired in and explored by the group centred on our struggle with engaging with our knowing-the-person knowledge while working in an environment that sought to reduce this to disease management or a knowing-the-case/patient (Liaschenko 1997). We recognized this struggle and its consequences for our divided worlds and divided selves explored earlier. However, less apparent but equally prescient was our nursing selves living on the boundaries of our different disciplines. Bakhtin's dialogism offers a challenge to engage more fully in the narratives underscoring our different specialist bases and so broadening our practice knowledge horizons. Put simply, our developing practice to address palliative care needs of patients with advanced COPD rested not so much on developing *respiratory* nursing practice but rather an on-going conscious conversation between the disciplines of respiratory and palliative nursing care with each extending their own practice horizons. Seen in this light it is more difficult to see how palliative respiratory care could be anything but an integral part of *both* respiratory and palliative care worlds.

Co-operative Inquiry Outcomes

For Marshall and Reason (2007) an on-going dialogue with the world and self underscores their idea of quality in research as taking an attitude of inquiry:

> This is a project with an ever-receding horizon rather than a state that can easily be achieved. Being willing to explore purposes, and being open to renewed insights into these, however provisional and shifting, is an underlying value in much of action research (Marshall and Reason 2007:371).

As with Chandler and Torbert (2003) being 'present in the moment' invites dialogue with self and world and awareness of 'the contested territory of what is worthwhile', what purposes are worthy' (Marshall and Reason 2007:372). Acknowledging and engaging with contested territory underscores the explicit value-based nature of action research, different worldviews and tensions therein.

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In other words, action research confronts the heteroglot of our inner and outer worlds. Perhaps, even more explicitly, an attitude of inquiry firstly, acknowledges the open boundaries between self and *Other* and secondly, and as such seeks an 'active and increasing participation with the human and more than human world' (Marshall and Reason 2007:373). A feature of this notion of attitude of inquiry is that it is implicitly an open-ended process since it is, by definition, always open to question resonating with Bakhtin's dialogue as unfinalizable. Put simply, the action researcher adopting an attitude of inquiry attends to increasing awareness of her frames of reference or horizon, engages with *Other*, and remains open to contradictions and paradoxes rather than finalizing a state of play. Inquiry is therefore participative, always emerging and open to different worldviews.

The open-endedness of our co-operative inquiry was underscored in our final review meetings at which we were discussing my drafts of our findings. While I was anxious to get opinions on how my writing reflected our inquiry process and individual contributions, our conversation moved quickly onto an *inquiry into the inquiry process* and the learning there from. We explored the journeys we had individually travelled from an unarticulated struggle against competing voices to naming and inquiring into that same struggle. In previous evaluation meetings we spoke about our emerging understanding of palliative care and illness and disease narratives. In this final review our conversation shifted towards our individual journeys and reappraisal of our engagement with colleagues. We revisited the idea of role and relationship scripts in our interactions with other disciplines and non-respiratory nursing colleagues. The open-endedness of our inquiry was itself an outcome and one which, for the group, lent support to continue to meet.

In contrast, I struggled to identify tangible outcomes that could be presented to management as evidence of addressing palliative care needs of patients with COPD. The inquiry had shifted towards a reflective process with limited action. Though, more patients were being referred to the palliative care team, this was still ad hoc and decision-making was not linked to any framework for needs assessment. Moreover, Eadie was now engaged in what could be construed as level one palliative COPD care as nurses struggled with their engagement with patients' illness experiences. We had achieved an understanding of palliative COPD care but were some distance from translating that understanding into a model that could be offered to other hospitals. The other members disagreed with me and viewed as significant our formation as a cross palliative and

respiratory care group and our bringing to the fore our local moral world of nursing and struggles therein. For them, this was the base upon which to integrate palliative care into their COPD nursing care. They believed that a palliative care conscientization process was established in respect of their own individual practice and relayed examples of this from their interactions with patients and doctors. In essence, the inquiry as a process of opening and maintaining a conversation about the heteroglot of palliative COPD care was of itself a framework, if an unconventional one, for developing respiratory nursing practice to address palliative care needs of patients with advanced COPD. Individually, members believed that palliative care was

Addressing the Features of a CI

The 8 defining features of a CI outlined by Heron and Reason (Heron 1996; Heron and Reason 2001) offer a framework for benchmarking the quality of this CI and its limited overt action.

> 1. As full involvement as possible of all subjects as co-researchers in all aspects of the research process in which participation is epistemic and political

This set out as a mechanistic inquiry with a pre-determined aim and objectives. However, as the inquiry progressed, we focused increasingly on our sense-making of respiratory nursing practice. Participation was epistemic to the extent that our sense-making revealed the heteroglot of COPD care and different ways of understanding the COPD experience and care needs. Political participation demanded that the group determined the emerging questions, ways of responding and findings. Issues of positionality and specifically, participation paradoxes challenged my early attempts towards addressing political participation. Learning to let the story of the inquiry unfold was difficult but I believed it was central if full participation was to be achieved. Ironically, Ciara and Fay's pulling back from actions towards the latter stages of the inquiry and preference for a more reflective process reflected their participation and assertion over the inquiry process.

> 2. Intentional interplay of reflection, making sense of experience, experience and action

Intentional interplay of reflection was an integral element of our sense-making of respiratory nursing practice. Our eventual understanding of palliative COPD care was formed from articulating everyday practice incidents in the context of our local moral world of nursing. Engaging with the contrasting palliative and acute care perspectives challenged us to look beyond our respective specialist care worlds. However, action arising from our sense making was limited such that our co-operative inquiry might be better understood as having evolved into a reflection group process. This suggestion was disputed by others in the group who saw shifts in their individual practice including actively seeking palliative care referrals, engaging with Eadie on a daily basis and attention to post discharge telephone follow-up.

> 3. Explicit attention to the validity of the inquiry and its findings through a mindfulness or heightened awareness of the process using inquiry cycles of action and reflection

We used transcripts and summaries of each meeting to reflect back on the process and ask 'where to from here' questions of meetings. The 'taking stock' summaries of the inquiry process at months 10, 16 and 17 broadened our reflection to the inquiry process as a whole. Following the first of these, we had arrived at an understanding of palliative COPD care and actions arising from that included a decision by Faye and Ciara to take an indirect approach to developing palliative care awareness within the ward. The second and third summaries generated greater understanding of the CI process as a whole: how we had arrived at a certain juncture and the relationship between actions taken and the next step. In this sense, reflecting on the lived experience of the inquiry process in the final meeting (month 17) drew comments about just coming to grips with the inquiry:

> Beth
> If we had known then what we know now, we might have done more
> CI/January2009.

However and notwithstanding the challenges of learning about the inquiry process as it proceeds, the space it provided for reflection and making sense of palliative COPD in the context of acute care became a dominant raison d'être for the inquiry. Had I tried to force decisions about actions to meet the requirements of a CI, I would have infringed the principle of political participation.

4. Extended epistemology integrating experiential knowing (through meeting and encounter), presentational knowing (through use of aesthetics and expression), propositional knowing (through words and concepts) and practical knowing (through practical skills). These different ways of knowing are 'extended epistemology' because they go beyond the propositional or conceptual knowledge that is privileged in academia.

Our arrival at our understanding of the conflict between illness and disease related speech and care, the idea of heteroglossia, was a consequence of integrating different forms of knowing in our reflecting and focus on everyday practice incidents. Typically, Denise's recalling her experience of a patient withdrawing from his fight against his condition, and Faye's commentary on patients' turning a corner, gave voice to different forms of knowing. References to shifts in individual practice, and attention and response to different narratives at play in acute care reflected a conscious integration of different forms of knowing in practice.

5. Skills required for an all-purpose experiential inquiry including discernment, attentiveness, emotional competence, ability to bracket and reframe concepts

Perhaps, 2 of the most important forces that influenced our developing understanding of palliative COPD care were 1) the importance we attributed to the idea of *Other* and 2) the heterogeneity of our group. In privileging *Other* we actively sought different ways of understanding practice. By heterogeneity, I mean that we recognised our different roles and disciplinary perspectives. Eadie's palliative care perspective challenged the disease oriented narrative that dominated the acute care discharge process and consultations with patients. At the same time, it was evident that integrating palliative care into the acute environment demanded attention to the interplay of disease and illness narratives. Typically, finding ways of meeting the care needs of patients in OPD with the pressures and time constraints of a COPD clinic demanded accepting that palliative care could not be easily integrated into OPD care.

In attention to *Other,* phase one set a clear agenda for the CI in terms of confronting the impact of System oriented care and its impact on patients' illness

experiences. During our meeting with patient participants in phase 2, this impact was revisited. Illness accounts were rehearsed and hospital-related diagnostic events were highlighted. Linking these to our everyday practice and our potential to influence a care related diagnostic event was central to our developing understanding of palliative COPD.

6. Primacy is given to transformative inquiries that involve action.

The extent to which our inquiry met this CI feature is far from clear. Our planned actions arising from the R-CNS sub-group did not materialise in the lifetime of the inquiry. Neither did we achieve action cycles arising from our review of discharge care. In our review meeting, Eadie did not believe we had made significant breakthroughs in establishing the 3 palliative care levels in COPD care. In short, we did not achieve the third objective of the project namely to identify how unmet palliative care needs might be met in the hospital context.

Yet, the group challenged this assessment citing shifts in practice at individual level and achieving some success in raising the profile of palliative care within the wider respiratory medical team. The group also challenged my separating the process from action. In this, the establishment of the inquiry process, the bringing together Eadie from palliative care and the respiratory nurses with CNS and CNM roles, and the focus on attending to different care perspectives was of itself a framework for developing palliative COPD care. Thus, for them, the inquiry process and the meetings therein were continuing cycles of reflection and action that became manifest in shifts in individual understanding and practice.

7. Access to the full range of human sensibilities for the inquiry.

During meetings we sought to confront the local moral world of nursing through acknowledging and responding to relationships built up with patients and, the conflicting narratives inherent in respiratory nursing care. Different emotions were played out during meetings: sadness over the deaths of patients; frustration over hierarchical practices and decision-making; and triumph when influencing a palliative care referral and care approach. We drew on these to explore patterns and understanding of practice. Typically, we explored Ciara's frustration at her inability to influence medical decision-making in one instance illustrating patterns of nurse/doctor interactions. Later, she drew on this to reframe her approach and influence decision-making. To this extent, accessing experiences in practice and

the attendant emotions, behaviour patterns, assumptions, cognitive distortions provided rich sources for exploring the local moral world of respiratory care.

Project Limitations

This project was underpinned by the principles of action research namely that the inquiry was context specific and problem oriented, and attended to:

1. primacy of the practical
2. many ways of knowing
3. participative and democratic process
4. emergent process

Thus, the research cannot claim generalizability or having met the requirements of validity associated with positivist research. However, I do not see this as a significant limitation. I was concerned with the contextual factors in play that influence the development of palliative COPD care including the interplay of disease and illness oriented care approaches and voices therein. If the findings here can illustrate the challenges arising from this interplay in practice in one particular setting and in so doing contribute to the debates underway about extending palliative care to COPD, then why might action research be considered a limitation.

Though phase one drew on mixed methods to establish the palliative care needs of patients who were attending the hospital site, the number of participants was not sufficient to claim generalizability of health status findings to the patient population at that site. Furthermore, the SGRQ and HADS instruments employed in phase one are intended to be self completion instruments. Though strictly adhering to the wording of each question, proponents of these instruments might argue that employing them in the way I did may have influenced responses and compromised validity. However, in opting to read out the questions, I was ensuring that participants could comment on the questions and respond in detail if they wished. In other words, I was seeking to give participants a greater say in the interview process.

Had these instruments been forwarded to participants for self completion, it is possible that family carers would have intervened either by completing the questionnaires on behalf of participants or calling out the questions and re-interpreting as they did so. Thus, the structured interview process may have

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given voice to participants to a degree not possible had the instruments been employed in the more usual manner for self completion. Moreover, the narratives generated from the interviews added meaning to the high anxiety and depression scores that were recorded.

Equally, proponents of interpretive research might argue the qualitative data generated from the structured interviews was compromised because the questions were by definition leading ones. However, in the semi-structured interviews, experiences and accounts were often repeated. The overwhelming finding from these accounts was that of COPD as permeating every aspect of one's life. The narrative accounts that were relayed from the structured interview questions spanned every day routines that dominated lives.

A further limitation is the possible contradiction between the idea attending to different voices in this project while also limiting the inquiry participants to patients and nurses. Arguably by not including others including carers, doctors and other allied healthcare professional, I was in effect silencing these. Though the focus was on nursing practice development, the practices of different disciplinary groups are interdependent. However, to have expanded the inquiry to include members of other disciplinary groups would have been logistically challenging if not impossible. Our intention to make sense of our nursing practice would have been diluted by broadening the focus of the inquiry. Our subsequent attention to care narratives drew attention away from voices as being disciplinary based and towards scrutiny or our own engagement with conflicts between illness and disease oriented care.

Our CI process failed to follow through on actions arising from early action reflection cycles. Thus, the extent to which what started out as a CI continued to be so, must be questioned. The CI process became more of a reflective group one as the inquiry progressed though this is disputed by the group. This may, in part, be linked with the unexpected departure of Ann resulting in less preparedness entering into phase 2 than originally anticipated. However, action research is about the reality of practice when events colour the inquiry process. Paradoxically, the shift in focus of the CI reflected the participative and democratic process in play.

Finally, the overriding question regarding the research framework is how has this project informed the development of practice to address palliative care needs of

patients with COPD. The 3 levels of palliative care express how palliative care should be understood in the wider clinical environment. While references are made in COPD guidelines to the importance of end of life care, there is no detail as to how palliative care might be addressed. In this project, the challenges for palliative care approach in an acute care environment are highlighted as conflicting care narratives. If the 3 levels of palliative care are to be embedded in practice then, as this project shows, the challenges need to be confronted by the respective palliative care and respiratory worlds. Moreover, it is likely that similar challenges exist for other life limiting chronic illnesses associated with uncertain trajectories and hospital-led treatment. This project has also indicated benefits in the development of palliative and COPD nursing groups in both generating an understanding of palliative COPD care and confronting the professional, disciplinary and organizational issues that militate against its adoption.

Final Conclusion and Recommendations for Policy

This inquiry was in part born from anecdotal accounts of respiratory nurses pointing to a mismatch between the desire for palliative COPD care and the reality of the acute care environment. When the National Advisory Committee on Palliative care (Department of Health & Children 2001) published its recommendations for levels 1, 2 and 3 palliative care, there was no discussion as to how this might translate into acute medical practice. In the intervening years, policy and service development has focused on OPD waiting times, and reducing bed occupancy and re-admission rates as part of a growing emphasis on chronic disease management (Department of Health and Children 2008). The pendulum moved in the direction of protocols for COPD management that focused on stabilisation of acute physical symptoms.

Embedding palliative care level 1 in acute respiratory nursing practice and level 2 in respiratory clinical nurse specialist practice requires a fundamental change in disease management approaches. In essence, the pendulum needs to move towards illness rather than disease focused care approaches. Such a swing is less a luxury and more a necessity if recent policies on palliative care in non-malignancy are to be realised (Health Service Executive and Irish Hospice Foundation 2008b; Health Service Executive 2009a). Randall and Downie (2006) cautioned against the technolization of palliative care. Their concerns were exemplified in our inquiry when Eadie was dealing with an increasing number of requests to deal with what she described as level one palliative care problems. Unless palliative care is embedded in acute medical care, simply raising awareness on its own is more likely to result in increased referrals to palliative care for illness related reasons. Patients' suffering will be reduced to a series of problems that can then be managed such as through counselling. In these circumstances, suffering is silenced; the patients' voice is finalised in Bakhtinian terms and so their suffering is compounded.

In our inquiry, integrating illness experiences into care was not just a starting point for embedding palliative approaches to practice; rather it was a fundamental unmet care need. The patient interviews revealed the interdependency between this fundamental need and optimum symptom management in disease terms. Our CI illustrated a further interdependency, between integrating illness experiences into care and addressing the local moral

world of respiratory nursing. Failure to address either interdependency will result in a shift towards a technical form of palliative care that will simply perpetuate the current inequities between palliative care for patients with cancer compared with that for people with chronic illnesses. Moreover, such a failure will conflict with the fundamental notion of addressing total pain in palliative care. In essence, this would not be palliative care as we currently understand it.

Our inquiry, on the other hand illustrated not just an interest in addressing illness care needs of patients with advanced COPD but rather the presence, however ad hoc, of palliative care approaches in practice. The difficulty for us appeared to be the underground or unofficial nature of attention to illness narratives in the face of highly disease focused respiratory care practice. Embedding levels 1 and 2 palliative approaches in COPD care requires a rendering official and privileging of illness oriented care. Our CI provided an environment in which to explore our local moral world while coming to a mutual understanding of our different respective languages from palliative and respiratory care. Though limited, our CI was a powerful mechanism for confronting the centripetal and centrifugal forces that influence disease and illness oriented respiratory nursing practice. Based on our learning, if we are to embed levels 1 and 2 palliative approaches into our practice the following recommendations need to be considered.

Recommendations

At Policy and Service Planning Level

1) COPD Strategy and Management Policy
Articulation of the 3 levels of palliative care needs to be extended to setting out strategies for their implementation in the context of current acute care delivery. Without this, the stated levels reflect more an aspiration rather than reality. To counter this, palliative care in chronicity needs to be actively pursued by the Health Services Executive (HSE), which is responsible for health strategy and service delivery, and the Health Information and Quality Authority (HIQA) which is responsible for overseeing standards of services and care delivery. At HSE level, this would prioritise palliative care in the development of specific disease (e.g. COPD) strategy development and articulate performance indicators in relation to palliative care integration. In so doing, the care pendulum might swing away from disease oriented care towards a more illness approach. At HIQA level, monitoring service delivery standards against performance indicators would

provide the impetus for operationalising the 3 palliative care levels in acute care including the development of care pathways. The active engagement of both the HSE and HIQA would encourage greater cross referencing between specialist practice-related guidelines and policy. COPD strategy and management policy documents refer to the importance of end of life care. This needs to be broadened to highlight palliative care as integral to advanced COPD care and with reference to palliative care strategy documents. These different strands, the HSE, HIQA and specialist guideline reports, are necessary if the conflicting care narratives that arise in practice are to be addressed.

2) Expanding Respiratory Nursing Role to Address the Primary Secondary Interface

The current impetus to expand specialist nursing practice through nurse prescribing, and nurse led clinics provides a basis for exploring the potential for CNS role expansion to address COPD palliative care. The experiences so far of the national nurse prescribing programme[22] illustrate the potential of expanding nursing practice within a planned framework as a basis for palliative COPD support and rapid assessment[23].

Specifically, the respiratory CNS role could be developed to include case management wherein pre-identified patients are assigned to her. This would position the R-CNS as an access point for support for the patient, family carer and primary healthcare professionals. The role could encompass home visits, rapid assessment support, acting as a hub for other clinical services for patients, and primary/secondary collaboration between the respiratory nurse and GPs or community services. A mechanism such as palliative and respiratory nursing review meetings and rapid access could provide links between the R-CNS and the palliative care team. The case management role has the added advantage in developing close illness oriented relationships with patients before end of life care thus facilitating advanced care planning and articulation of treatment choices. Similar to the nurse prescribing experience, positioning this R-CNS role expansion at policy level would ensure a national framework and standards for the delivery of advanced COPD care.

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[22]
http://www.hse.ie/eng/services/news/2009_Archive/Oct_2009/nurseprescribinge valuation.html
[23] See nurse prescribing framework documents as an example of a possible framework for a nurse led initiative within strict protocols:
http://www.nursingboard.ie/en/policies-guidelines.aspx

At Hospital Level

1) Integrated Care Pathway Development
Embedding levels 1 and 2 palliative is contingent on a shared understanding of what palliative COPD care means in practice. Integrated care pathways for advanced COPD developed in collaboration with specialist palliative care teams would enable the integration of palliative COPD in care planning. Such pathways could dovetail the policy development including R-CNS role expansion in relation to case management referred to above.

2) Dedicated Advanced COPD Nurse-led Clinics
In our inquiry, the difference was stark in time allocated for patient support in the palliative care clinics compared with that permitted in the COPD clinic. This represents a clear inequity in care of patients dying from COPD in contrast to those with cancer. A mechanism such as case management that would allow the R-CNS to address diagnostic events along the illness trajectory would help introduce greater equity in OPD support for patients dying from COPD. An additional nurse-led clinic would enable the R-CNS to respond to patients attending the respiratory clinic and who are in need of additional support at a given time.

3) Establishment of Palliative and Respiratory Nursing Groups in the Hospital Setting
Palliative COPD care needs to be built upon existing COPD and specialist palliative care knowledge. Our CI group highlighted the value in bringing together palliative and respiratory nurses to increase awareness and understanding of palliative COPD. The establishment of similar groups in acute care settings should seek to explore the local context of respiratory nursing practice including examination of care practices and factors influencing disease and illness oriented care approaches.

Level 2 palliative care requires additional palliative care knowledge for the R-CNS working in COPD care. The palliative and respiratory nursing groups need to therefore extend beyond awareness raising towards skills and knowledge development. This needs to include recognition of the need for additional palliative care education aimed at those working in specialist practices that

address chronic illnesses. Furthermore, this education needs to be underpinned by engagement with palliative care in an acute care context and conceptual frameworks relating to chronicity. In short, simply transposing palliative care from malignancy into chronic disease management frameworks will not support nursing practice development.

Our inquiry revealed competing narratives running across rather than between disciplines. There was evidence of illness oriented doctor patient interactions just as there was evidence of disease oriented care in respiratory nursing. Claims within nursing practice regarding the advocating for patients and patient centeredness need to be challenged with reference to competing narratives rippling through practice-based activities. However, our CI process also highlighted the close relationships built up over years between respiratory nurses and patients and the grief and toll that their deaths incur on these nurses. This needs to be acknowledged at hospital level and by management. Debriefing meetings would enable both acknowledgement of loss and learning arising from end of life care.

Professional Practice

1) Focus on Diagnostic Events in Illness Trajectory

A focus on diagnostic events along an illness as distinct from a disease oriented trajectory would serve to both heighten awareness of suffering or total pain in COPD and address unmet palliative care needs. A focus on the significance of diagnostic events could be mediated through post discharge home visits and follow up incorporating telehealth, texting or phone calls. Home visits should be undertaken by both ward-based and clinical nurse specialists to facilitate a shared understanding of illness oriented care. Discharge and follow up communication practices that are integral to specialist palliative care need to be considered in respiratory nursing practice. Specifically, discharge letters and related communications to GPs and public health nurses need to reflect illness or palliative oriented care.

2) Addressing Informal Carer Role

Family caregivers are given a high profile in palliative care philosophy. However, in acute care including that for COPD, carers remain in the background despite the high dependency experienced by patient participants in this project.

Research is needed in collaboration with ethicists that would focus on how a triadic relationship involving HCP, patient and family carer might be legitimised in clinical care while acknowledging the importance of privileging the patient's voice and autonomy. In addition, the nurse/carer relationship needs to be explored in respect of chronic illness in general and COPD specifically. Particular issues include the role and support needs of carers in relation to diagnostic events, post discharge, management of acute exacerbations at home and illness monitoring. Potential means of addressing carer support needs include tailored carer meetings during pulmonary rehabilitation programmes, information and support meetings, and incorporating telecommunications methods including texting and telehealth services.

Epilogue

"His language, so familiar and so foreign, will always be for me an acquired speech"

Stephen Dedalus (Joyce 1960:189)

This has been a complex project and one that continues to evolve. The project was a complex one, in part, because of the two distinct phases and the different ideas that informed the work. In the idea of Bildung and my related understanding of practice development it seemed necessary to address ideas that have recently shaped our understanding of chronic illness and nursing care therein. The increasingly blurred boundaries between disciplines, albeit within a strict hierarchy, added to the project's complexity. Different disciplinary worldviews intersected the heteroglot of hospital care. In the end, we had moved from holding to ideological differences between disciplines towards the idea of heteroglossia in healthcare that implicated all of us in a system wide silencing of illness experiences.

This final chapter emerged from my viva voce during which the examiners sought an inquiry into the inquiry thus stimulating further reflections on the project and in particular, the links between different strands. These final thoughts are presented in three parts. Firstly, I begin with the importance of early attention to the ideas of communicative action and power. This leads on to the idea of Bildung which underpinned the project and which gave meaning to my understanding of events as they unfolded. I finish with the continuing debate within our group as to the nature of our actions and their relatedness to action research cycles. The current dramatic changes in our Irish economy are felt in the continuing story of the project. One of our members has recently emigrated. The others remain in their respective roles but are dealing with increased pressures as a consequence of cutbacks. Negotiating through such pressures while attending to what we now understand as the local moral world of respiratory nursing has become an intrinsic part of the project's evolving story.

Habermas's Theory of Communicative Action and Foucault's notion of power have featured strongly in studies addressing relationships in healthcare and action research. My focus in this work on practice development and action research seemed incomplete without acknowledging these ideas and their place in shaping our current understanding of the environment of healthcare. The importance of

attending to opening a communicative space; the significance of System over lifeworld and the subtle ways power is mediated in healthcare rippled through my reading on chronicity. Though not framed within a Habermassian or Foucauldian lens, the respective writing of Charon (2006), Kleinman (1988), and Frank (2004), reflected issues of power and System over lifeworld all of which underpinned the disease illness dichotomy.

In phase 1, this reading offered insight into the initial conversations in interviews as opening a communicative space, acknowledging me as a nurse linked to the hospital and the participants as having lives to live. I was conscious of power shifting over the course of each interview as participants asserted their voice over the closed questions while also finding subtleties in the disease illness inequities even when acknowledging lay expertise. Typically, routines that individual participants had developed to address symptoms were often not disclosed to the healthcare professionals. Governmentality and power seemed implicit in the importance of being seen to act responsibly by not abusing the service even when experiencing an acute exacerbation with its attendant breathlessness. In phase 2, System and lifeworld were inextricably linked, as close relationships with patients were mediated through disease oriented care or the voice of the System. I viewed our struggles to acknowledge and respond to these relationships as situated on the boundaries of System and lifeworld and our different speechness addressing both. Our journey through these struggles took us to heterglossia and its part in our everyday speech. In this way, the Theory of Communicative Action, and governmentality and power were important pathways towards our understanding of the heteroglot of the acute care environment.

Over the course of this project, what I came to understand as the narratives of the System and the characters within, healthcare professionals, managers, support staff and patients, grew ever more entangled. The sometimes very close relationships between hospital staff and patients resulted in reciprocal bonding and awareness of individuals' life stories. Stories were shared. Nurses attended the funerals of patients including those who died at home. It was not uncommon during phase 1 interviews for participants to express concern over a staff member who was ill. Typically, one of the participants whom I had already met on several occasions over the course of the project told me one day that he had watched me walking through the hospital concourse and thought I seemed worried. His subsequent conversation was to express concern and also perhaps, curiosity. There is much that could be said about his concern: he was comfortable in

engaging me in this way within the hospital, and he was very possibly correct in reading my expression. I was in the process of cancelling at short notice, and for the second time, our phase 2 patient group meeting because of an outbreak of the winter vomiting bug.

Nevertheless, despite many such moments of sharing our worlds, there was also an implicit awareness of a dominant disease narrative and re/presentation with our focus on biomedical markers. References to self management strategies that were not part of this disease narrative were frequently not shared during clinics or admissions. Accounts of loss and contracting worlds were not recorded. Thus, the interactions between System and lifeworld and shifting power were complex. That Bakhtin's work should appear relevant is not, in hindsight, surprising. The languages of clinical medical and nursing journals, and writing in relation to chronicity were so utterly different that it seemed as if the language of healthcare was itself fractured into multiple stratifications reflecting both professional divisions and epistemological battles for authority and place. The above opening quote of Stephen Dedalus in Joyce's Portrait of an Artist as a Young Man might have been written for those negotiating through different languages of healthcare.

Bildung

My understanding of practice development as nursing's response to calls from the System; other disciplines; patients; and dominant discourses including disease oriented care, governance and evidence hierarchy, positioned Bildung as core to this project and its unfolding story. Bildung was a starting point from which I understood the import of learning to be open to and engage with that which is other in an acute care environment with all its competing and hierarchical voices. In the course of my early reading, I was fortunate to have had discussions with others who have written about Bildung in a post modern world.[24] These discussions directed me to various readings including an address by Gadamer shortly before his death (Cleary and Hogan 2001) and Thomas Mann's (1996) The Magic Mountain. Both readings represent Bildung as change and process including formation of self through internal growth, learning from other cultures, languages etc. Thus, at an early point in this project, I had come to understand

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[24] I am very grateful to both Paul Standish and Padraig Hogan who were so generous with their time to help me come to appreciate the richness of the idea of Bildung.

Bildung as an idea that would bring to our practice both personal and professional development that centred on a mindfulness or attentiveness and openness to other. This understanding became, for me, the driver in early planning meetings and later in problematising my approach to patient interviews and first person inquiry throughout.

Early planning meetings presented dilemmas associated with participation in action research. While I was seeking a collaborative space from which would emerge cycles of action leading to a mutual understanding of palliative COPD care in a hospital environment, others sought very different actions namely, health status measurement that could ultimately infringe on the action research principles of participation. This was an early lesson on how to respond to conflicting calls and engaging with other. The project structure was initially intended to front-stage the illness experiences of patients so that the *voice of the patient* was prominent at the start of our cooperative inquiry and we had evidence of care needs as we sought to develop practice. Once it was clear from early collaborative planning meetings that the project would be two-phased with the first drawing on more traditional albeit less than conventional interview methods, there was an inevitable challenge in presenting to a detached observer the links between the phases. Yet, our learning about the illness experiences described in phase 1 grounded our cooperative inquiry and set the scene for our own individual Bildung in profound ways. Phase 1 was thus the unseen foundation for and ultimately politicised our cooperative inquiry at different levels and to which I will now turn and through which I will hopefully reflect my own Bildung.

These are namely:
1. The patients' accounts and poor health status invited us from the start, to confront our local moral world of nursing that could so easily sever our attentiveness to other;
2. The illness experiences provided an important backdrop to our sense-making of care as disease oriented when reflecting on the death of KR;
3. The illness experiences were crucial to our ability to confront the system wide silencing of illness experiences and suffering and nursing's role therein.

Bildung and Confronting Local Moral World

Nursing practice development in the acute care environment is often linked with education typically relating to new ways of working, new standards or procedures. Bildung moves beyond this interpretation of education in the sense of normalisation or socialisation (Gur-ze'ev 2002), to that of self cultivation and autonomy of self but always in terms of relationship with other. In this sense Bildung addresses citizenship and moral world. The interviews in phase one set the scene for an immediate confrontation with our responsibility to the System and the norms of disease oriented approaches to care. Arising from the interviews, our starting point for the cooperative inquiry was an insight into the acute hospital environment or our world as a harsh environment for those with advanced COPD and who require regular inpatient and outpatient care. Denial of personhood with limited acknowledgement of illness experiences and knowledge of one's own expertise, featured strongly in participants' narrative accounts of hospital experiences in phase 1.

Seeing our hospital world in this light, we were drawn into a space of dual citizenship between responsibility to the hospital system with its attendant disease oriented worldview, and responsibility to our knowing the person relationships with patients and calls for a more illness oriented care. In short, the participant interview findings gave us much more than an understanding of illness experiences and care needs however rich this was; they gave us a means of stepping back from the world of acute care into which we are socialised. Though Eadie with her palliative care worldview challenged us to be attentive to illness concerns, the interviews brought to life the world and burden of COPD specifically; the sheer relentlessness of symptoms, loss and contracting worlds; and our contribution to this burden. Dual citizenship is a moral endeavour bringing an outsider status to both our worlds and responsibility to attending to each however conflicting they are. This was our Bildung.

Phase One as Backdrop to Early Focus on Grief

We framed the death of KR against my experiences with phase 1. Put another way, we were able to situate the death of KR and the attendant reflections on her care against my phase 1 experiences. The relentlessness of her symptoms and their complete takeover of her life was a recurring theme in our talk about her care. The respiratory nurses saw this through the prism of regular and prolonged admissions. Our discussions about phase 1 interviews invited us to consider her

final year in terms of part of a long decline in which COPD became her life and that of her family. Seen in this light, recalled moments of conversations with KR were both joyful and painful. They were joyful when illustrating the strong relationships that had been forged with her and her family. They were painful when illustrating the difficulties in entering into conversations with her about her fears, and death and dying.

In this sense, we also framed our understanding of phase 1 findings against reflections on care of KR. The everyday practice experiences we subsequently brought to the meetings brought a focus on the chasm between our moral values relating to ideal care and everyday practices. These practices denied illness experiences such as failing to engage with patients who were inviting conversations on death and dying. For me, these experiences aired in our meetings were always seen through the prism of phase 1 findings and reflections on KR's end of life care. Our conversations inevitably reverted to phase 1 and reflections on care of patients including KR such that the relationship between hospital based care and illness experiences were brought to the fore. In this sense our Bildung was our sense making of respiratory nursing in our unfolding moral values relating to illness oriented care and resistance to the norms of disease oriented care.

Phase One Giving Meaning to Silencing

As the inquiry progressed, we were increasingly attuned to the subtle and myriad ways in which illness experiences were silenced in everyday care. We denied illness oriented conversations in our formal interactions and when under pressure. We struggled in our attempts to find ways of addressing illness oriented care needs. During my viva voce, one examiner asked if what I was attempting in this project was 'an impossible task'. His question was at once both provocative and profound. The scale of the project was indeed challenging in terms of both attempting to identify and address care needs against a backdrop of dominant care narratives that silence the very care needs identified. A project that would 'simply' seek to identify care needs would almost certainly build on the work of others (Williams 1993; Skilbeck *et al.* 1998; Elkington *et al.* 2004; Elkington *et al.* 2005; Fraser *et al.* 2006). The departure point for this project was recognising this earlier work and attempting to engage with practice to begin to address needs. In my early planning meetings with Ann and others, there was recognition that we would need to have local and contextual understanding of needs if we

were to attempt to address them. In other words they were speaking to the importance of the local and context that is highlighted in action research. We were also speaking to a moral obligation to respond to the illness concerns raised by participants and their expressed wishes to have their experiences heard and addressed.

In this sense the examiner's question challenged the ambitiousness of action research when undertaken by a small group such as ours. Against that however, this project was ultimately about two conflicting philosophies of care namely those of palliative and acute medicine. One could just as easily replace the word palliative for advanced chronic illness care since, as I have argued, the suffering associated with chronicity equates with the idea of total pain in palliative care. Seen in this light, the examiner's question seems to me to be of profound importance since he is asking if attempting to address illness oriented care in our acute hospitals with their system wide silencing of illness experiences, is not an impossible task. Certainly, there were moments in this project when the task seemed an impossible one. Ciara and Faye's reticence and Beth and Denise's struggle to implement their plans and my own felt inadequacy in the face of barriers reflected this. Since our acute hospitals are the main point of contact for patients with advanced COPD, the question arises as to whether our hospitals and care therein are fit for purpose. The Irish health reform agenda is moving towards realigning care delivery so that chronic *disease* management is undertaken in more appropriate settings namely the community. However, this does not address never mind translate to more illness oriented care. The focus is on more efficient use of resources rather than conflicting philosophies of care.

It is against this backdrop that the idea of Bildung with its attendant qualities of cultivation of self, outsiderness, autonomy and seeking conversation offers a response to the examiner's question. Bildung enabled our cooperative inquiry for practice development to draw back from a technical educative or competency focus. We entered into a space that sought to engage with conflicting philosophies and citizenship in the world of hospital care. These are not everyday conversations in the clinical environment and for that reason the task of confronting our system wide dominant disease oriented care approach seems an impossible task. In hindsight, the project was ambitious in its stated intention to address palliative care needs. Rather, it might have been more realistic to seek to simply open a conversation about illness oriented care. However, that would not have been true to the early collaborative planning meetings and the project

aim that emerged from them. In other words, I would not have been true to the principles of participation and my idea of Bildung as always in engaging with other.

CI Action Exemplars

Since the CI group's final review, we continue to disagree on the question of whether or not ours was a cooperative inquiry in the end. We have a clear sense of having come a journey and achieved changes in practice that we have struggled to articulate. Yet the group disagree with my assessment of our journey being more a reflective than a cooperative inquiry one. Inevitably this debate found its way into my viva voce. The issue is perhaps less about whether or not actions arose and more about action cycles. In other words, the actions that emerged were not planned or framed as cycles. Interestingly, in our debate about the nature of our inquiry, the group regularly cited examples of personal shifts in approaches to care or small changes in practice rather than our only clearly defined action research cycle, the home visit post discharge. It would seem that these personal shifts or small changes were the more meaningful in some respects and in terms of overall practice development. In hindsight, our actions fell into 2 categories. There was a shift in the inner self, perhaps best expressed in terms of stepping into dual citizenship. In the 2nd category, small actions reflected changes in practice but all aimed at increasing awareness of palliative COPD care.

Actions as Inner Shifts

There was learning to acknowledge and respond to illness experiences as palliative COPD care. This meant accepting knowing-the-patient-as-person relationships as a legitimate type of healthcare knowledge and thus questioning our individual re/presentation of other. Examples of shifts in our thinking included confronting the significance of illness meaning making in patients accounts. In one such instance, Beth explored the significance for a patient of loss of a pet that represented a link to the past. The pet and the past were bound together in the losses this patient had endured in her life history and was now experiencing in terms of worsening condition and contracting world. Beth's exploration opened an understanding of the patient's individual illness meaning making that ran counter to her apparent ease with her prognosis. Beth's subsequent difficulty in presenting this within the more typical format of patient

notes, illustrated the gap between the patient's illness meaning making and system-wide re/presentation and, significantly, for Beth, a sense of misrepresentation.

Actions as Changes in Practice

In the second category Ciara's challenge to a medical team regarding a patient's need for treatment resulted in frustrated feelings all round. Our reflection on this experience centred on different kinds of evidence informing nurses and doctors' clinical judgements and learning to acknowledge this rather than seek direct confrontation. Subsequently, Ciara had successes in negotiating changes in care for another patient.   These achievements included revised treatment plans involving the palliative care team and a step towards an overall readiness for more referrals. Thus, the deliberate planning in how to present an argument to any medical team had wider implications for how we were able to begin to address palliative care needs.

In the R-CNS subgroup, Beth and Denise focused on developing a palliative oriented approach to care within the time constraints of their work.   They instigated two practice changes namely follow up phone calls with patients following discharge and actively seeking and recording Eadie's advice in patients' notes. The follow up phone calls were intended to open up conversations with patients about their post discharge illness experiences and respond to difficulties through advice or early clinic appointments. Establishing the phone calls as routine practice has proven to be challenging.   Nevertheless, The R-CNSs continue to target patients for follow-up post discharge phone calls. Recording Eadie's advice informed care planning while also highlighting the potential of the palliative team as a support for respiratory care.

Increasing the number of referrals to the palliative team at an earlier point in patients' end of life care remained a challenge throughout the project. However, the respiratory nurses increasingly sought Eadie's advice and made a point of recording this advice in order to increase awareness of palliative care needs. Though Eadie could visit a patient only after the formal referral procedures were instigated, by giving 'advice' directly to the respiratory nurses, she was increasing the visibility of palliative care while also supporting the nurses.

These shifts in thinking and practice might be better described as simply about opening a conversation about palliative COPD as illness oriented care. However,

nearly six months after our final review meeting, a senior nurse manager spoke of an increase in the number of patients with COPD being referred to the palliative care team. It would seem in hindsight the small actions taken by the group reflected more a low level subversive chipping away at rigid practices.

I began with Stephen Dedalus's quote that reflected his standing back or separation from different claims on him including church and family. It is perhaps this standing back or separation that best captures the essence of this project and the actions there from, in attempting to work within a system that militates against addressing the care needs that we identified. More than that, the project became one about our identity as dual citizens and separation from the claims for system oriented care that the System makes on us.

> His language, so familiar and so foreign, will always be for me an acquired speech. I have not made or accepted its words. My voice holds them at bay. My soul frets in the shadow of his language.
> Stephen Dedalus (Joyce 1960:189)

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Appendix One Hospital Anxiety and Depression Scale (HADS)

Appendix Two St George's Respiratory Questionnaire (SGRQ)

ST. GEORGE'S RESPIRATORY QUESTIONNAIRE
for COPD patients

(SGRQ-C)

This questionnaire is designed to help us learn much more about how your breathing is troubling you and how it affects your life.
We are using it to find out which aspects of your illness cause you most problems, rather than what the doctors and nurses think your problems are.

Please read the instructions carefully and ask if you do not understand anything. Do not spend too long deciding about your answers.

ID: _____

Date: _____/_____/_____ (dd/mm/yy)

Before completing the rest of the questionnaire:

Please select one box to show how you describe your current health:

Very good	Good	Fair	Poor	Very poor
☐	☐	☐	☐	☐

Version: 1ˢᵗ Sept 2005

St. George's Respiratory Questionnaire
PART 1

Questions about how much chest trouble you have.

Please select **ONE** box for each question:

Question 1. I cough:

most days a week	☐ a
several days a week	☐ b
only with chest infections.	☐ c
not at all	☐ d

Question 2. I bring up phlegm (sputum):

most days a week	☐ a
several days a week	☐ b
only with chest infections.	☐ c
not at all	☐ d

Question 3. I have shortness of breath:

most days a week	☐ a
several days a week	☐ b
not at all	☐ c

Question 4. I have attacks of wheezing:

most days a week	☐ a
several days a week	☐ b
a few days a month.........	☐ c
only with chest infections.	☐ d
not at all	☐ e

Question 5. How many attacks of chest trouble did you have during the last year?

3 or more attacks	☐ a
1 or 2 attacks.................	☐ b
none	☐ c

Question 6. How often do you have good days (with little chest trouble)?

no good days.................. ☐ a

a few good days .... ☐ b

most day are good .... ☐ c

every day is good .... ☐ d

Question 7. If you have a wheeze, is it worse in the morning?

no................................ ☐

yes............................... ☐

UK/ English version COPD

8. *How would you describe your chest condition?*

Please select **ONE**:

Causes me a lot of problems or is the most important problem I have

☐ a

Causes me a few problems .... ☐ b

Causes no problem .... ☐ c

9. *Questions about what activities usually make you feel breathless.*

For each statement please select ***the box*** that applies to you **these days**:

	True	False
Getting washed or dressed	☐	☐ a
Walking around the home..	☐	☐ b
Walking outside on the level	☐	☐ c
Walking up a flight of stairs	☐	☐ d
Walking up hills..	☐	☐ e

UK/ English version COPD

continued…

St. George's Respiratory Questionnaire
PART 2

10. *Some more questions about your cough and breathlessness.*

For each statement please select *the box* that applies to you **these days**:

	True	False	
My cough hurts	☐	☐	a
My cough makes me tired	☐	☐	b
I am breathless when I talk	☐	☐	c
I am breathless when I bend over	☐	☐	d
My cough or breathing disturbs my sleep	☐	☐	e
I get exhausted easily..	☐	☐	f

11. *Questions about other effects that your chest trouble may have on you.*

For each statement please select *the box* that applies to you **these days**:

	True	False	
My cough or breathing is embarrassing in public	☐	☐	a
My chest trouble is a nuisance to my family, friends or neighbours	☐	☐	b
I get afraid or panic when I cannot get my breath	☐	☐	c
I feel that I am not in control of my chest problem	☐	☐	d
I have become frail or an invalid because of my chest........	☐	☐	e
Exercise is not safe for me..	☐	☐	f
Everything seems too much of an effort	☐	☐	g

UK/ English version COPD

continued…

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12. *These are questions about how your activities might be affected by your breathing.*

For each statement please select *the box* that applies to you **because of your breathing**:

	True	False	
I take a long time to get washed or dressed	☐	☐	a
I cannot take a bath or shower, or I take a long time...........	☐	☐	b
I walk slower than other people, or I stop for rests..............	☐	☐	c
Jobs such as housework take a long time, or I have to stop for rests	☐	☐	d
If I walk up one flight of stairs, I have to go slowly or stop	☐	☐	e
If I hurry or walk fast, I have to stop or slow down..............	☐	☐	f
My breathing makes it difficult to do things such as walk up hills, carrying things up stairs, light gardening such as weeding, dance, play bowls or play golf	☐	☐	g
My breathing makes it difficult to do things such as carry heavy loads, dig the garden or shovel snow, jog or walk at 5 miles per hour, play tennis or swim	☐	☐	h

13. *We would like to know how your chest trouble <u>usually</u> affects your daily life.*

For each statement please select *the box* that applies to you **because of your breathing**:

	True	False	
I cannot play sports or games...	☐	☐	a
I cannot go out for entertainment or recreation....................	☐	☐	b
I cannot go out of the house to do the shopping..................	☐	☐	c
I cannot do housework...	☐	☐	d
I cannot move far from my bed or chair	☐	☐	e

UK/ English version COPD

continued…

14. *How does your chest trouble affect you?*

Please select *ONE*:

It does not stop me doing anything I would like to do... ☐ a

It stops me doing one or two things I would like to do .. ☐ b

It stops me doing most of the things I would like to do . ☐ c

It stops me doing everything I would like to do............ ☐ d

Thank you for filling in this questionnaire.

Before you finish, would you please check to see that you have answered all the questions.

UK/ English version COPD

Appendix Three MRC Dyspnoea Scale

Grade 1   Not troubled by breathlessness except on strenuous exercise

Grade 2   SOB when hurrying or walking up a slight hill

Grade 3   Walks slower than contemporaries on the level because of SOB, or has to stop for breath when walking at own pace

Grade 4   Stops for breath after walking 100m or after a few minutes on the level

Re: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD).

Dear

I am writing to invite you to participate in a study entitled: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD). COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. You are invited to consider participating in this study because of your experiences with COPD.

Please read the enclosed information, which describes the nature and purpose of the study and what participation will involve. You will also find a consent form. This is for your information. If you decide that you wish to participate in this study, I will ask you to sign the consent form when we meet. Before you sign this, I will discuss the research with you and answer any questions you may have.

I am an experienced nurse and am undertaking this research as part of my PhD thesis. I am undertaking this research because there is currently very little research on the nursing care needs of patients who have COPD. I hope the results from this research will help nurses to develop their knowledge and care of patients with COPD.

Should you wish to discuss your involvement in this study please complete the bottom part of this letter and return it as soon as possible using the stamped addressed envelope provided. I will then contact you to discuss participation and answer any questions you may have. Should you decide not to participate in this study, you will not be contacted further regarding this matter.

Yours sincerely

Geralyn Hynes

087 768 3373

Email: hynesge@tcd.ie

Reply Slip Accompanying letters to Potential Project Participants

Name (Block Capitals) _____

Please tick the appropriate box: ☐

I am a Person with COPD: ☐

I am a Nurse working in the clinical practice   ☐

   I am a Consultant or Allied Health Professional involved in COPD care ☐

   I wish to be contacted to discuss participation in the study entitled: **Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD)**.

I can be contacted at the following telephone number _____. I understand that by agreeing to discuss the study with the researcher, I am not consenting to participate in the research.

Signature: _____

Title of study: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD).

1. INTRODUCTION:

You are invited to take part in this study because of your experience of COPD. As you know COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema.

2. PURPOSE OF THIS STUDY

The purpose of this study is to find out how nurses can best respond to the needs of people who have advanced COPD. The study is therefore only concerned with those patients whose breathing difficulties have resulted in them needing to be admitted to hospital. The researchers hope that nurses will find ways to improve patient care.

The researcher, Geralyn Hynes, is an experienced nurse. This study is part of her thesis for the degree of PhD in nursing.

3. PROCEDURES: WHAT WILL THE STUDY INVOLVE?

The researcher wants to find out about the experiences of patients with COPD. She would like to meet you for about 45 minutes to learn about how your illness has affected your life. She will have three short questionnaires that ask questions about your symptoms and how these affect you daily. She will ask you to fill in the questionnaires. If you prefer, she will assist you by reading out the questions and filling in your answers as you call them. You may have a family member or friend with you during this time. The questionnaires are anonymous. Your name will not appear in any questionnaire and an identity number will be used instead

When the questionnaires are completed the researcher may invite you to meet her again so that she can find out more about your thoughts on your illness. This second interview will last no more than 40 minutes. If you wish to finish earlier, the researcher will do so and this will not affect the research.

With your permission the conversation of this interview will be taped so that after the meeting the researcher can make an accurate record of the discussion for her research. After the interview the recording will be analysed. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tape will be kept in a secure place. If you wish to have a transcript of the interview, the researcher will be happy to provide you with this. These two meetings will take place in your home or in hospital, depending on which you prefer.

Later in the coming year, the researcher will invite patients who have COPD to a meeting to discuss ways nurses might help people to improve their quality of life. There will be three of these meetings. If you are invited to one of these meetings you should not feel in any way obliged to attend. If you choose to attend one meeting, you should not feel in any way obliged to attend either of the other two meetings.

The findings from this research may be submitted for publication or presented at a conference. You will not be identified in any publication or conference paper from this research. This research may help others to have a better understanding of COPD.

4. WHO CAN TAKE PART IN THE STUDY
You are invited to participate in this study if:
- you have advanced or severe COPD
- you required hospitalisation because of COPD within the past 12 months.
- you understand the purpose of the research
- you wish to take part in this research

5. WHO CANNOT TAKE PART IN THE STUDY?
You cannot participate in this study if:
- you required hospitalisation in the past year for reasons other than COPD
- you do not have advanced or severe COPD
- you are in an intensive care unit or are acutely ill at the time of selection
- you are unable to participate in the interview process
- you do not understand the purpose and process of the research
- you are unwilling or unable to participate in the study

6. BENEFITS:

There is no promise or guarantee of any benefit from this research. It is hoped that hearing people's experiences of having COPD and any suggestions they may make for meeting their needs, may help nurses to find ways of improving the experiences and care of those with COPD. The study is an opportunity for people to tell their experiences of COPD and its impact on their lives.

7. RISKS:

There are no known risks to those who take part in this study. However some people may become upset while talking about how COPD has affected their daily lives. If this happens, you may end the interview. If you wish you may resume the interview at another time of your choosing. You can withdraw from the study if you wish at any point.

People with COPD may become breathless during interviews. If this happens to you, the researcher will offer to stop the interview, and assist you. You may continue the interview at another time that is more convenient for you.

8. CONFIDENTIALITY:

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report, paper or publication. You identity will not be given to anyone outside the research group. All information will be kept anonymous and confidential.

9. COMPENSATION:

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in this study.

10. VOLUNTARY PARTICIPATION:

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. WHO IS SUPPORTING THIS STUDY?

The Health Research Board funds this study through a Clinical Fellowship for Nursing and Midwifery.

12. PERMISSION:

This research has been granted ethical approval by the Research Ethics Committees of your hospital and the Faculty of Health Sciences, Trinity College Dublin.

13. FURTHER INFORMATION:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Geralyn Hynes who can be telephoned at 087 7683373. Alternatively you can contact Dr. Mary McCarron, Study supervisor at the School of Nursing and Midwifery, Trinity College Dublin by telephone at 01-8962694 or by e-mail mccarrm@tcd.ie

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Appendix Six Consent Form for Persons with COPD

Title: Developing Respiratory Nursing Practice for Patients with Advanced Chronic Obstructive Pulmonary Disease

Researcher's Contact Details:

Ms Geralyn Hynes. Phone number 087 7683373 Email hynesge@tcd.ie

Background and procedures: COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. The purpose of this study is to discover how best respiratory nurses can respond to the needs of people who have advanced COPD. Participation will involve one meeting. During this you will be asked general background questions. Then you will be asked specific questions about how COPD affects your day to day life including the level of breathlessness you experience. Following this you may be invited to participate in a second interview at a later date. For this second interview you will be asked to describe your experiences of COPD. The findings of this study will be presented as a thesis and may be submitted for publication and/or presentation at a conference. You will not be identified in any publication from this research. The findings will also be used as a basis for further study on how nurses can develop their care of patients with COPD.

DECLARATION (Please read and tick if you agree):

I have read the study information sheet and this consent form. ☐

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. ☐

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential.
☐

I understand that if I wish to do so, I may have access to my interview transcript.

☐

I understand that my permission will be sought to record my interview ☐

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. ☐

I have received a copy of this agreement and I understand that the results of this research may be published. ☐

I understand I may withdraw from the study at any time. ☐

PARTICIPANT'S NAME (BlockCapitals):…………………………………………..

CONTACT NUMBER: …………………………………………………………..

PARTICIPANT'S SIGNATURE:………………………………………………..

RESEARCHER'S NAME_____

RESEARCHER'S SIGNATURE_____

DATE _____

Appendix Seven Letter for Semi-structured Interview

Developing respiratory nursing practice to address care needs of patients with chronic obstructive pulmonary disease (COPD).

As you may be aware, a research project is underway in this hospital that aims to inform and develop respiratory nursing practice specifically in relation to patients with advanced chronic obstructive pulmonary disease (COPD). As part of this project, we have been meeting with patients to get a better understanding of their experiences of living with COPD. This leaflet is for people who have already participated in the project by meeting with the researcher, Geralyn Hynes. We would like to learn more about how the illness has been for participants on a day to day basis since the previous interviews.

If you have already met with the researcher, Geralyn Hynes

If you met with the researcher, Geralyn Hynes, she would like to hear how you have been since then.

What will this interview involve?

If you choose to meet again with her, she would like to learn about how you have been since the first interview. This interview will last about 45 minutes. If you choose not to meet with her again, this will not affect the research and will not in any way affect your care.

How do I get further information about this research?

You can get further information about this research from the respiratory nurses in the hospital clinical or by contacting the researcher, Geralyn Hynes.

How do I contact the researcher?

You can contact the researcher, Geralyn Hynes, by phone: 087 7683373; email hynesge@tcd.ie. Alternatively, you can leave your contact details with the respiratory nurses and they will contact the researcher.

Appendix Eight Poster

Developing respiratory nursing practice to address care needs of patients with chronic obstructive pulmonary disease (COPD).

A research project is underway in this hospital that aims inform and develop respiratory nursing practice specifically in relation to patients with advanced chronic obstructive pulmonary disease (COPD).

As part of this project, we aim to identify care needs among patients. Later we aim to explore how respiratory nursing practice can develop to address these needs.

Who will be involved?

If you were admitted over that past year for treatment of COPD, you may receive a letter inviting you to meet with the researcher, Geralyn Hynes, to talk about your experience of living with COPD.

You may also receive an invitation towards the end of 2008 to join in a patient group discussion to discuss ways nurses might help people with COPD to improve their quality of life.

Leaflets are available from the respiratory nurses with further information.

If you receive a letter inviting you to meet with the researcher, you do not have to take part in this study. If you agree to take part you may change your mind at any time.

Developing respiratory nursing practice to address care needs of patients with chronic obstructive pulmonary disease (COPD).

A research project is underway in this hospital that aims inform and develop respiratory nursing practice specifically in relation to patients with advanced chronic obstructive pulmonary disease (COPD). As part of this project, we aim to identify care needs among patients. Later we aim to explore how respiratory nursing practice can develop to address these needs.

Who will be involved?

If you were admitted over the past year for treatment of COPD, you may receive a letter inviting you to meet with the researcher, Geralyn Hynes, to talk about your experience of living with COPD. You may also receive an invitation towards the end of 2008 to join in a patient group discussion to discuss ways nurses might help people with COPD to improve their quality of life.

The researcher, Geralyn Hynes, is an experienced nurse. This study is part of her thesis for the degree of PhD in nursing.

What will the study involve?

If you choose to participate, the researcher would like to meet you for about 45 minutes to learn about how your illness has affected your life. She will have three short questionnaires that ask questions about your symptoms and how these affect you daily. The researcher may also invite you to meet her again for about 40 minutes so that she can find out more about your thoughts on your illness. If you wish to finish earlier, the researcher will do so and this will not affect the research. The questionnaires are anonymous. Your name will not appear in any questionnaire or research report.

Later in the coming year, the researcher will invite patients who have COPD to a meeting to discuss ways nurses might help people to improve their quality of life. There will be three of these meetings. If you are invited to one of these meetings you should not feel in any way obliged to attend. If you choose to attend one meeting, you should not feel in any way obliged to attend either of the other two meetings.

How can I get further information?

Speak to your respiratory nurse and she will be happy to put you in contact with the researcher.

Appendix Nine Demographic Details

Age _____

Tick as appropriate

Gender   Male _____   Female _____

Area of residence
Urban   _____
Rural   _____

Married/partner   _____
Widowed   _____
Separated   _____
Single   _____

Living alone   Yes _____   No _____

Main Carer*
Spouse/partner   _____
Child   _____
Service supported
Care attendant   _____
Other (state)   _____

Tick if coming to home
Home help   _____
Carer is one who provides physical and social care to the respondent in his/her home.

Opening interview question

'Tell me what life is like for you now living'.

Topic guide

- How COPD has affected life
- Understanding of COPD
- Impact on relationships
- Impact on socialization
- Impact on physical functioning capacity and activities of daily living
- Experience of healthcare
- Current feelings about illness
- Current feelings about future
- Coping mechanisms

Examples of probes

- Can you tell me more about that
- How did that make you feel?
- That's interesting, can you say more

Conclusion to the interview:

- Explain how/when/where interview data will be stored and disposed of
- Answer any questions the participant raises
- Remind the participant of researcher contact details and that they can have a copy of the interview transcript if they wish
- Check participant well-being
- Thank participants for their involvement

A topic guide will be used to ensure aspects of impact of illness on life, symptoms, understanding of illness, anxieties and sources of help (formal and informal) are included.

Appendix Eleven Data Integration

Example of integration between SPSS outputs and other quantitative data such as demographics and the qualitative interviews which facilitated cross tabulation of different data sources so as to robustly interrogate the data.

Quantitative data was imported to NVivo. This allowed each participant's quantitative and qualitative data to be explored. In this slide a transcript is shown from an audio file of an interview with Participant 32 alongside his demographic details and SGRQ total and domain scores.

Appendix Twelve Coding Stripes

Example of 'coding stripes' which allowed the researcher to track where any given text segment (unit of meaning) was also coded to other themes or categories of themes

This slide shows the first stage of coding of a transcript of an interview with Participant 1. In this segment, I have asked her what life is like for her. She responded by referring to loss of social life, the effort involved in going out and panic attacks. The coding stripes capture overlapping early coding: frustrations, loss of independence, burden on daily life and general feeling of loss.
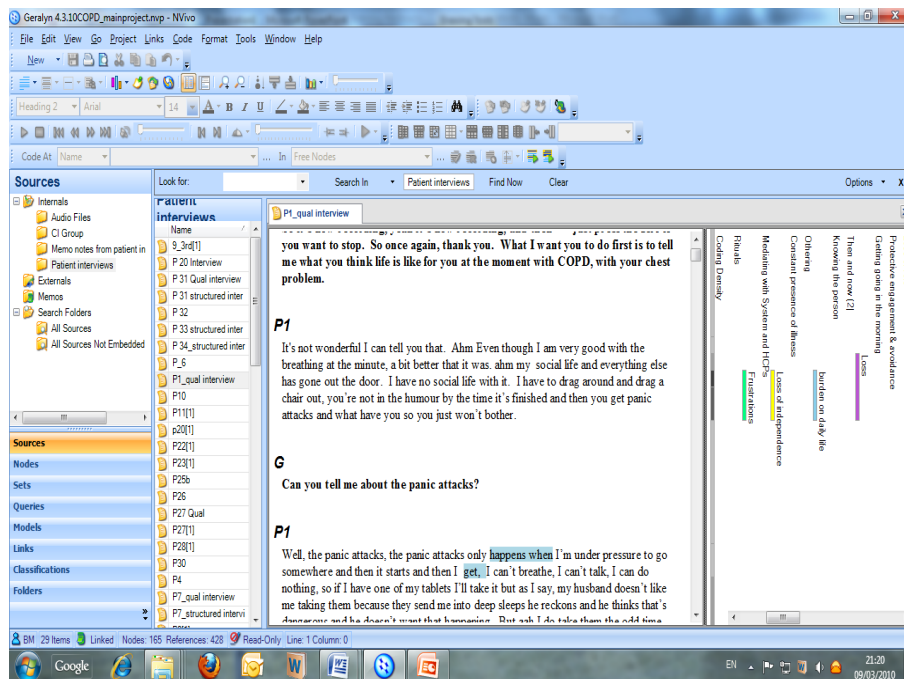
Appendix Thirteen Re-coding

Example of the complex relationship between coded and re-coded content as shown between a parent, child and grandchild set of nodes. For example, data from the theme/node 'negotiating illness' is 'coded on' to 'illness effects' which in turn is further subdivided into; 'adapting' , 'formal healthcare' and 'illness response'
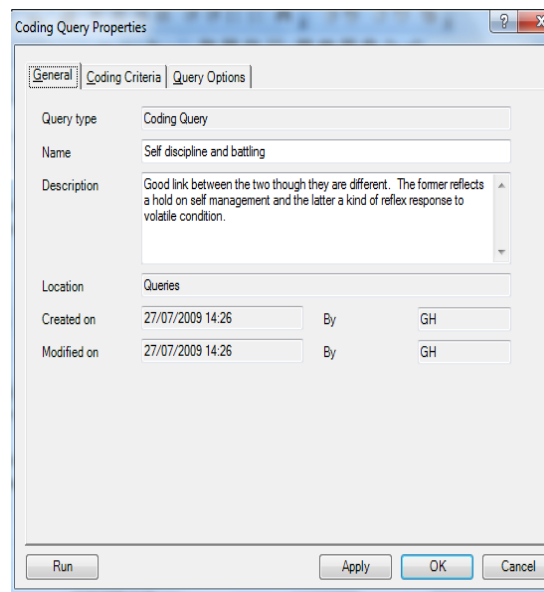
This slide shows early stages of recoding as nodes are explored for their content and links with other nodes. Models helped explore relationships between nodes and inform the development of themes.
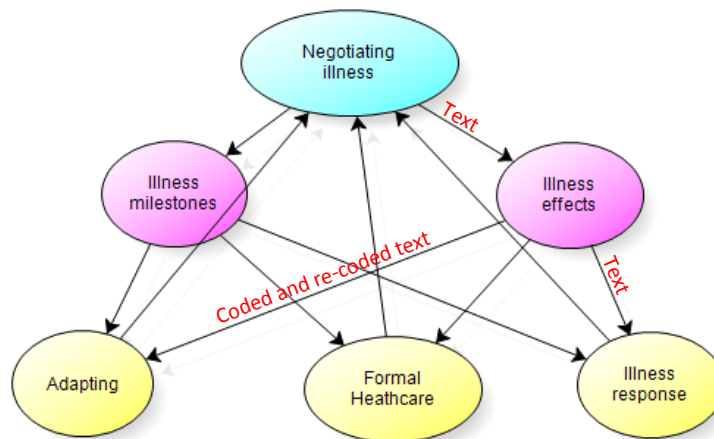
Appendix Fourteen Coding Query

Example of a typical query which gathers and collates data from disparate sources, themes and sub themes so as to offer new insights into previously coded content

In this slide I describe a coding query that indicated a relationship between self discipline and battling. The query identified overlap between the 2 node but also indicated their different dimensions. Self discipline reflected a sense of keeping some hold over symptoms while battling reflected something more onerous and reaction to a volatile condition.

Example of the relationship between quantitative scoring and coded text segments or units of meaning

In this slide a matrix table is generated of emotion as a theme and the anxiety and depressions scores of 7 and greater. Each cell shows proportion of sources coded for each subtheme and score. The quoted segments behind each cell can then be opened and explored for similarities and differences across scores. In this way, congruence and discrepancy between segments and scores can also be examined.
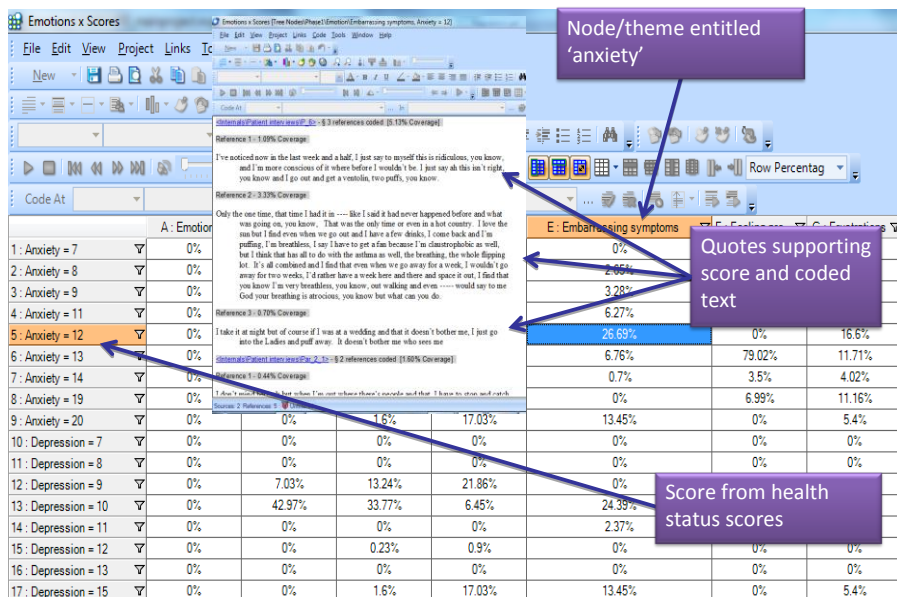
Appendix Sixteen Matrix Table

Depression Scores and Coding Matrix

This matrix table shows depression scores recorded in the interviews and all initial coding. Matrix tables such as this enabled a broad view across the data for relationship patterns. The number in each cell reflect the number of sources coded.

	Depression = 0	Depression = 1	Depression = 2	Depression = 3	Depression = 4
Symptoms, disease & co-morbidity	0	0	0	0	0
Physical sensation	1	0	0	0	1
Breathlessness	0	0	0	0	0
Severe day to day breathlessness	2	0	0	0	3
Breathlessness	1	2	1	1	3
Tenuous control	2	0	0	0	3
Co-morbidity	0	0	0	0	0
Comorbidity	1	2	0	1	3
Symptom complications	1	0	0	0	1
Mediating illness with world	0	0	0	0	0
Memory of encounter and bad experience	0	0	0	0	0
Gratitude	0	0	0	0	1
Encounters that had impact	0	0	0	1	0
Interpreting information	1	0	0	1	2
Othering	1	0	0	0	0
Importance of social contact	0	0	0	0	1
Managing social encounter	1	0	1	0	2
Information mismatch	1	0	0	1	0
Discharge	0	0	0	0	0
Getting help	1	1	0	1	5
crisis stage	2	1	0	1	2
Relationships	0	0	0	0	0
Lack of Understanding	1	0	0	0	0

Family holidays	0	0	1	0	2
Relationships	0	0	0	0	1
Barriers to participating in family events	0	0	0	0	0
Making childlike	0	0	0	0	0
Role relinquishing	0	0	0	0	3
socialising & outside interests	0	0	1	0	3
Engaging or Interacting with HCPs and service	0	0	0	0	0
Communication with HCP	2	0	0	1	0
Disenfranchised from HCPs	1	0	0	0	0
Mediating with System and HCPs	1	0	0	0	0
Responsibility of self to work with team	1	1	0	0	2
Sensitive to image in hospital	0	0	0	0	1
Frustrations in Clinic	0	0	0	0	0
Lifeworld	0	0	0	0	0
Acknowledging disease progression	1	0	0	1	5
Adapting	1	1	1	0	6
Loss	0	0	0	0	0
Loss	0	0	1	0	5
Loss of role	0	0	0	0	6
Loss of Participation in Family Celebrations	0	0	0	0	3
Loss of independence	0	0	0	0	1
Loss of control	1	0	0	0	1
Self image	0	0	0	0	0
Self-conscious	1	0	0	0	3
Changing body appearance	0	0	0	0	0
Self image	2	1	0	0	2
Engaging in every day	0	0	0	0	0

activities					
Engaging in normal home activities	2	1	1	0	4
Managing the home environment	2	1	1	0	2
Getting going in the morning	0	1	0	0	1
Engaging in everyday activities	2	2	1	1	5
Illness response	0	0	0	0	0
Self management	0	0	0	0	0
Managing medication	2	0	1	1	2
Exercise	2	1	0	1	5
Coping mechanisms	2	1	0	1	2
Dealing with infection	1	1	0	0	1
Self management	1	2	0	1	4
Triggers	1	1	0	1	1
Homehelp	1	0	0	1	0
Side effects of Medication and Illness	0	0	0	0	2
Lay knowledge	0	0	0	0	0
Lay knowledge	2	2	1	1	5
Asserting own Knowledge	1	0	0	0	1
Family response	0	0	0	0	0
Protective engagement & avoidance	0	0	0	0	1
Supports	2	0	1	0	2
keeping hold of self and world	0	0	0	0	0
Self discipline	1	1	0	0	1
Rituals	1	2	1	0	6
Striking out	0	1	0	0	1
Sleep	0	1	1	0	0
Tight versus loose control	0	0	0	1	1
planning ahead	2	0	0	0	4
carer relationship	0	0	0	0	0
Mutual burden	0	0	0	0	0

Shared experience	0	1	0	0	4
Caregiver and care recipient relationship	0	0	0	0	3
Watchful	0	0	0	0	0
Carer engagement in treatment	0	0	0	0	4
Carer protectiveness	1	1	0	0	5
Carer worries	0	0	0	0	4
Healthcare	0	0	0	0	0
Communication with HCPs	0	0	0	0	0
Knowing the person	1	0	0	0	3
HCP giving confidence	1	0	0	0	1
HCP Competence	1	0	0	0	1
Inexperienced Doctor	1	0	0	0	0
Haphazard approach of HCP	0	0	0	0	0
Consultant as trainer versus carer	1	0	0	0	0
Qualities of meaningful and positive encounters with HCP	1	0	0	0	1
Knowing the case	1	0	0	0	0
Being in hospital	0	0	0	0	0
Immediate acute care in ED	0	0	0	0	0
Familiarity with ED routine	0	0	0	0	0
Exacerbation in hospital	0	0	0	1	2
Named nurse	0	0	0	0	0
being in hospital	2	0	0	1	2
Ambulance	0	0	0	0	0
Admission	2	1	0	0	0
Appreciation of Hospital context	1	0	0	0	0
Negotiating	0	0	0	0	0

healthcare					
Contradictions in care	0	0	0	0	0
Implications of simple HCP requests	0	0	0	0	1
GP Familiarity with Patient	1	0	0	0	3
Expectations re HCP	1	0	0	1	2
Engaging the HCP in management and care	1	0	0	0	2
Continuity of Care Doctors	1	0	0	0	0
Consultant or HCP as hero	0	0	0	0	0
Experienced Doctor	1	0	0	0	1
Unexplained changes in treatment	1	0	0	0	0
Multiple team management	0	0	0	0	0
Conflicting advice re treatment	0	0	0	0	0
Duplication of medication	0	0	0	0	0
Pulmonary rehabilitation	0	0	0	0	3
watching	1	0	0	0	0
Private company support	0	0	0	0	1
OPD	0	0	0	0	0
Preferred OPD approach	0	0	0	0	0
OPD	1	0	0	1	1
Nurse as monitor of treatment	0	0	0	1	0
Contact with other patients	0	0	0	0	0
Wish to see consultant	0	0	0	0	0
Emotion	0	0	0	0	0
Living with Fear	0	0	1	0	2
Panic	0	1	0	1	1
Depression	0	0	0	0	0
Embarrassing symptoms	1	0	1	0	1
Feeling	0	0	0	0	0

pressured by carers					
Anger	0	0	0	0	0
Defeated	0	0	0	0	0
Grieving	0	0	0	0	2
Future	0	0	0	0	0
Future	1	0	0	1	2
Fear	1	0	0	1	0
Hope	1	0	0	0	2
Frustrations	1	0	0	0	1
Contracted world	0	0	0	0	0
Illness burden	0	0	0	0	0
burden on daily life	2	0	1	0	6
Unpredicatbility	0	0	0	0	3
Tied to oxygen	0	0	0	0	2
Life now	2	1	1	0	7
Social isolation	1	0	1	1	1
Exhaustion	0	0	0	0	1
NIV	0	0	0	0	0
Constant presence of illness	1	1	1	0	4
current state	1	1	0	1	3
Trajectory milestones	0	0	0	0	0
Diagnostic event	0	0	0	0	0
Diagnostic Event	2	0	0	1	4
Battling	1	0	1	1	2
Then and now (2)	1	0	1	1	3
Contextualizing meaning making	0	0	0	0	0
Move to oxygen	1	0	0	0	0
explanatory meaning	2	1	0	1	2
Illness Progression	1	1	0	0	4
Smoking	0	0	0	0	0
deterioration with smoking cessation	0	0	0	1	0
smoking	0	0	0	1	1

Appendix Seventeen Patterns in Data

Example of the patterns in the data showing the relationship between quantitative scoring and coded text segments or units of meaning coded to the group of nodes entitled 'Symptom Lifeworld Engaging Illness Response' and the self scoring by participants. Numbers in the grid represent cases (participants) in this example

The initial broad inspection of matrix tables included assessment of frequency and density of coding across cells. In this instance, frequency was higher in relation to self management. Density was greater in respect of managing exercise, medication and the home environment. High density often indicated number of times an individual participant referred to a particular point e.g. managing medication.

Appendix Eighteen Cross Tabulation

Example of the cross tabulation between the symptom scores and participants' descriptive coded content under the group of themes entitled 'diagnostic event'

Matrix tables enabled themes to be explored according to health status scores. The theme 'diagnostic event' did not appear to fit with any of the questions on the health status instruments. In this slide, a matrix table is generated of diagnostic event and the SGRQ symptom domain. This enabled an exploration of sources coded according to scores.

Appendix Nineteen CI Information Sheet

A brief introduction to cooperative inquiry.

In traditional research on people, the roles of researcher and subject are mutually exclusive. The researcher controls the inquiry process while the subjects provide the data. In cooperative inquiry these exclusive roles are replaced by a cooperative relationship, so that *all* those involved work together as co-researchers and as co-subjects. Together, they design, manage and draw conclusions from the inquiry, and they undergo the experience and action that is being explored. This is not research on people, but research *with* people. Cooperative inquiry may involve 4 phases of reflection and action.

In phase 1 a group of co-researchers come together to explore an agreed area of inquiry. They may be professionals who wish to inquire into a particular area of practice, members of an organization who want to look at structures; ill people who want to assess the impact of particular healing practices and so on. In the first part of phase 1, they agree on the focus of their inquiry, and develop together a set of questions or propositions they wish to investigate. Then they plan a method for exploring this focal idea in action, through practical experience. Finally, in phase 1 they devise and agree a set of procedures for gathering and recording data from this experience.

In phase 2 the co-researchers now also become co-subjects: they engage in actions agreed; and observe and record the process and outcomes of their own and each other's experience. In particular, they are careful to notice the subtleties of experience, to hold lightly the conceptual frame from which they started so that they are able to see how practice does and does not conform to their original ideas.

Phase 3 is in some ways the touchstone of the inquiry method. It is a stage in which the co-subjects become fully engaged with their experience concerning their inquiry. This may allow different views of the emerging inquiry so that superficial understandings are elaborated and developed. Or it may lead them away from the original ideas into new fields, unpredicted action and creative insights.

In phase 4, after an agreed period in phases 2 and 3, the co-researchers reassemble to share the experiential data from these phases, and to consider their original ideas in the light of it. As a result they may develop or reframe these ideas; or reject them and pose new questions. They may choose, for the next cycle of action, to focus on the same or different aspects of the overall inquiry. This cycle between reflection and action is then repeated several times. Ideas and discoveries tentatively reached in early phases can be checked and developed; investigation of one aspect of the inquiry can be related to exploration or other parts; new skills can be acquired and monitored; experiential competencies are realized; the group itself becomes more cohesive, self-critical, and skilled in its work.

Adapted from John Heron's single page introduction: http://www.human-inquiry.com/cionepag.htm accessed 25th February 2008

Appendix Twenty Consent Form for CI

Title: Developing Respiratory Nursing Practice for Patients with Advanced Chronic Obstructive Pulmonary Disease
Researcher's Contact Details:
Ms Geralyn Hynes. Phone number 087 7683373 Email hynesge@tcd.ie

Background and procedures: COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. The purpose of this study is to discover how best respiratory nurses can respond to the needs of people who have advanced COPD. Participation will involve taking part in working group meetings with other nurses. During these meetings you will be invited to participate in planning, developing, implementing and evaluating nursing interventions to address the palliative care needs of patients with COPD. The findings of this study will be written up as a report and may be submitted for publication and/or presentation at a conference. You will not be identified in any publication or paper from this research

DECLARATION (Please read and tick if you agree):
I have read the study information sheet and this consent form. ☐

I have had the opportunity to ask questions and all my questions have
been answered to my satisfaction. ☐

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential. ☐

I understand that if I wish to do so, I may have access to transcripts of meetings in which I participated. ☐

I understand that my permission will be sought to record my interview ☐

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. ☐

I have received a copy of this agreement and I understand that the results of this research may be published. ☐

I understand I may withdraw from the study at any time. ☐

PARTICIPANT'S NAME (BlockCapitals):…………………………………………..
CONTACT NUMBER: ………………………………………………………….
PARTICIPANT'S SIGNATURE:…………………………………………………..
RESEARCHER'S NAME
RESEARCHER'S SIGNATURE
DATE

Title: Developing Respiratory Nursing Practice for Patients with Advanced Chronic Obstructive Pulmonary Disease

1. INTRODUCTION
You are invited to take part in this study because of your experience of COPD. As you know COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. You may have already spoken with the researcher, Geralyn Hynes about your experience of COPD.

2. PURPOSE OF THIS STUDY
The purpose of this study is to find out how nurses can best respond to the needs of people who have advanced COPD. The study is therefore only concerned with those patients whose breathing difficulties have resulted in them being admitted to hospital. The researchers hope that nurses will find ways to improve patient care.

The researcher, Geralyn Hynes, is an experienced nurse. This study is part of her thesis for the degree of PhD in nursing.

3. PROCEDURES: WHAT WILL THE STUDY INVOLVE?
The researcher will invite you to attend a meeting with others who have COPD to discuss different ways nurses can help patients cope with their illness and have a better quality of life. During this meeting the researcher may ask the group to comment on different aspects of their care. This meeting will take about 45 minutes. It will take place in a room in the hospital. The researcher can arrange transport for you to attend the meeting if the need arises. There may be approximately 3 such meetings over an 18-month period. If you are invited to one of these meetings you should not feel in any way obliged to attend. If you choose to attend one meeting, you should not feel in any way obliged to attend either of the other two meetings. If for any reason you are unable to attend a meeting at the last moment this will not affect the group. There will be no more than 12 people at any one meeting.

With your permission the researcher will tape-record the meetings so that the researcher can make an accurate record of the discussion for her research. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tape will be kept in a secure place. If you wish to have a transcript of the interview, the researcher will be happy to provide you with this. The findings from this research may be submitted for publication or presented at a conference. You will not be identified in any publication or conference paper from this research. The research may help others to have a better understanding of COPD.

4. WHO CAN TAKE PART IN THE STUDY
You are invited to participate in this study if:
- you have advanced or severe COPD
- you required hospitalisation because of COPD within the previous one-year period.
- you understand the purpose of the research
- you wish to take part in this research

5. WHO CANNOT TAKE PART IN THE STUDY?

You cannot participate in this study if:

- you required hospitalisation in the past year for reasons other than COPD
- you do not have advanced or severe COPD
- you are in an intensive care unit or are acutely ill at the time of selection
- you are unable to participate in the interview process
- you do not understand the purpose and process of the research
- you are unwilling or unable to participate in the study

6. BENEFITS:

There is no promise or guarantee of any benefit from this research. It is hoped that hearing people's experiences of having COPD, and any suggestions they may make for meeting their needs, may help nurses to find ways of improving the experiences and care of those with COPD. The study is an opportunity for people to tell their experiences of COPD and its impact on their lives.

7. RISKS

There are no known risks to those who take part in this study. However some people may become upset while talking about how COPD has affected their daily lives. If this happens you may end the interview. If you wish you may resume the interview at another time of your choosing. You can withdraw from the study if you wish at any point.

People with COPD may become breathless during conversations. If this happens to you, the researcher will offer to assist you out of the room and ensure that you can rest if you require this. Should you require further assistance the researcher will call your respiratory nurse specialist. If you choose, you may continue the interview at another time if that is convenient to you.

8. CONFIDENTIALITY

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report. You identity will not be given to anyone outside the research group.   All information will be kept anonymous and confidential.

9. COMPENSATION

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.   There is no payment for participation.

10. VOLUNTARY COMPENSATION

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. WHO IS SUPPORTING THIS STUDY

Health Research Board through the Clinical Fellowship for Nursing and Midwifery is funding this study.

12. PERMISSION FOR THIS STUDY

This research has been granted ethical approval by the Research Ethics Committees of your hospital and the Faculty of Health Sciences, Trinity College Dublin.

13. FURTHER INFORMATION

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Geralyn Hynes who can be

telephoned at 087 7683373 or by email hynesge@tcd.ie Alternatively you can contact Dr. Mary McCarron, research supervisor at the School of Nursing and Midwifery, Trinity College Dublin by telephone at 01-6082694 or by email mccarrm@tcd.ie If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Re: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD).

Dear

I am writing to invite you to participate in a study entitled: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD). COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. You are invited to consider participating in this study because of your experiences with COPD.

Please read the enclosed information, which describes the nature and purpose of the study and what participation will involve. You will also find a consent form. This is for your information. If you decide that you wish to participate in this study, I will ask you to sign the consent form when we meet. Before you sign this, I will discuss the research with you and answer any questions you may have.

I am an experienced nurse and am undertaking this research as part of my PhD thesis. I am undertaking this research because there is currently very little research on the nursing care needs of patients who have COPD. I hope the results from this research will help nurses to develop their knowledge and care of patients with COPD.

Should you wish to discuss your involvement in this study please complete the bottom part of this letter and return it as soon as possible using the stamped addressed envelope provided. I will then contact you to discuss participation and answer any questions you may have. Should you decide not to participate in this study, you will not be contacted further regarding this matter.

Yours sincerely

Geralyn Hynes
Phone: 087 768 3373
Email: hynesge@tcd.ie

Appendix Twenty Three Participant Information Re Patient Participant Group Meeting

Title of study: Developing respiratory nursing practice to address palliative care needs of patients with chronic obstructive pulmonary disease (COPD).

1. INTRODUCTION

You are invited to take part in this study because of your experience of COPD. As you know COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. You may have already spoken with the researcher, Geralyn Hynes about your experience of COPD.

2. PURPOSE OF THIS STUDY

The purpose of this study is to find out how nurses can best respond to the needs of people who have advanced COPD. The study is therefore only concerned with those patients whose breathing difficulties have resulted in them being admitted to hospital. The researchers hope that nurses will find ways to improve patient care.

The researcher, Geralyn Hynes, is an experienced nurse. This study is part of her thesis for the degree of PhD in nursing.

3. PROCEDURES: WHAT WILL THE STUDY INVOLVE?

The researcher will invite you to attend a meeting with others who have COPD to discuss different ways nurses can help patients cope with their illness and have a better quality of life. During this meeting the researcher may ask the group to comment on different aspects of their care. This meeting will take about 45 minutes. It will take place in a room in the hospital. The researcher can arrange transport for you to attend the meeting if the need arises. There may be approximately 3 such meetings over an 18-month period. If you are invited to one of these meetings you should not feel in any way obliged to attend. If you choose to attend one meeting, you should not feel in any way obliged to attend either of the other two meetings. If for any reason you are unable to attend a meeting at the last moment this will not affect the group. There will be no more than 12 people at any one meeting.

With your permission the researcher will tape-record the meetings so that the researcher can make an accurate record of the discussion for her research. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tape will be kept in a secure place. If you wish to have a transcript of the interview, the researcher will be happy to provide you with this. The findings from this research may be submitted for publication or presented at a conference. You will not be identified in any publication or conference paper from this research. The research may help others to have a better understanding of COPD.

4. WHO CAN TAKE PART IN THE STUDY

You are invited to participate in this study if:
- you have advanced or severe COPD
- you required hospitalisation because of COPD within the previous one-year period.
- you understand the purpose of the research
- you wish to take part in this research

5. WHO CANNOT TAKE PART IN THE STUDY?

You cannot participate in this study if:

- you required hospitalisation in the past year for reasons other than COPD
- you do not have advanced or severe COPD
- you are in an intensive care unit or are acutely ill at the time of selection
- you are unable to participate in the interview process
- you do not understand the purpose and process of the research
- you are unwilling or unable to participate in the study

6. BENEFITS:

There is no promise or guarantee of any benefit from this research. It is hoped that hearing people's experiences of having COPD, and any suggestions they may make for meeting their needs, may help nurses to find ways of improving the experiences and care of those with COPD. The study is an opportunity for people to tell their experiences of COPD and its impact on their lives.

7. RISKS

There are no known risks to those who take part in this study. However some people may become upset while talking about how COPD has affected their daily lives. If this happens you may end the interview. If you wish you may resume the interview at another time of your choosing. You can withdraw from the study if you wish at any point.

People with COPD may become breathless during conversations. If this happens to you, the researcher will offer to assist you out of the room and ensure that you can rest if you require this. Should you require further assistance the researcher will call your respiratory nurse specialist. If you choose, you may continue the interview at another time if that is convenient to you.

8. CONFIDENTIALITY

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report. You identity will not be given to anyone outside the research group. All information will be kept anonymous and confidential.

9. COMPENSATION

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights. There is no payment for participation.

10. VOLUNTARY COMPENSATION

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. WHO IS SUPPORTING THIS STUDY

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13. FURTHER INFORMATION

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Geralyn Hynes who can be

telephoned at 087 7683373 or by email hynesge@tcd.ie . Alternatively you can contact Dr. Mary McCarron, research supervisor at the School of Nursing and Midwifery, Trinity College Dublin by telephone at 01-6082694 or by e-mail mccarrm@tcd.ie If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Appendix Twenty Four Consent Form for Patient Participant Group

Meeting Phase Two

Title: Developing Respiratory Nursing Practice for Patients with Advanced Chronic Obstructive Pulmonary Disease
Researcher's Contact Details:
Ms Geralyn Hynes. Phone number 087 7683373 Email hynesge@tcd.ie

Background and procedures: COPD is a medical term for different respiratory conditions such as chronic bronchitis and emphysema. The purpose of this study is to discover how best respiratory nurses can respond to the needs of people who have advanced COPD. Participation will involve participating in a meeting with other patients with COPD. During these meetings you will be invited to comment as you wish on your experiences of care and ways of improving care. The findings of this study will be as a report and may be submitted for publication and/or presentation at a conference. You will not be identified in any publication from this research

DECLARATION (Please read and tick if you agree):
I have read the study information sheet and this consent form. ☐

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. ☐

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential. ☐

I understand that if I wish to do so, I may have access to meeting transcripts in which I participated. ☐

I understand that my permission will be sought to record my interview ☐

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. ☐

I have received a copy of this agreement and I understand that the results of this research may be published. ☐

I understand I may withdraw from the study at any time. ☐

PARTICIPANT'S NAME (BlockCapitals):…………………………………………..
CONTACT NUMBER: ……………………………………………………….
PARTICIPANT'S SIGNATURE:…………………………………………………..
RESEARCHER'S NAME_____
RESEARCHER'S
SIGNATURE_____
DATE _____

Faye
Greater awareness of linking in palliative care we kind of separated before

Denise
I think a greater understanding as well of own roles within palliative care and it's ok to link up for advice

Beth
Recognition of the needs of patients for COPD like particularly advanced like in clinic people will say why is your clinic staying so long and initially I'd wonder gosh is it was inefficiency whereas now I'd just try to hem like and explain that these patients have different needs than surgical patients. You know we possibly need more education needs for staff members because they don't understand the needs of these patients. I can see where they are coming from but they don't understand the needs they think that these doctors are not efficient. So I think what that's bringing up is need for increased awareness of PC and chronic illness

Faye
Psychological needs are far greater

Eadie

Cause we would have for patients nearly hour slots

Beth
Where we had 33 last Wednesday and then trying to give proper time

Eadie
I suppose what I got from was the whole thing for nurses when they are trying to get things changed. The patients turn quite quickly and then become palliative in the eyes of the doctors whereas the nurses would have seen things earlier.

Me
you are so tied to the agenda of the institution that however we were able to articulate patients' needs that you seem limited in what can be done what is possible to do at ward level and I think it has given me a lot of pause for thought because anyone coming on a clinical course will say of course we are patient oriented but if they are thinking that's what they have to say but not what is happening that's a huge gap for them. I'm really struggling with what does it mean to be a ward based nurse anymore you know with that kind of agenda that's driving things. It's with the best of intentions that everyone is trying

Faye
You kind of just accept it you feel you have to just manage with what you got

Me
From a management point of view they are hugely supportive and that's very much the case but because care is so institutionally driven their language is different….. They think it's [ideas from project] great but then how do we do this what resources

We seem trapped in a particular way of thinking.

Eadie

The ideal would be joint clinics ……

Me
the second question is what was good about the process

Beth
I think linking

Denise
Getting to know each others issues

Beth and learning to know about each person's role

Faye
And I suppose just even time to sit down and think about what you are doing and why you are doing it even that in itself

Beth
Even allowing yourself the time to discuss these issues you know to think about the issues like the reflective time is good

Eadie
I would see it…. I've found it quite helpful and learning about the respiratory point of view you know it's nice to bounce things off each other but the best thing would be to be actually involved with the patients' care but you don't get to you know the odd time I might pop my head in and introduce myself as Eadie cause I'm not actually involved but I'd like to actually build up the relationship you know but it's nice to bounce things about

Denise I think sometimes we are very hard on ourselves so it's hard to accept that we are doing a good job and pushing the boundaries a bit

Eadie
They are actually providing level one and two you know the challenge is to get in level three. At the beginning I think they did not see they were providing level one and two. Even on the ward they are providing level one and two

Me re first meeting and guidelines

Eadie
I think it would be nice to get feedback from patients in the pulmonary rehab. I think there are some that are not ready for the palliative care talk

RE consolidating what we have learned: e.g. interviewing patients post rehab re palliative care talk, also patients who had palliative care input

Denise
I don't think we're ready to finish

Beth
I agree I found it a huge support the

Denise
Plus we don't all get to meet it's a good forum to break things up and to discuss things

Eadie
You know the interviews and questionnaire you did with patients and their feedback could those findings be amalgamated to a poster and then giving information about palliative care and then place in the have posters up in outpatients department for patients coming in so it would encourage the patients to ask about palliative care themselves.

Beth
Just to create awareness across the hospital the education and research forum it's a lunch time meeting and is multidisciplinary and is well attended across the board probably less so by the staff nurses because they don't get time to go. I suppose the respiratory and palliative care would be a good forum to increase awareness

Eadie
Yeah X did n=one and it was well attended but we were trying to get away from palliative care as disease related and then it's not so much the nurses cause they have awareness it's the journal clubs that X does the education there this week.

Talk about presenting at the research meeting or medical journal club meetings and if people are willing to present within the group as a continuing way of encouraging palliative care referrals

Appendix Twenty Six Taking Stock Meeting

January 2009
Example of summarising the inquiry process and emerging themes to date that was circulated and explored at one meeting

Palliative care in COPD is to address the COPD experience as one that has symptom, cultural, lifeworld, and explanatory and emotion meanings while recognizing that understanding these can only be achieved over time and through a practitioner/patient partnership.   Achieving an optimum patho-physiological response is the practitioner's first line response but this must be followed in the longer term by engagement with what it means to the individual patient to experience COPD.

COPD experience can be understood in terms of what it means to be chronically ill in the symptom, cultural, lifeworld, and explanation and emotional sense.
Our inquiry so far:

1) Advanced COPD is one's life – COPD permeates every aspect of living from constantly working to limit the ever present risk of severe breathlessness, to an individual's sense of self through dealing with loss, uncertainty, relationship with others and society, and formulating ways of explaining to self what it means to have the illness. Having advanced COPD is not something one can compartmentalise – it *is* one's life

2) Caring for patients with COPD presents us with a choice of being either disease or illness focused where disease reflects the pathophysiology and behavioural science approaches. Illness focus reflects an engagement with what it means to experience living with COPD and includes symptoms but also more than that. When focused on illness, we lose the sense of certainty about how to manage suffering because we can't manage it; we can, at best come to understand, or to 'walk the journey' or to 'bear witness' to the patient's unique experience of what it means to experience COPD.

Therefore…..
Accepting COPD as a chronic illness is to recognise that illness and life are one i.e. illness permeates every aspect of life and how one lives and engages with life. As practitioners, we cannot know or understand the individual's unique illness experience based on our focus on COPD in the disease sense (pathophysiology).

Where this takes us….

We must find different ways of understanding the illness experience in the symptom, cultural, lifeworld, and explanatory and emotional sense.

The role of the Nurse is to bear witness to the patient's illness experience and journey. Bearing witness can be understood as an attitude of inquiry looking to the other person. This means stepping out from our own comfort zone and welcome the uncertainty that we experience when we glimpse the other person's world, fear etc.

The aim of COPD care is to reduce disablement in the on-going experience of an illness and prevent or minimise social and undesirable consequences of chronicity or the experience of COPD as a chronic illness

There are two aspects the practitioner needs to consider:

1) address technical/biomedical concerns to bring about optimum pathophysiological response

2) address the need for a broader approach such as nurse entering three stages of exploring an individual's COPD and what it means to him/her. The stages place the role of the nurse as ethnographer. They are 1)empathic listener; 2)translator; 3)interpreter.

Empathic listener: includes participant observation; patient assessment in biomedical/nursing sense; looking for patient's own explanatory mode;, practitioner's explanatory model; what the patient's COPD illness means to her in terms of family and social interaction; what are her concerns and her fears; what signals are there regarding family interaction, home visit, healthcare negotiation and emotions arising from that.

These slides show views of the weighting of sub-themes in relation to each other and show emphasis on particular subthemes based on sources coded.

Lifeworld - weighting of participant concerns

A : Acknowledging disease progression
B : Loss
C : Self image
D : Engaging in every day activities
E : Illness response
F : keeping hold of self and world
G : carer relationship
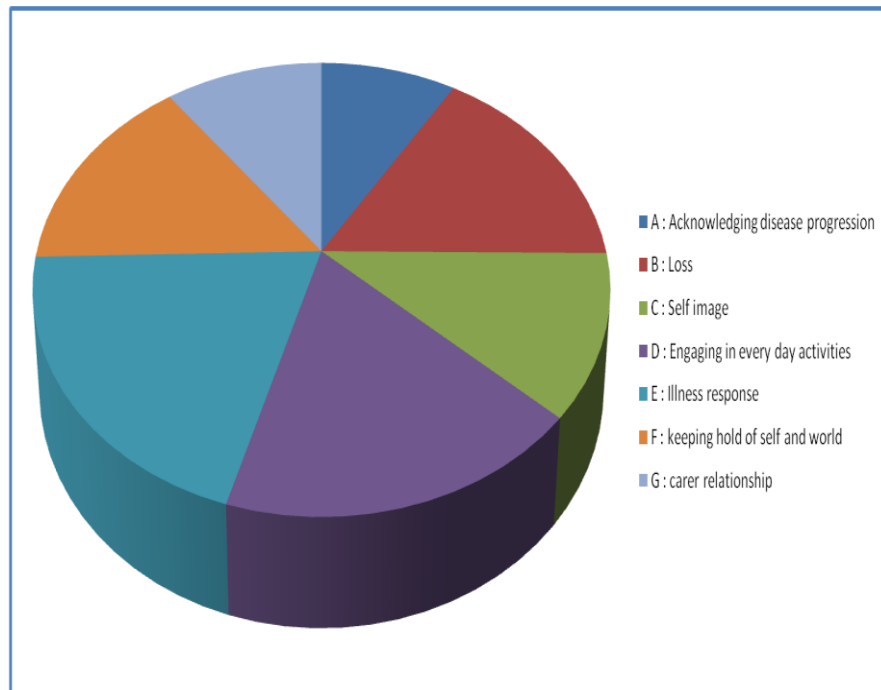
Emotion - Weighting of Participant Concerns

- A : Living with Fear
- B : Panic
- C : Depression
- D : Embarrassing symptoms
- E : Feeling pressured by carers
- F : Anger
- G : Defeated
- H : Grieving
- I : Future
- K : Fear
- L : Hope
- M : Frustrations
- N : chronicity
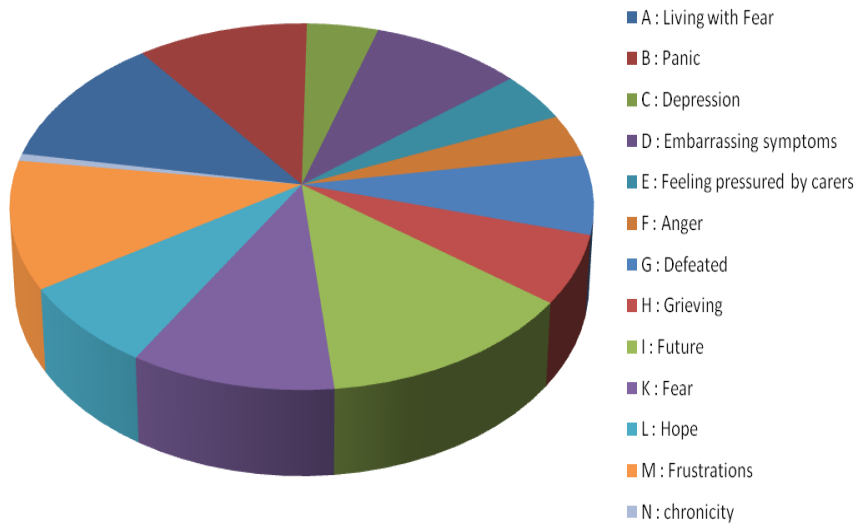
Contracted World: Weighting of Participant Concerns

- A : Illness burden
- B : Trajectory milestones
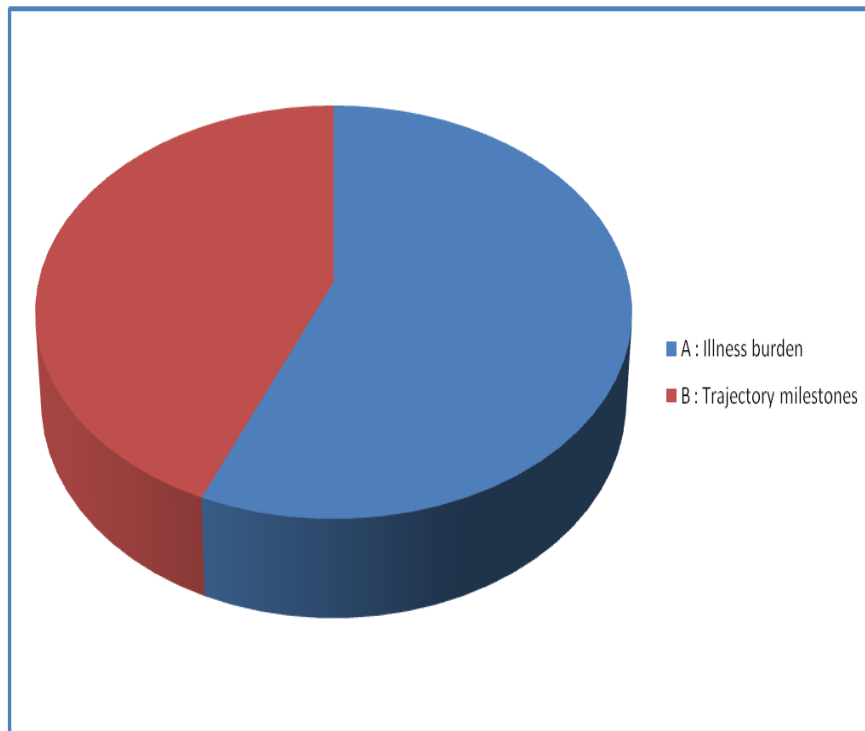
Appendix Twenty Eight Health Status Scores

ID	Anxiety	Depression	MRC	Symptom	Activity	Impact	Total
1	19	9	4	44	92	74	74
2	12	6	3	63	76	39	54
3	5	7	4	100	100	40	69
5	20	15	4	85	100	85	90
6	12	10	4	80	100	67	79
7	11	10	4	68	100	80	84
9	13	6	3	63	92	66	73
10	8	10	4	43	92	68	71
11	9	2	3	56	84	71	72
20	13	9	4	66	76	60	66
21	8	13	4	80	100	85	89
22	1	4	1	96	0	47	41
23	3	3	3	71	9	15	24
25	5	0	4	63	76	24	47
26	13	12	4	80	100	75	84
27	5	6	4	51	84	51	61
29	2	1	4	37	54	15	31
30	14	10	4	78	92	71	79
32	1	4	4	58	68	60	62
33	8	11	4	67	76	36	54
34	5	1	4	46	44	19	31

Example of scores greater than 8 against the 'Lifeworld' theme and sub themes surrounding 'loss'

This matrix table was generated of the theme 'Lifeworld' and its subthemes plotted against anxiety scores of 8 and greater. Frequency and density of sources coded indicate higher density of coding around higher anxiety scores.

Appendix Thirty Matrix Cross Tabulating

Example of matrix showing section of matrix cross tabulating impact scores and contracted world or lifeworld themes.

Matrix table indicates no obvious pattern between scores and themes.

Appendix Thirty One Anxiety and Depression, and Lifeworld, Emotion and Contracted World

Example of Anxiety & Depression Cross Tabulated with the category of themes entitled 'Lifeworld'

	A : Acknowledging disease progression	B : Loss	C : Self image	D : Engaging in every day activities	E : Illness response	F : keeping hold of self and world	G : carer relationship
1 : Anxiety = 0	0	1	1	1	1	0	0
2 : Anxiety = 1	4	5	3	3	6	5	6
3 : Anxiety = 2	0	0	1	1	1	1	0
4 : Anxiety = 3	1	0	0	1	1	1	0
5 : Anxiety = 4	1	1	0	1	1	1	0
6 : Anxiety = 5	3	3	4	5	5	5	3
7 : Anxiety = 7	0	1	0	1	1	0	1
8 : Anxiety = 8	2	4	2	6	6	4	5
9 : Anxiety = 9	0	1	0	1	1	1	0
10 : Anxiety = 11	1	2	2	2	2	2	2
11 : Anxiety = 12	1	3	2	2	3	1	1
12 : Anxiety = 13	3	8	5	8	9	6	2
13 : Anxiety = 14	0	1	1	1	1	1	0
14 : Anxiety = 19	1	1	1	1	1	1	1
15 : Anxiety = 20	1	1	1	1	1	1	0
16 : Depression = 0	1	1	2	2	2	2	1
17 : Depression = 1	0	0	1	2	2	2	1
18 : Depression = 2	0	1	0	1	1	1	0
19 : Depression = 3	1	0	0	1	1	1	0
20 : Depression = 4	5	7	4	5	8	6	6
21 : Depression = 5	2	3	1	3	4	3	3
22 : Depression = 6	3	7	6	6	7	6	3
23 : Depression = 7	0	0	0	0	0	0	0
24 : Depression = 8	0	1	0	1	1	0	1
25 : Depression = 9	3	3	1	4	4	2	1
26 : Depression = 10	2	5	5	5	5	4	3
27 : Depression = 11	0	1	0	2	2	1	1
28 : Depression = 12	0	1	1	1	1	1	0
29 : Depression = 13	0	1	1	1	1	0	1

Example of Anxiety & Depression Cross Tabulated with the category of themes entitled 'Emotion'

	A : Living with Fear	B : Panic	C : Depression	D : Embarrassing symptoms	E : Feeling pressured by carers	F : Anger	G : Defeated	H : Grieving	I : Future	J : Future	K : Fear	L : Hope
1 : Anxiety = 0	0	0	0	0	0	0	0	0	0	0	0	0
2 : Anxiety = 1	1	1	0	1	0	0	0	2	2	2	0	2
3 : Anxiety = 2	0	0	0	0	0	0	0	0	0	0	0	0
4 : Anxiety = 3	0	1	0	0	0	0	0	0	1	1	1	0
5 : Anxiety = 4	1	0	0	0	0	0	0	0	0	0	0	0
6 : Anxiety = 5	2	2	0	2	1	1	0	1	2	2	2	2
7 : Anxiety = 7	1	1	1	1	1	1	1	0	1	1	1	0
8 : Anxiety = 8	3	5	0	3	0	0	0	2	4	2	4	0
9 : Anxiety = 9	1	0	0	1	0	0	0	0	0	0	0	0
10 : Anxiety = 11	2	1	0	1	0	1	1	0	2	2	2	1
11 : Anxiety = 12	1	0	1	2	0	1	1	0	0	0	0	0
12 : Anxiety = 13	5	4	3	2	3	2	6	3	6	4	4	5
13 : Anxiety = 14	1	0	0	1	1	0	0	1	1	1	1	0
14 : Anxiety = 19	0	1	1	0	1	0	1	1	1	1	0	1
15 : Anxiety = 20	1	1	1	1	0	0	1	0	1	1	1	1
16 : Depression = 0	0	0	0	1	0	0	0	0	1	1	1	1
17 : Depression = 1	0	1	0	0	0	0	0	0	0	0	0	0
18 : Depression = 2	1	0	0	1	0	0	0	0	0	0	0	0
19 : Depression = 3	0	1	0	0	0	0	0	0	1	1	1	0
20 : Depression = 4	2	1	0	1	0	0	0	2	2	2	0	2
21 : Depression = 5	3	2	0	0	1	0	2	3	2	1	1	2
22 : Depression = 6	4	3	2	4	3	1	1	2	3	2	2	2
23 : Depression = 7	0	0	0	0	0	0	0	0	0	0	0	0
24 : Depression = 8	1	1	1	1	1	1	1	0	1	1	1	0
25 : Depression = 9	1	2	1	0	1	2	3	1	3	3	2	3
26 : Depression = 10	4	1	1	4	1	2	2	1	4	4	4	1
27 : Depression = 11	0	2	0	2	0	0	0	1	2	0	2	0
28 : Depression = 12	1	1	1	0	0	0	1	0	0	0	0	0
29 : Depression = 13	1	1	0	0	0	0	0	0	1	1	1	0
30 : Depression = 15	1	1	1	1	0	0	1	0	1	1	1	1

Example of Anxiety & Depression Cross Tabulated with the category of themes entitled 'Contracted World'

	A : Illness burden	B : Trajectory milestones
1 : Anxiety = 0	1	0
2 : Anxiety = 1	5	4
3 : Anxiety = 2	1	0
4 : Anxiety = 3	1	1
5 : Anxiety = 4	1	1
6 : Anxiety = 5	5	4
7 : Anxiety = 7	1	1
8 : Anxiety = 8	6	3
9 : Anxiety = 9	1	1
10 : Anxiety = 11	2	2
11 : Anxiety = 12	3	2
12 : Anxiety = 13	9	8
13 : Anxiety = 14	1	1
14 : Anxiety = 19	1	1
15 : Anxiety = 20	1	1
16 : Depression = 0	2	2
17 : Depression = 1	2	0
18 : Depression = 2	1	1
19 : Depression = 3	1	1
20 : Depression = 4	7	5
21 : Depression = 5	4	2
22 : Depression = 6	7	6
23 : Depression = 7	0	0
24 : Depression = 8	1	1
25 : Depression = 9	4	4
26 : Depression = 10	5	5
27 : Depression = 11	2	1
28 : Depression = 12	1	1
29 : Depression = 13	1	0
30 : Depression = 15	1	1

Appendix Thirty Two Themes with Mild Depression Score as Attributes

Mild Depression (Score 8-10) as Attribute and Lifeworld: Congruence and Discrepancy*

Lifeworld (Congruent)	Lifeworld (Discrepant)
Well, I'd safely say now, without fear of contradiction, if I didn't have an interest in crosswords I don't know, I'd probably be in the mental home <Internals\Patient interviews\P7_qual interview> I'm grossly overweight, but you know, as I said, I get so depressed and then you see. This is what happens you know and I'm not able to do things I want to do. I mean I love gardening. I haven't done that in two years and that flower bed I have to see which are the weeds and which are the flowers, you know, and that really upsets me because I can't do it. and then I might get one day where I have a load of energy and I go overboard and next thing I'm wrecked, wrecked from doing too much, you know, just no energy, constantly having no energy <Internals\Patient interviews\P_6>	No and even, they even arranged for the priest to come to me the way I don't have to go to Mass, you know that kind of a way. The priest comes to me once a month so, it's since last Christmas I got worse you might as well say but other than that no, I cope, you know the way, I'm coping well enough. <Internals\Patient interviews\P10> I would be a good enough driver but with the traffic now and all, I prefer to walk and I'd walk up as far as to the traffic lights to go to the chemist and all. I'd walk, now I'd rarely get up that far and I'd sit down in the chemist……. But then when I'd come out and walk back down……… well I'd be better <Internals\Patient interviews\P30> -

*Congruence reflects quotes that seem in keeping with score while discrepancy reflects quotes that appear to conflict with score.

Mild Depression (score 8-10) as Attribute and Contracted World: Congruence and Discrepancy*

Contracted World (Congruent)	Contracted World (Discrepant)
There's times you get fierce frustrated you know. Like the other day if I was doing something I shouldn't be doing I think I'll never be right <Internals\Audio Files\P_20_08071400>	I'm no worse like you know I'm satisfied enough. It's just you know I'm not going to get any better. I just have to mind myself. That's it <Internals\Audio Files\P_20_08071400>
I have no energy now sometimes. I'd go and do a bit of work and then sure I'm flattened. I get disheartened and say feck it I'll leave it till tomorrow. I used to work hard before and worked everywhere but I wouldn't do it now <Internals\Audio Files\P_20_08071400>	I have good days every day <Internals\Patient interviews\P10> I am very good with the breathing at the minute, <Internals\Patient interviews\P1_qual interview>
That wouldn't worry me at all but it's the getting tired out. Now with me last Sunday week, not yesterday, …..we had a great day but then I was dead after it. I can't accept that. <Internals\Patient interviews\P30> -	Some days I could feel right well and I could be great but then when it comes to about five o'clock or half five in the evening, it's gone. <Internals\Patient interviews\P7_structured interview>
But that's only since last year, you know, since I was very sick last Christmas. It's only since then. I went to the shop *every day* <Internals\Patient interviews\P10> -	

Mild Depression (score 8-10) as Attribute and Emotional Response: Congruence and Discrepancy*

Emotional Response(Congruent)	Emotional Response (Discrepant)
I get really annoyed and it upsets me, you know, and it's only lately and I've noticed it in the last two years, that it's been getting worse instead of better and ok the age isn't helping either, the weight isn't helping but there again it's catch 22. The minute I start loosing weight, they put me back on steroids, and the weight goes back up again, you know. <Internals\Patient interviews\P_6>	That's what I'm wondering myself, am I ever going to get any better do you know what I mean. I know I am not going to be 100% with my age and everything but you think you might get a little bit of relief or better do you know what I mean. More relief or aah that's what I'd be thinking now. I think one of the doctors said I'd never be the same again like but like I don't know but aah I think now he said that <Internals\Audio Files\P_20_08071400>
yeah there's no aah there's no aah there's no going outside the door going anywhere. Now, he would go if I wanted but I can't bear the thoughts of getting myself ready to go out. I've lost all interest in going out anywhere and that does that to you <Internals\Patient interviews\P1_qual interview>	
Everything, the house, when I die I haven't a will made if anything happened, all these things gets into my head. What will the dogs do, what will the chickens do, what will the, you know. <Internals\Patient interviews\P30>	

Appendix Thirty Three Ethical Approval