

**The experiences and monitoring of people living
with chronic obstructive pulmonary disease and
utilising long-term oxygen therapy**

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**“Human beings who are almost unique
in having the ability to learn from the experience of others
are also remarkable for their disinclination to do so”**

(Douglas Noel Adams) (Born 11 March 1952)

Abstract

The aims for this study were to gain a greater understanding of how the lives of long-term oxygen therapy [LTOT] recipients with chronic obstructive pulmonary disease [COPD] are affected, either negatively or positively, by the use of LTOT and the monitoring associated with its use. This study explored the experiences of 14 people recruited from the community setting, within two geographical regions within New Zealand. The participants were long-term (> 6 months) recipients of LTOT, which was prescribed and administered to minimise the deleterious physical, social and psychological effects of hypoxic COPD.

There is a paucity of research exploring the experiences and monitoring of people with COPD who utilise LTOT. This paucity of research is particularly evident within the New Zealand context. To date, research has predominantly focussed on patient's experiences of, and adherence to, LTOT. Little is known about the monitoring activities people who use LTOT undertake and patients' experiences of arterial blood gas [ABG] analysis and/or spirometry.

A plethora of studies have endeavoured to identify the negative and positive impacts of LTOT, including limitations to daily living and the health benefits, however the majority of studies have been undertaken utilising a quantitative methodology, which did not seek to explore the patient's reality. Qualitative methodology has the advantage of providing an in-depth insight into the patient's real-world experiences of COPD and LTOT.

A general inductive methodology employing thematic analysis was utilised to analyse the data collected from semi-structured face-to-face interviews consisting of 26 open-ended questions. The interview questions sought to elicit information regarding, i) the participant's experiences of aspects of monitoring, including ABG analysis and spirometry, ii) the participant's experience of the positive, negative and necessary aspects of LTOT, iii) the participant's journey with COPD, including knowledge of their disease, important support systems and coping mechanisms, and iv) the participants' experience of the psychological impacts of COPD.

Inductive thematic analysis provided the framework by which to analyse the raw data. The key findings were that participants described the benefits of LTOT to far outweigh the negative aspects. Four major themes emerged from the data: i) 'Smoking', ii) 'Oxygen therapy: The good, the bad and the necessary', iii) 'The COPD journey', and iv) 'Feel the panic and breathe anyway' (Psychological aspects of COPD). The impact of LTOT on the lives of a participant and their family was profound and multifactorial. The use of LTOT was associated with an overall improvement in the participant's perceptions of wellbeing however, LTOT posed restrictions on freedom, daily living, leisure activities and on the lives of family members. For some participants, the use of LTOT was associated with embarrassment and stigmatisation and viewed as the inevitable and very visible end result of a history of smoking. The overwhelming physical benefit of LTOT was lessening the participant's degree of dyspnoea and increasing their ability to cope with and participate in everyday life, albeit within the restrictions of their disease and oxygen therapy.

The strategies the participants employed in order to cope with the demands and challenges of the COPD journey demonstrated both congruence and dissimilarity and each participant had developed strategies to lessen the impact of LTOT on their daily lives. The participant's ability to cope with their disease was reliant on several factors including, knowledge and ongoing education, informal and formalised support systems, avoidance techniques and the availability of emergency responders in times of perceived crisis.

The psychological impacts of COPD and LTOT cover a wide gamut of emotions including depression, worthlessness and self-blame. These emotions impact negatively on the lives of the participants and their families. The participants were unanimous in their descriptions of the impact of debilitating breathlessness, associated anxiety and panic. The participants' descriptions of the panic they experience on a daily basis provides a valuable insight into the psychological impact of breathlessness, and the profound interruption it imposes on the participant's ability to function and participate in activities of daily living. Depression, self-blame and worthlessness were experienced by the participants, and in many cases LTOT provided an outwardly visible representation of their disease, further exacerbating the degree of psychological impact.

The interviews provided valuable insight into the benefits, barriers and challenges associated with the use of LTOT and its monitoring. In order to enhance the acceptability and maximise the therapeutic efficacy of LTOT, clinicians need to practice alongside and include patients in the development and monitoring of insightful interventions and innovative management strategies.

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List of abbreviations

ABG	Arterial blood gas
CO₂	Carbon dioxide
DHB	District Health Board
DLCO	Diffusing capacity of the lung for carbon monoxide
FVC	Forced vital capacity
FEV₁	Forced expiratory volume in one second
FiO₂	Fraction of inspired oxygen
H	Hydrogen
H₂O	Water
H₂CO₃	Carbonic acid
HCO₃	Bicarbonate
kPa	Kilopascal
Lpm	Litres per minute
LTOT	Long-term oxygen therapy
mmHg	Millimetres of mercury
nm	Nanometres

O₂	Oxygen
PaCO₂	Partial pressure of carbon dioxide in arterial blood
pH	Potential hydrogen
SaO₂	Percentage of oxygen saturation of arterial blood
SpO₂	Peripheral percentage saturation of haemoglobin by oxygen
STOT	Short-term oxygen therapy

CHAPTER ONE: Overview of thesis and background

1.1 Introduction

This chapter provides an overview of the thesis and details the structure and content of the chapters. Historical perspectives including scientific discoveries and knowledge pertaining to chronic obstructive pulmonary disease [COPD] are highlighted and a definition of COPD is provided. An exploration of epidemiology provides a background to the study and highlights the significance of the research undertaken. This thesis explored the experiences of those individuals who, because of the severity of their COPD, must utilise long-term oxygen therapy [LTOT]. LTOT is a medication and monitoring is an essential component of ongoing management and support for persons with COPD, and health professionals involved in their care. Consistent with the research literature, the terms patient, participant, person/s, individual/s and client were utilised interchangeably in this thesis.

1.2 Overview of thesis

COPD has an associated high degree of mortality and morbidity and a steadily increasing level of personal, psychological, and fiscal burden (Rennard, 2009). Clinical management of COPD encompasses optimisation of functioning and prevention of deterioration, and emphasis is placed on the importance of oxygenation, predominantly LTOT, in the maximisation of patients' wellbeing and associated quality of life. Seminal literature highlights aspects of, and the

importance of, oxygen therapy in COPD, however there is a paucity of literature exploring patients' experiences of oxygen therapy and monitoring (Agusti, Carrera, Barbe, Munoz, & Toghiani, 1999; Nocturnal Oxygen Therapy Trial Group, 1980; Plant, Owen, & Elliott, 2000). An exploration of patients' experiences may provide valuable information to inform and guide the clinical management of persons with COPD, and utilising LTOT, with an ultimate goal of overall improvement in health related life quality and maximal therapeutic management which is cost effective.

The aim of this study was to explore and gain an enhanced understanding of the positive and negative aspects of LTOT, as experienced by the individual, and to gain a greater understanding of the participants' experience of monitoring associated with the delivery and maintenance of LTOT. Utilising a qualitative methodology named Thomas's (2003) general inductive approach, this study sought to examine the experiences of 14 participants, with moderate to severe COPD, who utilise LTOT and live in a community setting. The ability to continue to reside within their chosen community appears to be of importance to people with COPD who indicate a strong preference for medical care and support within the least intensive setting (Robinson, 2005).

The thesis is divided into five chapters. The first chapter provides an introduction and background to this thesis and provides the rationale for conducting this research. Chapter two explores and reviews the contemporary literature regarding COPD and LTOT. Chapter Two is further divided into four main themes. The first theme presents an overview of current knowledge regarding COPD pathophysiology and cellular pathogenesis. An overview of the risk factors for development of COPD is offered and finally a review of current literature on the

diagnosis and staging of COPD is presented. Secondly, an overview of contemporary and historical oxygen therapy in COPD including an overview of oxygen delivery devices and technologies is presented. Thirdly, aspects of monitoring associated with the use of LTOT are explained. Lastly, literature is explored that highlights the experiences, including psychological, of people with COPD and on LTOT. Chapter three details the methodology utilised for this study and the interview structure utilised to amass the narrative data.

Chapter four presents the results of the study and provides an interwoven analysis within each subsection. There are four thematic sub-sections within this chapter namely: i) ‘Smoking’, ii) ‘Oxygen therapy: The good, the bad and the necessary’, iii) ‘The COPD journey’, and iv) ‘Feel the panic and breathe anyway’ (psychological aspects of COPD). Chapter five discusses this current study’s findings through the lens of, and within the context of, existing research literature and guidelines for COPD and LTOT management. The limitations and implications of the study are presented with areas for future research highlighted. Finally an overall conclusion is presented.

1.3 Background

This section provides an overview of COPD, including historical perspectives and epidemiology and will highlight the significance and magnitude of the burden of COPD and the implications of the addition of LTOT.

In 1679, a physician called Bonet discovered, during an autopsy, a pair of “voluminous lungs” and this description provides the first documented findings of what today is termed emphysema (as cited in Petty, 2006). The first references to the chronic bronchitis components of COPD were made in 1814 by Badham. Badham (as cited in Petty, 2006) described the chronic cough and hypersecretion of mucous as symptoms of disabling disorders termed “*bronchiolitis*” and “*bronchitis*”. The term “*catarrh*” was formulated as an umbrella terminology to describe the signs and symptoms known today as the chronic bronchitis component of COPD. Later the same century a clinician, pathologist and inventor of the stethoscope described the following findings during an autopsy.

In opening the chest, it is not unusual to find that the lungs do not collapse, but they fill up the cavity completely on each side of the heart. When experienced, this will appear full of air... The bronchus of the trachea are often at the same time a good deal filled with mucous fluid. (Laennec, 1821, p. 89, as cited in Petty, 2006)

After these early and pioneering descriptions modern medicine sought to further define the signs and symptoms of COPD. Today various definitions exist to define COPD, however a globally accepted definition was proposed as a result of a collaborative undertaking. The definition is as follows: COPD “Is a preventable and treatable disease with some significant extra pulmonary effects that may contribute to the severity in individual patients. The pulmonary component is characterised by airflow limitation that is not fully 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 Lung Disease, 2006, p. 2).

Providing a definition of COPD was one aim of the collaboration. Another aim of the World Health Organisation and the United States' National Heart, Lung and Blood Institute (known as GOLD) was to increase public, patient and clinician awareness and knowledge of COPD, and to impact positively on the disease's growing worldwide burden of morbidity and mortality (Global Initiative for Chronic Obstructive Lung Disease, 2006). COPD is a major chronic illness that results in substantial morbidity and mortality. Worldwide COPD affects approximately 10% of adults over 45 years old and COPD is becoming increasingly implicated in statistics highlighting hospitalisation, morbidity, mortality and financial burden (Cydulka, Rowe, Clark, Emerman, & Camargo, 2003). In New Zealand, COPD is the instigating disease for one third of all hospital admissions and the resultant health expenditure is 8% of the total budget allocation (The Thoracic Society of Australia and New Zealand (New Zealand Branch Inc), 2003).

1.4 Epidemiology

To explore the fiscal burden of diseases with high prevalence, a health survey called a "Portrait of Health" was undertaken in New Zealand. This survey utilised a multi-stage, stratified, probability proportionate to size sample from randomly chosen geographical regions. As part of this New Zealand health survey which was undertaken in 2006/07, all adult participants over the age of 45 years were asked if they had ever been informed by a health professional of a diagnosis of COPD and if they were currently receiving medications to treat their COPD. One in 15 adults confirmed a diagnosis of COPD, equating to a total of 96,100 adults. Women were more likely statistically (7.4%) to have received a diagnosis of COPD when compared to the male population

(5.6%) (Ministry of Health, 2008). Table 1.1 depicts New Zealand prevalence of COPD by ethnicity.

Table 1.1: Prevalence of COPD by ethnicity

Ethnic Group	Prevalence (95% CI)	Number of Adults
European/ other	6.7 (5.9 – 7.5)	84800
Maori	12.9 (9.4 – 16.4)	14200
Pacific	5.7 (3.3 – 9.1)	2700
Asian	2.4 (1.2 – 4.1)	2000

From: *A portrait of health. Key results of the 2006/07 New Zealand Health Survey* (p. 150), by Ministry of Health, 2008, Wellington: Author. Reprinted with permission.

The degree of deprivation experienced by the participants produced significant differentials in statistical results. Women who live in areas of high deprivation have triple the prevalence of COPD in comparison to those from a less deprived area. This finding was not reproducible for the male population. 39.4% of people with COPD were prescribed medications which included inhalers and/or tablets whilst 59.6% of people did not use any prescription medications. Less than 2% of participants were utilising oxygenation as a treatment for their COPD. The reason for the low percentage of reported LTOT use is that only those patients with moderate to severe COPD meet the strict criteria for prescription (Ministry of Health, 2008).

After adjusting for age, the incidence of COPD in Maori males was twice the incidence for all males aged 45 years and older and Maori females also displayed an increased prevalence of COPD. In contrast, the Asian population over the age of 45 years was less likely than the total population to have been diagnosed with COPD (Ministry of Health, 2008). In another New Zealand study, an audit of acute admissions as a result of COPD identified the likelihood of the Maori COPD patient group to present acutely at a younger age and these presentations contributed to 23% of all admissions to Waikato Hospital over a six month period (Chang, et al., 2007).

COPD is a major cause of morbidity and mortality worldwide and in First World countries, such as New Zealand, COPD was ranked fifth as a cause of mortality in adults aged 45 and older. Due to the burgeoning growth in the aged population worldwide, the prevalence of COPD is expected to continue to rise (Mannino & Buist, 2007). COPD instigates 9,250 hospital discharges and accounts for up to 1.5% of all bed days (Broad & Jackson, 2003). COPD initiates approximately 200,000 general practitioner visits and greater than 453,300 dispensed medications, causes years of disability with impaired quality of life and is estimated to cost the New Zealand tax payer between 25-40 million dollars each year (Broad & Jackson, 2003).

COPD produces a multi-dimensional effect on its afflicted patients including manifestations of debility, physical impairment, diminished quality of life and an increased incidence of mortality. These aspects in turn impact on the physical, psychological, social and spiritual wellbeing of those persons affected by COPD. Secondary to the degree of chronicity and high and burgeoning prevalence of COPD, the disease commands a high degree of resource utilisation culminating in

frequent primary, secondary and tertiary interventions with the associated fiscal burden of such interventions. Due to the magnitude of the problem further research is recommended (Rennard, 2009).

CHAPTER TWO: Literature review

2.1 Introduction

This chapter provides an overview of literature pertaining to COPD and LTOT. The chapter commences with a brief overview of the pathophysiology of COPD including a discussion on acute exacerbations of COPD. Cellular pathogenesis of COPD is highlighted followed by an overview of the risk factors for COPD including genetic considerations. The diagnosis and staging of COPD are then discussed. The history of oxygen therapy in COPD is explored followed by a discussion of the implementation and management of LTOT. The discussion includes national and international guidelines, oxygen delivery technologies and short-term oxygen therapy. This chapter then provides a brief overview of aspects of monitoring in COPD and finally overviews the experiences of people with COPD.

2.1.1 Pathophysiology of COPD

Various schools of thought and some debate persist over a globally accepted definition of COPD and various guidelines from different countries have a tendency to adopt their own interpretative definitions. These differing definitions are important to the extent that they influence therapeutic interventions. Several authors suggest COPD is a chronic respiratory condition that manifests as gradually worsening breathlessness that is often experienced in conjunction with sputum production and a persistent cough (Asthma Association Bangladesh, 2005; O'Donnell, et al.,

2003; O'Donnell, et al., 2008). Celli (2006) found although COPD is predominantly a respiratory disease involving the lungs it has the potential to produce numerous and significant systemic comorbidities resulting in multi-system impacts and physiological responses. In COPD the airflow limitation tends to be progressive and irreversible however, Celli concurs with the GOLD definition which considers that COPD is preventable and treatable which in turn suggests a degree of positivity regarding the disease pathway (Global Initiative for Chronic Obstructive Lung Disease, 2006). Prevention, treatment and management of COPD entails planning and collaboration at all levels of the health care system including primary, secondary and tertiary (American Thoracic Society & European Respiratory Society, 2004).

Broad and Jackson (2003) concluded COPD is a broad non-specific terminology describing airway and airflow obstruction and limitation as a result of emphysema or bronchitis. These authors concluded the incidence of COPD is dramatically limited by abstention from smoking. In spite of abstention from smoking, approximately 10-20% of those persons dying from COPD have no previous history of tobacco use and the aetiology of their disease is considered occupation and/or exposure related. Non-smoking related causes of COPD include exposure to substances such as toxic fumes, heavy air pollutants and particulate matter such as occupational dust (Rennard, 2009).

Debate persists as to the degree to which COPD is preventable and treatable and to the degree of reversibility of airflow restriction. Debate also persists as to the role asthma plays in the development of COPD and as a pathological component of COPD. Some varying schools of thought will be detailed next.

The terminology COPD encompasses an array of pathophysiological presentations including emphysema, bronchitis, asthma and bronchiectasis, all of which demonstrate a degree of airway remodelling and obstruction. COPD typically manifests as persistently non-reversible reduced forced expiratory flow rates FEV₁/FVC and exhibits increases in the residual volume and residual volume/total lung capacity ratio. A ventilation perfusion mismatch and uneven distribution of ventilation also occur in COPD which in turn impacts on the body's ability to undertake adequate and effective gaseous exchanges (Bach, Brown, Gelfand, & McCrory, 2001).

COPD exists as a multifactorial disease consisting of elements of emphysema and bronchitis and in up to 85% of cases is as a result of tobacco smoking, thus COPD is considered a preventable disease (The Thoracic Society of Australia and New Zealand (New Zealand Branch Inc), 2003). Literature reports asthma may also add to and/or coexist with the disease known as COPD (Bach, et al., 2001; Global Initiative for Chronic Obstructive Lung Disease, 2006; Rennard, 2009).

Asthma is considered an important chronic airways disease with characteristics of airway obstruction which, in contrast to the airway obstruction evident in COPD, is usually reversible. In some individuals who remain chronically exposed to toxic particulate, including cigarette smoke, the reversibility of their airway obstruction may become decreased and potentially develop to the extent that reversibility is not possible. These individuals exhibit a mixed presentation of asthma and COPD like inflammation with increased eosinophil levels which may make disease differentiation difficult (Global Initiative for Chronic Obstructive Lung Disease, 2006).

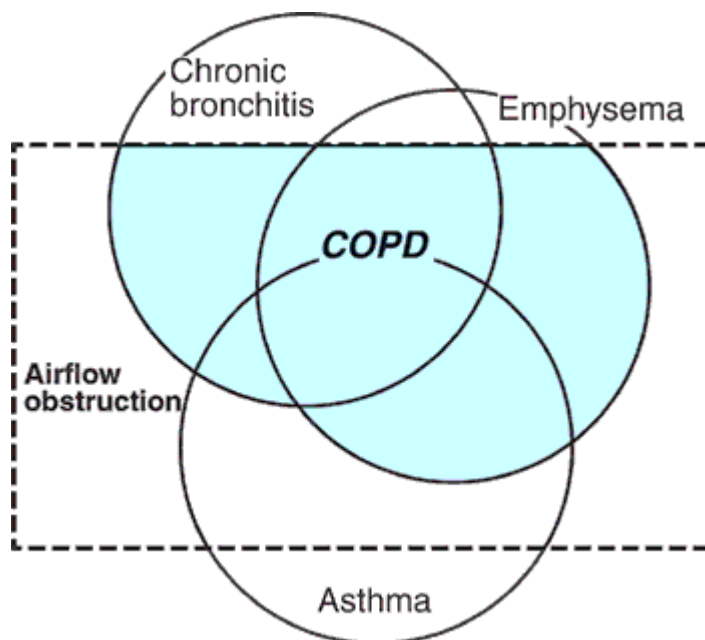
Asthma is characterised by mucous plugging, oedema and bronchoconstriction. Rennard (2009) states “asthma is a chronic inflammatory disorder of the airways in which many cells and cellular elements play a role. The chronic inflammation is associated with airway responsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness and coughing, particularly at night or in the early morning. These episodes are usually associated with widespread, but variably, airflow obstruction within the lung that is often reversible either spontaneously or with treatment” (p. 2).

One of the defining features of asthma is a predilection for airway hyper-responsiveness and bronchoconstriction secondary to exogenous stimuli including methacholine and histamine. A Dutch argument proposed by Orie (1961) found there are some symptom overlaps between those patients with asthma and those with COPD. Symptoms which overlap include airflow obstruction, airway responsiveness and pulmonary symptomology including structural degradation. In another study it has been found that asthmatics requiring treatment are 10 times more at risk of developing COPD when compared to the general population (Silva, Sherrill, Guerra, & Barbee, 2004). As a result of symptom overlap between asthma and COPD, misdiagnosis and under-diagnosis of COPD presentations have historically been evident, occasionally resulting in a diagnosis at an advanced stage of the disease process (Daheshia, 2005).

In contrast, a British hypothesis suggests that COPD and asthma exist as quite separate and defined diseases. The British hypothesis suggests asthma exists as a result of allergic reactions and COPD manifests as a result of inflammation and damage related to smoking (Scadding,

1959). Ongoing debate persists as to the role, if any, asthma plays in the development of COPD. The GOLD guidelines suggest due to differing pathology asthma and COPD are quite separately defined diseases (Global Initiative for Chronic Obstructive Lung Disease, 2006). In contrast, the 1995 American Thoracic Society guidelines depict a diagram (Figure 2.1) highlighting a degree of overlap between asthma, bronchitis and emphysema in cases of COPD (American Thoracic Society, 1995).

Figure: 2.1: American Thoracic Society Venn diagram



From: “Standards for the diagnosis and care of patients with chronic obstructive pulmonary disease,” by American Thoracic Society, 1995, *American Journal of Respiratory Critical Care Medicine*, 152, p. 2. 1995. Reprinted with permission.

The other widely accepted components which make up the disease of COPD include emphysema and bronchitis. Emphysema is a condition in which the alveoli are destroyed effectively limiting the degree of gaseous exchange available. Emphysema is defined as “abnormal and permanent

enlargement of the airspaces that are distal to the terminal bronchioles. This is accompanied by destruction of the airspace walls, without obvious fibrosis (there is no fibrosis visible to the naked eye)” (Rennard, 2009, p. 2).

Bronchitis is a chronic condition consisting of an over production of viscous mucous in the airways (bronchioles) resulting in coughing and production of phlegm. Bronchitis “is defined as a chronic productive cough for three months in each of two successive years in a patient in whom other causes of chronic cough have been excluded” (Rennard, 2009, p. 2)

The underlying pathological process in COPD is progressive airflow obstruction which is often in conjunction with an inflammatory response as a result of exposure to toxic gases and/or particulate. COPD symptomology including increasing shortness of breath, chronic cough, sputum production and wheeze are potentially treatable if recognised early. Despite early recognition, treatment and smoking cessation, reversibility of airway remodelling and damage and/or cure is not possible (Broad & Jackson, 2003). The risk factors implicated in COPD include inherent personal and environmental risks, namely genetic deficiencies, airway hyper responsiveness, a history of smoking, or other inhalational exposures. In a small cohort of patients with COPD, no precipitating exposures or risk factors are able to be identified and the causal link remains obscure (Rennard, 2009).

2.1.2 Acute exacerbations

Patients with COPD are prone to acute exacerbations of their illness secondary to infection and are particularly vulnerable during the winter months. Exacerbations become more frequent as the disease progresses and are associated with increased mortality and morbidity and fiscal burden secondary to increased rates of hospitalisation. An exacerbation of COPD is defined as “a sustained worsening of the patient’s symptoms from their usual stable state that is beyond normal day-to-day variations, is acute in onset, and requires a change in medications” (National Institute for Clinical Excellence, 2004, p. 30). Albert and Calverley (2007) suggest the incidence of exacerbations varies within the COPD patient cohort and most COPD patients will experience exacerbations at some stage during their disease trajectory. The authors temper this statement with an over-rider that exacerbations may be absent even for the patient group with disease classified as severe. They consider the increasing incidence of exacerbations is an important indicator of the diseases progression and the patient’s health-status deterioration.

Symptoms of an exacerbation may include upper respiratory symptoms, increased cough and sputum production with a change in sputum colour and consistency. Patients with more advanced disease are more likely to experience severe breathlessness with increased cardiorespiratory effort resulting in peripheral oedema and cyanosis which may include a degree of hypoxia resulting in confusion. The precipitants to an exacerbation may include bacterial or viral infections, exposure to pollutants such as ozone and sulphur dioxide, temperature and weather changes and the patient’s non-adherence to smoking cessation therapies (Barnett, 2007).

Psychological and physiological symptoms including chronic and acute shortness of breath and

resultant anxiety and depression are frequently experienced by the patient during an exacerbation of their illness (Gore, Brophy, & Greenstone, 2000).

2.1.3 Cellular pathogenesis of COPD

The signs and symptoms of COPD are derived from changes at a cellular level and will be briefly overviewed in this next section. The inhaled toxins driving the development and progression of COPD induce a proliferation of inflammatory cells and increased levels of neutrophils and macrophages are evident in the bronchoalveolar lavage of smokers. Alveolar macrophages have been linked to increased release levels of interleukin (IL)-8 and tumour necrosis factor alpha (TNF α) and the degree of lung destruction appears directly proportional to the count of alveolar macrophages per cubic millimetre. Macrophages and neutrophils (microphages) have the capacity to elicit structural changes, parenchymal destruction and pulmonary inflammation as a result of the production of proteinases and bioreactive oxidants. Proteinases are enzymes which reduce proteins into amino acids and peptides and bioreactive oxidants are an oxidising agent (Daheshia, 2005, p. 342).

The epithelium covering the airways has been implicated in the release of numerous mediators including chemokines namely P38, nuclear factor Kappa Beta and interleukin 6 and 8 resulting in increased levels of steroid resistant inflammation. T Lymphocytes with a predominance of CD8 cells were identified in various tissues including the small airways and paratracheal lymph nodes

and show a directly proportional increase in relation to the severity of an individual's disease (Daheshia, 2005, p. 342).

2.2 Risk factors for COPD

Several authors and guidelines have identified and debated numerous risk factors for the development of COPD. It has been unequivocally established that the most important risk factor for COPD is cigarette smoking (Celli, 2006; Chang, et al., 2007; Global Initiative for Chronic Obstructive Lung Disease, 2006; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009). Cigarette smoking and other risk factors for COPD will be reviewed in the following sections.

2.2.1 Smoking

Several studies have described an important inverse relationship between FEV₁ (volume of air exhaled within one second of a forced expiratory manoeuvre) manifesting as decreased lung capacity and the degree of intensity of smoking as described in pack years (Celli, 2006; Chang, et al., 2007; McGraw-Hill's AccessMedicine, 2009). By 1964 it was acknowledged within the United States of America that cigarette smoking was the most important precedent in relation to mortality and morbidity associated with emphysema and bronchitis. The current high percentage of COPD within the male population is explained by a historically higher prevalence of smoking

amongst males, however due to the rate of smoking uptake within female groups, this gap has lessened over the past half century. It would appear that the causal relationship between smoking and a history of COPD has been proved beyond dispute, however there exists some individual variance in airway remodelling secondary to smoking. This observed phenomenon would imply other significant factors impact on FEV₁ (McGraw-Hill's AccessMedicine, 2009).

For the patient the physiological and psychological burden of COPD is further exacerbated by a degree of prejudice which appears to exist within the medical profession towards those who have smoked and developed COPD. Eighty one percent of 1051 physicians agreed with the statement that COPD is a self-inflicted illness and up to 30% of clinicians were reluctant to adhere to current COPD guidelines for those patients who continued to smoke (Barr, et al., 2005). In addition, Rennard (2003) found despite the fact that the majority of smokers will develop airway impairment, doctors only formally diagnose 15-20% of COPD patients.

2.2.2 Passive or second-hand exposure to smoking

Although maternal smoking results in retarded lung development in children and the newborn infant exposed to smoke in-utero risks significant reduction in pulmonary function the impact of passive or second-hand smoking in COPD causation remains unclear. The authors suggest further research is necessary to establish, or discount, a causal link between passive smoke exposure and COPD (Celli, 2006).

2.2.3 Respiratory infection

Although respiratory infections are common causes of infective exacerbations of COPD, there appears to be no clear causal relationship between childhood and adult respiratory infections on the onset or progression of COPD. A causal relationship between respiratory infections and onset or progression of COPD is difficult to substantiate due to a paucity of longitudinal research data (McGraw-Hill's AccessMedicine, 2009). In contrast, Mannino and Buist (2007) are of the opinion that respiratory infections play an important role as a precedent for the development of COPD. The authors found respiratory infections in childhood and early adulthood may produce important structural changes and produce deleterious effects on airway responsiveness.

2.2.4 Occupational exposures and ambient air pollution

Mannino and Buist (2007) concluded in countries with lower standards of living and less stringent health and safety regulations the incidence of occupational or domestic exposure to dusts, chemicals and particulate matter assumes greater importance as a risk factor for development of COPD. In contrast, previous studies have suggested that exposure to airborne particulate such as coal dust, independent of cigarette smoking, is a risk factor for development of COPD, however research suggests this is only evident for those workers exposed to cadmium. Cadmium exposure results in decreased FEV₁, FEV₁/FVC and DLCO). This is consistent with airflow restrictions and emphysematic structural changes seen in COPD. There appears to be a causal link between prolonged exposures to smoke produced by the combustion style of cooking

prevalent in some Third World countries. This causal link is evidenced by a higher incidence of COPD amongst the female population of these countries (British Thoracic Society, 1997; Celli, 2006; McGraw-Hill's AccessMedicine, 2009).

2.2.5 Genetic considerations

It is estimated that 1:300 persons within the United States of America inherit a severe alpha 1 antitrypsin deficiency. Between 1-2% of COPD patients demonstrate a severe deficiency which in turn puts them at a greater risk of developing early onset COPD. Despite the incidence of Alpha 1 antitrypsin deficiency diagnostic testing is rarely undertaken. Fifty percent of generalist physicians and 37% of respiratory specialists report they perform the test infrequently (Barr, et al., 2005; Celli, 2006). Despite a comprehensive literature search, statistical information on the New Zealand population incidence of alpha 1 antitrypsin deficiency appears somewhat lacking.

2.3 Diagnosis and staging

COPD should be considered in all individuals who report symptoms which include any two or more of the following: chronic sputum production, chronic cough, shortness of breath at rest or on exertion, or a history of any current and/or previous exposures to occupational pollutants and passive and active smoking. It is suggested that individuals may under-report the degree to which they are affected by dyspnoea as they are inclined to subconsciously reduce their level of activity

to lessen the impact of their symptoms. Literature found that up to 20% of individuals with diagnostically confirmed severe airway impairment will present symptom free and/or deny any current symptoms (Rennard, 2009).

In 2006 in the United States of America, COPD was the fourth leading cause of death and by 2020 COPD will be ranked third worldwide in mortality causation (Celli, 2006). Despite this high prevalence, COPD has the potential to be under-diagnosed and there is a potential that fewer than half of affected individuals have a formal diagnosis. The origins of the low percentage of formal diagnosis are possibly twofold with patients themselves under-presenting and under-reporting the magnitude of their symptoms. The patients also potentially accept the impact and overall symptomology and limitations of the disease as rationalisable secondary to their smoking history (Celli, 2006).

Pulmonary function testing is the mainstay of COPD diagnosis and encompasses tests such as spirometry which provides readings such as FEV₁ and FVC. A FEV₁/FVC ratio of less than 70% predicted is considered the level at which, in combination with COPD compatible symptoms, a diagnosis of COPD is considered. Pulmonary function testing provides other important lung function assessments including inspiratory capacity, vital capacity, total lung capacity, functional residual capacity and residual volume which can be indicative of the hyperinflation evident in COPD. The FEV₁/FVC ratio is employed to provide staging of the severity of the individual's disease (Rennard, 2009).

Some literature is critical of the limitations of this method of severity staging and recommend implementation of the BODE index. The BODE index encompasses aspects of airway obstruction (FEV₁), body mass index, the Medical Research Council dyspnoea score and the six minute walk test which serve to address the importance of extra pulmonary manifestations on the severity of disease impact. The BODE index can also be used to assess therapeutic response and is depicted in Table 2.2. Adjuncts to COPD diagnosis include physical examination, medical imaging and ABG analysis (Rennard, 2009).

Table 2.2: The BODE index score

BODE Index Scoring				
Variable	Points			
	0	1	2	3
FEV ₁ (% predicted)	≥65	50-64	36-49	≤35
Walk distance in 6 min (m)	≥350	250-349	150-249	≤149
MMRC dyspnea scale	0-1	2	3	4
Body mass index	>21	≤21		

MMRC=Modified Medical Research Council.
Celli et al. *N Engl J Med.* 2004;350:1005-1012.

From: “The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease,” by Celli, et al., 2004, *The New England Journal of Medicine*, 350, p. 1007). 2004. Reprinted with permission.

Table 2.3 depicts COPD severity staging using FEV₁/FVC percentages.

Table 2.3: Staging of COPD

Stage	Characteristics
I: Mild COPD	FEV ₁ /FVC <70% FEV ₁ > 80% predicted
II: Moderate COPD	FEV ₁ /FVC <70% 50% < FEV ₁ < 80% predicted
III: Severe COPD	FEV ₁ /FVC < 70% 30% < FEV ₁ < 50% predicted
IV: Very Severe COPD	FEV ₁ /FVC < 70% FEV ₁ < 30% predicted or FEV ₁ < 50% predicted plus chronic respiratory failure

FEV₁: Forced expiratory volume in one second; FVC: Forced vital capacity; respiratory failure: arterial partial pressure of oxygen (PaO₂) less than 60mm Hg (8.0 kPa) with or without arterial partial pressure of CO₂ (PaCO₂) greater than 50 mm Hg (6.7 kPa) while breathing air at sea level.

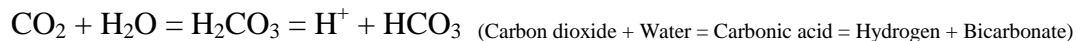
From: *Global Initiative for Chronic Obstructive Lung Disease, Global strategy for the diagnosis, management and prevention of chronic obstructive pulmonary disease* (p. 3), by Global Initiative for Chronic Obstructive Lung Disease, 2006, Spain: Author. Reprinted with permission.

2.4 Oxygen therapy in COPD

Adequate oxygenation at a cellular level is essential to maintain the homeostatic balance of the human body and to facilitate the functions necessary to enable human life. Atmospheric oxygen is inhaled via the conducting airways to the lungs where it is absorbed by gaseous exchange into the bloodstream and transported to the site/s of demand including the organs, bones and muscles. Oxygen is necessary to meet the aerobic respiratory needs of the body's cells during oxidative metabolism. Oxidative metabolism supplies 90% of the body's energy needs. Carbon dioxide is produced as a by-product of this pathway along with the energy produced and requires excretion to maintain homeostasis. COPD has the potential to adversely affect gaseous exchange through a decrease in alveolar ventilation secondary to hypoxemia and hypercapnia (Porth, 2005, p. 790).

Figure 2.2 illustrates the acid base buffering system necessary to maintain homeostasis in the human body.

Figure 2.2: Acid and base buffer equation



Adapted from: *Pathophysiology: Concepts of altered health states (7th ed.)* (p. 790), by C. M. Porth, 2005, Philadelphia: Lippincott Williams & Wilkins.

Oxygen was originally discovered in August 1774 by a chemist named Joseph Priestley.

Priestley heated red mercuric oxide and obtained a colourless gas which he termed

“*dephlogisticated air*”. Priestley and two mice were the first living creatures to breathe this gas and Priestley remarked on the “light and easy feeling” experienced post inhalation. Oxygen was also discovered by a German chemist named Carl Wilhelm Scheele whom some believe may have made the important discovery in 1773, a year earlier than Priestley. Oxygen was given its name by Antoine Lavoiser (a friend of Priestley’s) who had repeated the original experiments.

Oxygen was first used clinically in 1868 during a dental procedure and for the treatment of bacterial pneumonia in 1885, in the United States of America. Dr George Holtzapple heated chlorate of potassium and black oxide of manganese and the oxygen produced was piped to the patient via a length of rubber tubing. The piped oxygen was considered to have assisted the patient’s recovery. Albeit efficacious, piped oxygen was considered cumbersome and to alleviate this problem around the beginning of the 20th century, the first nasal cannula delivery device was introduced. Within quick succession followed the advent of alternative devices which offered the

patient, and the clinician, a choice of means by which to deliver the desired oxygen therapy (Petty, McCoy, & Doherty, 2006).

In 1922 Alvan Barach considered the widespread use of oxygen may have been hampered by an absence of a means by which to acceptably and comfortably deliver the therapeutic oxygen dosage (Barach, 1922). In 1922 the mode of delivery was by way of a tube and funnel resulting in the delivery of 2% of oxygen however, Barach remained convinced that a small degree of patient discomfort and inconvenience were superseded by the important and clearly evident gains in physical wellbeing. Barach describes the use of oxygen chambers in England to treat the soldiers exposed to poisonous gases and noted that the “results constitute an instance in which effective treatment with oxygen accomplished definite improvement and cure” (p.1). Barach also identified the detrimental effects of “acute anoxemia” and suggested that these harmful manifestations were able to be effectively treated with oxygen therapy, resulting in markedly reduced morbidity and mortality. This remains the ultimate aim of contemporary oxygen therapy as espoused by all seminal literature and guidelines to date.

In the mid 1950s, Barach devised and promoted the use of ambulatory oxygenation systems to improve the patient’s ability to participate in activities of daily life (Barach, 1959). Barach was the first person to systematically and purposely treat pneumonia utilising oxygen therapy via an oxygen tent system. The oxygen tent was originally developed by Leonard Hill. By 1955, 860 patients in Wales and Monmouthshire regions (pop 2.6 million) were receiving oxygen (via cylinders) prescribed by Barach and two other doctors namely, Cotes and Gilson. Barach died in 1976 and has been credited as the foremost authority driving the development of oxygen therapy

and systems, and for highlighting the therapeutic value of LTOT (Barach, 1959; Petty, et al., 2006).

In 1965, the Linde Corporation produced the first commercially available liquid oxygen systems. At the same time, the Denver Group recruited six patients in order to study the physiological effects of supplemental oxygenation on their pre-existing pulmonary hypertension, polycythaemia and severely limited exercise tolerance. The six patients were subject to a one month control period during which physical and physiological functioning were maximised utilising pharmacotherapeutics, including antibiotics, if indicated. The patients were also provided with a high calorie diet and graduated exercise programmes to increase overall exercise tolerance. Baseline measurements including pulmonary artery pressure, pulmonary vascular pressures and cardiac output were obtained from each of the patients, at the end of this initial one month period. Throughout the next four weeks the study group were maintained on the high calorie diet, exercise and medication regime, with the addition of supplementary oxygenation to maintain the individual's oxygen saturations above 90% at rest and on exertion (Petty, et al., 2006).

At the end of the second month, baseline measurements were repeated and the resultant recordings showed dramatic reductions in pulmonary vascular resistance and pulmonary artery pressures in four of the study group. The four participants also showed a dramatic increase in overall exercise tolerance. One of these four participants became the first Denver home oxygen patient and the improvements in his quality of life and physical functioning have been reported in literature (Petty, et al., 2006).

In 1968 the Denver group followed 20 patients with moderate to severe COPD who were receiving long-term (up to 18 months duration) liquid portable ambulatory oxygen and documented evidence of physiological improvements. The improvements included a marked decrease in right ventricular size and cor pulmonale and an improvement in electrical functioning of the heart. The study also highlighted evidence of a dramatic decrease in individual patient's hospitalisations which the Denver Group attributed to the prescription of LTOT. Meanwhile in the United Kingdom, researchers were concerned with ascertaining the amount of oxygenation necessary to effectively decrease the degree of pulmonary hypertension in COPD patients. The studies concluded that some patients exhibited an improvement in the severity of their pulmonary hypertension with between 12-15 hours of oxygenation (Petty, et al., 2006).

The United States of America Nocturnal Oxygen Therapy Trial [NOTT] (1980) and the Medical Research Council Clinical Trial [MRC], 1981 United Kingdom, were two major randomised clinical trials aiming to investigate the potentially positive physiological effects of nocturnal oxygen therapy (NOT) or continuous oxygen therapy (COT) and LTOT respectively (Petty, et al., 2006). The NOTT conducted a six centre study which enrolled 203 patients with hypoxemic COPD who were followed for a period of 12 months (mean 19.3 months). The patients were randomly allocated to two study cohorts. One group received continuous oxygen therapy and the other group received nocturnal oxygenation. Each group's oxygenation was delivered via a nasal cannula device titrated in whole litres per minute to maintain PaO₂ (Resting arterial) between 60-80mmHg. The minimum allowable increase in resting arterial PaO₂ was 6mmHg. The systems used to deliver the oxygen varied and included oxygen concentrators, compressed gas (stationary and portable) and liquid portable oxygen tanks. Over the duration of the study, 64 patients died

(41 = nocturnal oxygen, 23 = continuous oxygen) with the overall conclusion that mortality was halved in the cohort receiving continuous oxygen therapy when compared to the nocturnal therapy group. Another important finding was that in the more severely unwell patients with the largest reported impairments in brain, lung and psychological (cerebral, respiratory) function, the greatest improvements were noted (Nocturnal Oxygen Therapy Trial Group, 1980).

The MRC multicentre trial was the first controlled LTOT trial which enrolled participants with cor pulmonale secondary to chronic bronchitis and/or emphysema. Strict inclusion criteria ensured all the participants were diagnosed with irreversible chronic obstructive airways disease. The MRC Working Party enrolled 87 participants (all under 70 years of age) and then randomised them to two groups. The first group received oxygenation via a nasal cannula for at least 15 hours per day and the second (control) group did not receive oxygen therapy. The oxygen flow rate was usually two litres per minute or if necessary a higher flow rate in order to achieve a PaO₂ of > 60mmHg and was delivered to the patient for a period of up to five years (Medical Research Council Working Party, 1981).

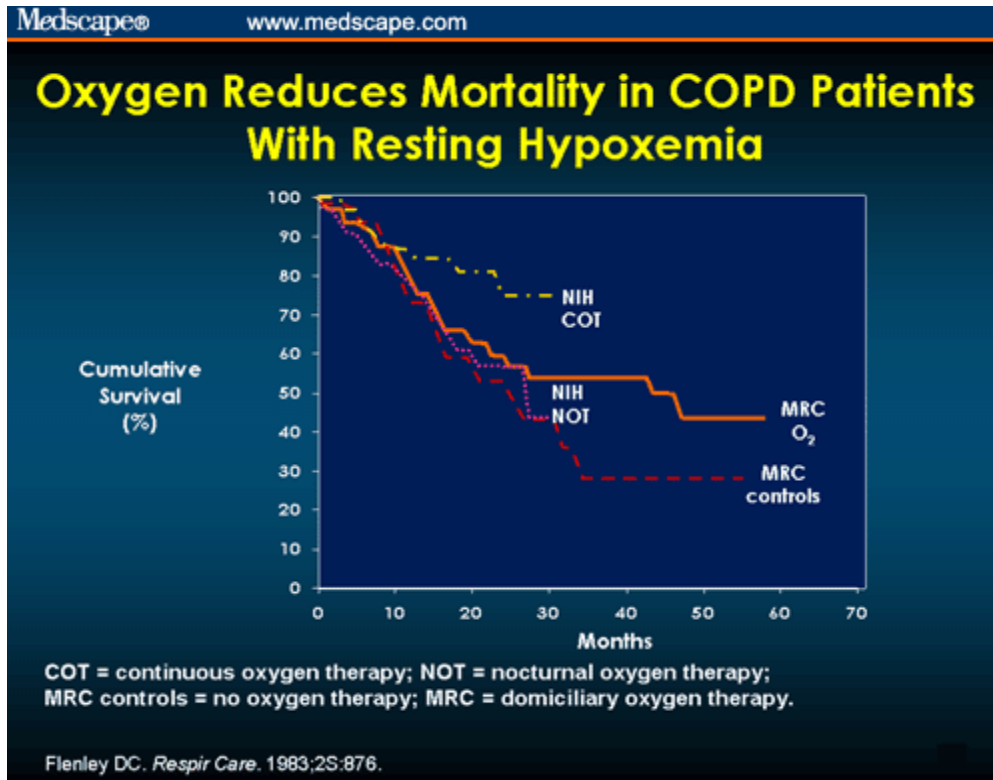
Findings promote the therapeutic value of correction of nocturnal hypoxemia in an effort to prevent the development of cor pulmonale associated with pulmonary hypertension however, interestingly, the results did not support the value of LTOT to effect a reduction of existing pulmonary hypertension. The study also highlighted that for the male population the therapeutic benefits of LTOT appear to be delayed, in that a decrease in overall mortality only became evident after 500 days of continuous LTOT therapy whereas, the females in the treatment group exhibited an immediate reduction in mortality. The research group remain unclear as to the

reasons for this finding and suggest that males may potentially die before the benefits of LTOT are fully established and realised. The study findings suggest LTOT potentially offers greater benefits for women, when compared to the male population, and overall LTOT appears to be a safe and effective treatment for the population group with “hypoxic cor pulmonale, with CO₂ retention, and secondary polycythaemia due to chronic bronchitis and emphysema” (Medical Research Council Working Party, 1981, p. 685).

Other clinically important, non-objective findings included self-reported improvements in the participant’s level of holistic wellbeing. Despite the ability of the researchers to demonstrate physiological improvements there was no apparent decrease in the study group’s rate of hospitalisations. This finding could be explained by the close and vigilant surveillance afforded to the participants. The study participants reported marked improvements in their overall sense of wellbeing, with discernable improvements in their ability to participate in the activities of daily living in conjunction with increased social mobility. The participants reported improved appetites and increased physical mobility and although not quantifiable, these self-reports highlighted the psychological and physical improvements as a result of LTOT (Medical Research Council Working Party, 1981; Nocturnal Oxygen Therapy Trial Group, 1980).

Figure 2.3 depicts the overall combined evidence in improvement in mortality and survival as highlighted by the MRC and NOTT trials.

Figure: 2.3: Mortality and survival as highlighted by MRC and NOTT



From: “Long term oxygen therapy – state of the art,” by Flenley, 1983, *Respiratory Care*, 28, p. 877. (American Association for Respiratory Care), 1983. Reprinted with permission.

In an attempt to maximise patient outcomes and to reduce the associated fiscal burden of COPD international and national guidelines have been developed to guide management.

Contemporary seminal literature and guidelines include publications such as (British Thoracic Society, 1997; Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2006; National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009; Petty, et al., 2006) all of which promote the use of LTOT for the therapeutic management of COPD based on the two groundbreaking trials detailed

previously. The guidelines' variances in recommendations and parameters for prescription of LTOT will be highlighted individually.

The BTS guidelines usually recommend patients with “COPD who have a PaO₂ of < 7.3kPa, with or without hypercapnia, and an FEV₁ of < 1.5 litres, should receive LTOT. If the PaO₂ is between 7.3 and 8.0 kPa and there is evidence of pulmonary hypertension, peripheral oedema or nocturnal hypoxemia, LTOT should be considered” (p. S14). The guidelines conclude that LTOT should be delivered for at least 15 hours per 24 hour period and provided by an oxygen concentrator with portable cylinders as a back-up option. Portable oxygen cylinders are the only form of ambulatory oxygen currently available in the United Kingdom (British Thoracic Society, 1997).

The GOLD Guidelines (2006) found that oxygen therapy is one of the most important non-pharmacological interventions for those COPD patients with disease classified as very severe. The guidelines state that “the primary goal of oxygen therapy is to increase the baseline PaO₂ to at least 8.0 kPa (60mmHg) at sea level at rest, and/or produce an SaO₂ at least 90%, which will preserve vital organ function by ensuring adequate delivery of oxygen” (p. 58). The authors recommend LTOT should be used for at least 15 hours per day and preferably longer, with an aim of improving the physical and psychological wellbeing of patients. They also conclude that LTOT is the most expensive component in the treatment of the COPD outpatient and recommend the use of oxygen concentrators provides the most cost efficient means of LTOT delivery (Global Initiative for Chronic Obstructive Lung Disease, 2006).

The NICE guidelines (2004) suggest LTOT is “indicated in patients with COPD who have a PaO₂ less than 7.3 kPa when stable or a PaO₂ greater than 7.3 and less than 8 kPa when stable and one of: secondary polycythaemia, nocturnal hypoxemia (oxygen saturation of arterial blood [SaO₂] less than 90% for more than 30% of time), peripheral oedema or pulmonary hypertension” (p. 19). The NICE guidelines extend this recommendation to suggest groups of patients who require further assessment for LTOT including those patients presenting with some or one of the following. Namely, moderate to severe airflow obstruction (FEV₁ 30-49% predicted and FEV₁ less than 30% predicted), patients with cyanosis, polycythemia, peripheral oedema, elevated jugular venous pressure, and patients with a SpO₂ less than or equal to 92% whilst breathing room air. The authors suggest the use of LTOT for at least 15 hours per day with the potential for greater benefits in those patients who receive oxygenation for 20 hours per day (National Institute for Clinical Excellence, 2004).

The COPDX (2006) guidelines suggest “long-term continuous oxygen therapy (at least 15 hours a day) is appropriate for patients who have a PaO₂ consistently < 55mmHg (7.3 kPa; SpO₂ 88%) when breathing air, at rest and awake [evidence level 1]” (p. 40). “Polycythaemia (haemoglobin level > 170g/L), clinical or electrocardiographic evidence of pulmonary hypertension, as well as episodes of right heart failure, are consistent with the systemic effects of chronic hypoxemia, and long-term continuous oxygen should be supplied if the stable PaO₂ is 55-59 mmHg (7.3-7.9 kPa; SpO₂ < 90%). Continuous oxygen therapy is of most benefit for patients with increased arterial PaCO₂ (> 45mmHg, or 6 kPa)” (p. 40). The authors concur that LTOT for more than 15 hours per day prolongs life and reduces mortality in COPD. The authors stipulate that the LTOT patient must have stopped smoking at least one month prior to the introduction of oxygen

therapy. They also recommend that due to the costs incurred with LTOT, it should only continue to be administered to those patients who demonstrate an obvious benefit from the treatment provided (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

At a more local level, the Canterbury District Health Board's 'Blue Book'¹ (2005) suggests LTOT should be instigated for between 16-24 hours per day in those COPD patients who have a $\text{PaO}_2 < 55\text{mmHg}$ or a PaO_2 of 55-60mmHg with signs of polycythaemia, cor pulmonale, or pulmonary hypertension. The overall aims of LTOT involve the correction of hypoxemia whilst avoiding or minimising the risk of CO_2 retention. Another aim is the reduction of right sided heart failure and a reduction in the degree of polycythaemia evident, thus enhancing overall survival rates. The authors suggest LTOT may prevent nocturnal desaturations whilst improving the patient's sleep quality with an overall improvement in quality of life experienced by LTOT recipients. Other important considerations include an improvement in the patient's neuropsychological status and sense of wellbeing and very importantly, a reduction in health costs and associated fiscal burden (Beard, 2005).

The aims of the "Blue Book" directly correlate with the findings of the two seminal studies namely, the MRC and NOTT, which highlight the psychological and physiological benefits of LTOT (Medical Research Council Working Party, 1981; Nocturnal Oxygen Therapy Trial Group, 1980). In contrast, controversy exists as to the potential for detrimental effects as a result of LTOT. A review undertaken in 2008 suggests that an increased risk of hypercapnia as a result

¹ The Canterbury District Health Board 'Blue Book' is a copyrighted, edited publication which provides evidence based guidelines on which to base the clinical management of several common medical conditions.

of LTOT is a consideration already recognised, however the review highlights the potential for LTOT to accelerate the risk of cellular damage through oxidant injury. The review considers further research is necessary to identify the potentially damaging and toxic effects of injudiciously implemented LTOT and highlights the need to identify appropriate LTOT recipients utilising optimal screening processes (Kim, Benditt, Wise, & Sharafkhaneh, 2008).

2.5 Modes of oxygen delivery and oxygen technologies

Prior to the 1970s, early LTOT consisted of a supply of several large and cumbersome industrial oxygen cylinders with permanent humidification attached to promote improved patient comfort. As the LTOT recipient was typically end-stage and bed-bound, the need for ambulatory oxygen was negated. During the late 1970s, the contemporary oxygen concentration unit was developed resulting in decreased costs and increased convenience for both the supplier and the recipient of the oxygen. Failing electrical or mechanical breakdown, the LTOT patient was guaranteed a continuous supply of oxygen. Portable oxygen tanks were made available to enable the rare ambulate patients to leave the house for brief periods of time, to attend to activities of life. Liquid oxygen was developed and grew in popularity as the patients, for whom LTOT was prescribed, became less end-stage and more ambulant and better able to enjoy the benefits and freedom (lightness and increased delivery time) that liquid oxygen afforded (Petty, et al., 2006).

Liquid oxygen systems conserve space by converting the oxygen into a liquid form which takes up less volume. Liquid oxygenation gained in popularity as the physiological and psychological

benefits of the optimisation of LTOT became more evident and the patients' desire to continue to perform their usual activities of daily life increased. Over the past two decades two important changes in the prescription of LTOT have become evident. Younger LTOT patients, with early disease symptomology, are becoming increasingly prevalent and as such LTOT delivery devices are being developed to meet their desire to continue regular activity within and outside of their home. Steel cylinders have been replaced with aluminium along with a reduction in cylinder size from E (680 litres) to M (140 litres). Oxygen conserving devices have produced a 3:1 savings ratio enabling the LTOT patient to enjoy up to four hours of mobility with a flow delivery of two litres per minute (Petty, et al., 2006).

LTOT comes under the umbrella of domiciliary oxygen, the delivery and prescription of which is tailored to the individual patient. Domiciliary oxygenation encompasses long-term maintenance therapy, namely LTOT, short-burst oxygenation for acute exacerbations and periods of exertion and ambulatory oxygenation to enable the patient to remain independently and socially mobile (Lynes & Kelly, 2009). The COPDX guidelines suggest LTOT may be delivered by three differing methods all of which demonstrate equivalence in efficacy. The authors highlight the use of portable cylinders with the addition of oxygen conservation devices, stationary oxygen concentrators and liquid oxygen systems which possess the capacity to be refilled as needed (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

2.5.1 Ambulatory oxygen

Nationally, and at a local level there appears to be a minority of LTOT patients who utilise ambulatory oxygen systems. At a local level, approximately three quarters of patients utilising LTOT are supplied with small portable oxygen tanks to enable them to leave the home and participate in activities within the community (M. Gluyas, personal communication, April 27, 2010). In 1922, Barach highlighted the benefits of some form of ambulatory oxygen delivery to improve the patient's exercise tolerance and to assist the patient to leave the house to better enjoy and maximise the activities of daily living (Barach, 1922).

Interestingly, the Canterbury District Health Board's "Blue Book" mentions ambulatory oxygen within the section detailing LTOT and then offers no further elaboration beyond a recommendation that portable oxygen must be approved by a respiratory physician (Beard, 2005). The COPDX guidelines mention ambulatory oxygen therapy and consider benefits are most evident when implemented intermittently for those patients who experience exertional desaturations. The authors suggest that contemporary evidence does not conclusively support the use of long-term ambulatory oxygen therapy in COPD however, due to the remoteness of many areas in New Zealand, the ability to utilise intermittent or ambulatory oxygenation may prove advantageous in emergency situations (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

The GOLD guidelines briefly mention ambulatory oxygenation with a declaration that conclusive evidence remains lacking and that to maximise the benefits of ambulatory

oxygenation, patients require appropriate education regarding its use (Global Initiative for Chronic Obstructive Lung Disease, 2006). In contrast, the NICE guidelines devote a full page to guiding the use of ambulatory oxygen therapy and suggest that those LTOT patients who experience exercise desaturation and then demonstrate an improvement in exercise capacity via ambulatory oxygenation should have this prescribed (National Institute for Clinical Excellence, 2004). The BTS guidelines detail the use of ambulatory oxygenation and suggest the use of portable oxygenation may enhance the patient's adherence to and hourly period of LTOT and can improve exercise tolerance (British Thoracic Society, 1997). A New Zealand study explored the benefits of ambulatory and training oxygenation and concluded that ambulatory oxygen is useful for those patients already receiving LTOT and who wish to remain mobile and able to leave the house when desired. Liquid oxygen is another form of ambulatory oxygen however, this is not available in New Zealand (Young, 2005).

2.5.2 Stationary oxygen

Nationally the predominant delivery system for LTOT is the oxygen concentrator which consists of a large sized (14-15kg), electrically powered unit which has the ability to concentrate atmospheric air into oxygen. This oxygen is then filtered and delivered to the patient via low-flow (usually 2 Lpm) and nasal cannulas. Some home-based concentrator units have the ability to fill portable cylinders and this is managed by the patient within their home environment. According to M. Gluyas (personal communication, September 29, 2009) this application, although available, is not widely used within New Zealand potentially due to cost and safety

considerations. The oxygen concentrator units used within the Canterbury District Health Board are Millennium (brand name), and more recently Respironics (brand name), at a cost of \$1260 per unit. The units require minimal maintenance with a filter change annually and the units are usually flow-governed at the prescribed flow rate in order to ensure safe oxygen delivery and minimise patient involvement and/or interference. The supply of LTOT is not means tested and is available free of charge long-term for those patients who qualify for LTOT therapy (M. Gluyas, personal communication, September 29, 2009). The only restriction imposed is the cessation of smoking at least one month prior to the commencement of LTOT (Canterbury DHB, 2006).

At a local level, the education of LTOT patients regarding their oxygen concentrators is usually offered by the maintenance team in the patient's own home on the day of discharge. The district nursing team then provides a follow-up visit in the evening to ensure the patient and their family is comfortable and competent with the use of the concentrator. The concentrator unit, which constantly emits a low volume sound, is usually placed in an adjacent room to the patient's bedroom and the patient is supplied with enough oxygen tubing to permit relatively unfettered mobilisation around their dwelling (M. Gluyas, personal communication, September 29, 2009).

2.5.3 Nasal cannula

Due to the low-flow nature of oxygen delivery via the concentrator unit, the nasal cannula is deemed the least invasive and most appropriate oxygen delivery device. The nasal cannula

consists of tubing which can be extended to allow the patient to mobilise throughout the house whilst continuing to wear the cannula. The cannula permits the patient to eat and drink and converse more freely without having the physical barrier presented by a facemask. The cannula has two small tubes which fit inside the patient's nostrils and soft thin tubing which hooks around the patient's ears. The nasal cannula is usually run at flow rates between 0.25-4 Lpm and delivers between 24-36% oxygen. Due to the high variability of ambient inspired air, as a result of the patient's ventilatory pattern, the oxygen percentage is very sensitive and inversely proportional. For example, the less respiratory effort the higher the fractional concentration of oxygen delivered (FiO_2). For flow rates below 1 Lpm a low flow oxygen meter or regulator is recommended and flow rates above 4 Lpm are not recommended secondary to an increased risk of nasal dryness and irritation (Canterbury DHB, 2006).

The OxyArm (OA) patented by (Southmedic Inc, Canada) is considered an alternative to the nasal cannula and equivalent in provision of oxygenation and maintenance of saturation levels. The OxyArm is described as a minimal contact oxygen delivery device which consists of a headset with a rigid ambidextrous boom able to deliver oxygenation to those patients who may find the nasal cannula anxiety producing or damaging to the nares (Canterbury DHB, 2006; Paul & Otvos, 2006).

2.5.4 Transtracheal

The GOLD (2006) guidelines mention the transtracheal mode of oxygen delivery however, the guidelines advise it is a specialised application and should only be implemented in areas where expertise is available to monitor and adjust the oxygenation. Transtracheal delivery involves the delivery of oxygenation directly into the trachea completely bypassing the nasal and oral cavities. The advantages of transtracheal oxygen delivery include more accurate oxygen delivery and a potential reduction in the work of breathing, and although more invasive, patient acceptance appears high (Global Initiative for Chronic Obstructive Lung Disease, 2006; Tiep & Carter, 2007; Tiep & Carter, 2008).

2.5.5 Venturi

The venturi (variable concentration mask) mask consists of a face mask with a trunk-like extension to which entrainment ports are connected. The ports permit extremely accurate titration of oxygen percentages delivered to the patient by allowing a precise dilution of oxygen by mixing with room air. The venturi mask should be the initial mask of choice for COPD patients during an acute exacerbation and the 24% port should be used initially if there is a possibility of CO₂ retention. In New Zealand, blue and white ports are available and when driven by the recommended oxygen flow rate, deliver percentages of oxygen 24%-55%. The venturi mask is capable of delivering controlled oxygenation, however the use of blood gas analysis is

still advised to ensure the controlled percentage is adequate for the patient's current presentation (Beard, 2005; Canterbury DHB, 2006).

2.6 Acute and short-term oxygen therapy

Short-term oxygen therapy [STOT] may be deemed more appropriate than LTOT for a particular group of COPD patients, especially after an acute exacerbation of their illness. Literature stipulates that criteria varies between assessments for STOT and LTOT following an acute exacerbation and recommend for PaO₂ levels between 50-55mmHg a waiting period of one to three months should be instigated before an assessment for LTOT is completed (Canterbury DHB, 2006). For those COPD patients with a PaO₂ of less than 50mmHg the authors advise a four week period of STOT may be indicated with a reassessment at the end of this period. The guidelines recommend “a single ABG measurement of PaO₂ is not a sufficient indicator for LTOT” (p. 247) and recommend all COPD patients considered as potential candidates for LTOT should have a repeat post acute ABG (on room air) within 48 hours of discharge. If the patient's room air resting PaO₂ is less than 55mmHg, the patient should be placed on oxygenation at 1 Lpm and the ABG measurement repeated. The aim is to titrate the oxygenation to the lowest possible flow rate which is sufficient to achieve a PaO₂ of 55mmHg or greater (Canterbury DHB, 2006).

Interestingly a Chinese study involving 17 participants argues the current static measurement of PaO₂ in order to prescribe LTOT, may be inadequate and recommend continuous oxygen

monitoring, utilising pulse oximetry, may have the potential to provide a more accurate prescription of oxygenation. The authors argue within the outpatient setting, continuous pulse oximetry measurement is a cost effective, therapeutically effective and feasible method of prescribing LTOT (Zhu, et al., 2005). A study by Gustafson, Lofdahl and Strom reiterates the need to reassess the patient's suitability for LTOT if the oxygen therapy was commenced during an acute exacerbation of the disease. The authors argue their study highlighted the lowered survival rate for patients commenced on LTOT during an acute exacerbation and recommend a more accurate prescription of LTOT (Gustafson, Lofdahl, & Strom, 2008). A 2007 review of drugs (including oxygen) in COPD considers the purported benefits of short-burst oxygen therapy have been disproven and hence this form of oxygenation in COPD is not recommended. In contrast, the treatment of hypoxemic COPD patients with LTOT has proven outcomes and indications, however the authors suggest doubt persists regarding the appropriate use of LTOT (Albert & Calverley, 2007).

2.7 Debate

Several authors have produced literature and studies which highlight the ongoing controversy regarding the most therapeutically correct percentage and oxygen delivery mechanisms, particularly during an acute exacerbation of COPD (Plant, et al., 2000). Although this study is focussing on the patient's experience of LTOT, the management of acute exacerbations is an important aspect of ongoing and complementary oxygen therapy and may have the potential to be lifesaving. Commentators suggest for those patients with a history of COPD maintaining the

SaO₂ between 87-92% is a “safer approach” than attempting to deliver higher concentrations of oxygenation in order to maintain “disproportionally” elevated oxygen saturations (Joosten, Koh, Bu, Smallwood, & Irving, 2007; Plant, et al., 2000). In contrast, several studies suggest many medical professionals afford too much consideration to the small percentage of COPD patients at risk of hypercapnia at the expense, or risk, of keeping the greater percentage of patients within levels of oxygenation considered to be hypoxic (Feller-Kopman & Schwartzstein, 2008; Murphy, Driscoll, & O'Driscoll, 2001; National Institute for Clinical Excellence, 2004).

2.8 Monitoring in COPD

Monitoring in COPD includes aspects of objective measurement including: spirometry, ABG analysis, and the use of non-invasive pulse oximetry. Oxygen prescription and monitoring of the patient's adherence to their prescription is an important aspect of monitoring and serves to enhance the therapeutic benefits of LTOT. Smoking cessation advice and constant reinforcement is considered the most important aspect of monitoring. The importance of action planning as a form of monitoring and management will be addressed in Chapter five.

2.8.1 ABG analysis

The nasal cannula is the most widely used mode of LTOT delivery in New Zealand (Canterbury DHB, 2006) however, the GOLD guidelines suggest due to the potential wide variability of FiO₂

delivered by the nasal cannula, additional ABG analysis should be performed in order to accurately titrate a satisfactory level of individual oxygenation (Global Initiative for Chronic Obstructive Lung Disease, 2006). ABG analysis involves the puncture of the radial artery and aspiration of approximately 3ml of blood for analysis. The sample is analysed for many levels including acid base status, namely pH, pCO₂, pO₂, HCO₃, and base excess. These measurements provide an accurate indication of the patient's metabolic and respiratory status and are an important indicator of deterioration or improvement.

The COPDX (2006) guidelines recommend ABG analysis should be undertaken in all COPD patients with severe disease “those being considered for domiciliary oxygen therapy (e.g., whose FEV₁ is < 40% predicted or < 1L, whose oxygen saturation as measured by pulse oximetry [SpO₂] is < 92%), those with pulmonary hypertension, and those with breathlessness out of proportion to their clinical status). Respiratory failure is defined as a PaO₂ < 60mmHg (8kPa) or PaCO₂ > 50mmHg (6.7kPa). The latter is termed “ventilatory failure” and is accompanied by either compensated (chronic) or uncompensated (acute) acidosis. Acute respiratory acidosis indicates a need for assisted ventilation” (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009, p. 49). The Gold (2006) guidelines indicate although pulse oximetry is useful to determine and evaluate a patient's level of oxygenation and oxygenation requirements, ABG analysis is necessary and definitive to ascertain the degree of severity of an acute exacerbation. “A PaO₂ < 8.0 kPa (60mmHg) and/or SaO₂ < 90% with or without PaCO₂ > 6-8 kPa, 45-60mmHg) in a patient with respiratory failure is an indication for mechanical ventilation” (Global Initiative for Chronic Obstructive Lung Disease, 2006, p. 63).

Despite the predominance of ABG analysis to initiate and assess the efficacy of LTOT, a growing number of studies highlight the use of capillary sampling as a less painful, less invasive and equally accurate procedure to obtain the necessary blood gas levels (Dar, Williams, Aitken, Woods, & Fletcher, 1995; Pitkin, Roberts, & Wedzicha, 1994; Yildizdas, Yapicioglu, Yilmaz, & Sertdemir, 2004). Due to the close proximity of nerves, veins and arteries within the anatomical region deemed appropriate for ABG puncture, the procedure is not without risk and a skilled practitioner is paramount to ensure patient safety. Despite the skill of the practitioner, the procedure remains a traumatic and painful experience and may in some cases result in a reluctance to attend hospital for treatment. This non-attendance has the potential to be catastrophic for the patient especially in an acute exacerbation of recurrent respiratory illness (Dar, et al., 1995).

Within contemporary practice and at a local level, the initiation of LTOT is determined by two main forms of measurement, namely ABG analysis and pulse oximetry. These tests may be performed at rest or shortly after a period of exertion in an attempt to provide an optimal level of oxygenation (Canterbury DHB, 2006). A study undertaken in 1999 highlighted the potential for error in oxygenation utilising these methods and the authors argue that the clinical setting assessment fails to capture the potential for desaturation experienced by LTOT patients when performing their usual activities of daily living within their own environment (Pilling & Cutaia, 1999).

Medical professionals and international and national guidelines have highlighted the importance of oxygen saturation level monitoring and the measurement of ABG to guide the application and

usage of supplemental oxygenation, including LTOT. These levels are considered objective and measureable however, despite the lack of objectivity and reliance on subjective reports, 51% of primary care physicians and 10% of respiratory specialists considered symptoms were an additional indication for the implementation of oxygen therapy (Barr, et al., 2005).

Controversially, a study undertaken in Italy suggests in acute exacerbations of COPD ABG analysis is not routinely undertaken, resulting in inappropriate oxygenation or conversely inappropriate withholding of oxygen (Antonelli Incalzi, et al., 2002).

2.8.2 Pulse oximetry

Pulse oximetry is a quick, simple to use, alternative to ABG measurement and an alternative means by which to objectively measure a patient's SpO₂. Pulse oximetry involves the use of technology which uses an infrared light beam to assess the amount of haemoglobin which is carrying oxygen molecules and then provides computerised LED reports to enable visual assessment. A probe is attached to the patient's finger or earlobe and this probe is able to emit light in two wavelengths (605nm and 805nm). The oximeter then calculates the difference between haemoglobin absorption at the two wavelengths thus providing a percentage of saturated haemoglobin (Fearnley, 1995).

Pulse oximetry is cost effective, non-invasive, and portable and provides an immediate means by which to monitor a patient's oxygenation. There are limitations to its use and accuracy and these are particularly evident in cases of hypovolaemia, hypotension, shivering, and some cardiac

arrhythmias. Most importantly, for those patients with respiratory failure, oximeters cannot provide information regarding the blood levels of CO₂. Pulse oximetry does not have the capability to distinguish between carboxyhaemoglobin and oxyhaemoglobin and will report an inaccurate percentage of oxygenated haemoglobin with obvious implications for practice and LTOT monitoring (Fearnley, 1995).

2.8.3 Smoking cessation

Smoking cessation is considered the most important factor in COPD monitoring and management and the GOLD guidelines suggest even those patients with existing COPD may benefit from smoking cessation. Potential and proven benefits include the prevention, or retardation, of airflow obstruction, and a potential degree of reduction of disease progression (Global Initiative for Chronic Obstructive Lung Disease, 2006). For those patients with early mild disease processes, smoking cessation has been shown to reduce the degree of long-term mortality however, this improvement may not be evident for those patients with well established COPD (Albert & Calverley, 2007). Smoking is complicit in 85-90% of COPD cases and is implicated in many pathological processes, including heart disease and diabetes. In a concerted effort to target current smokers who are admitted as patients within the Canterbury District Health Board's institutions, a smoking assessment and smoking cessation interventions are instigated for all medical and surgical patients on admission (Appendix A). This strategy is termed the "ABC Strategy for Smoking Cessation". A review of smoking cessation undertaken at Christchurch Hospital in 2009 found that for a 12 month period from 2009 to 2010, \$16,685 was

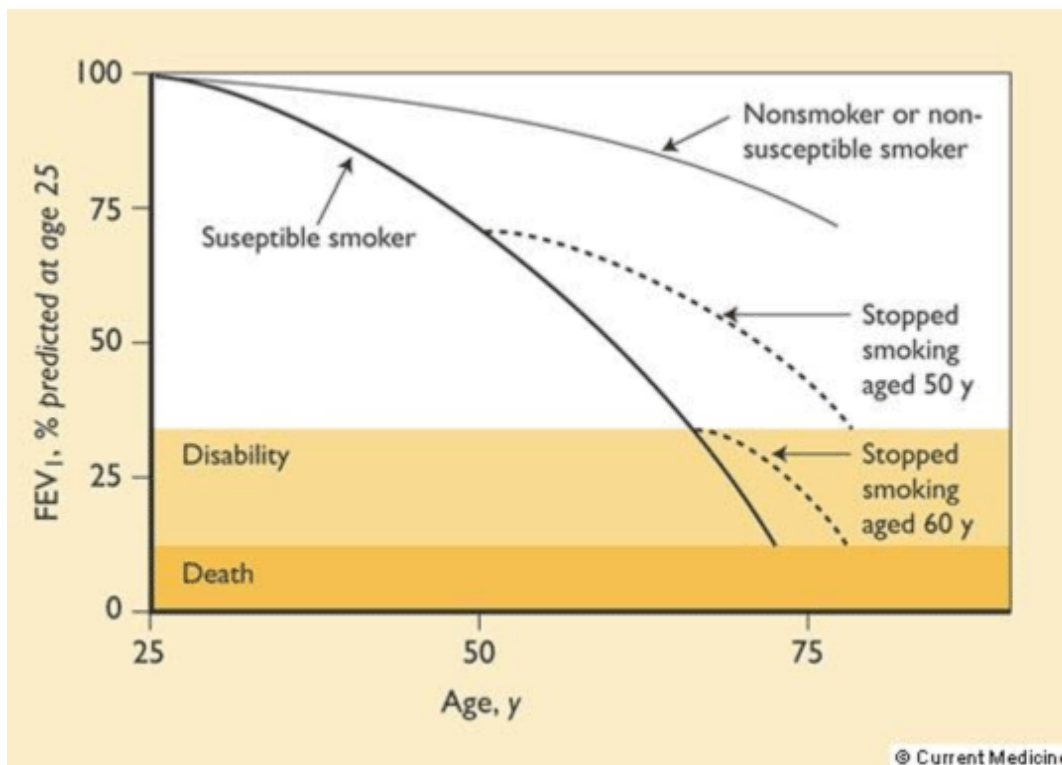
spent on nicotine replacement therapy [NRT]. This figure is triple the amount spent on NRT in 2005 and correlates with an increased patient target from 15%-67% in June of this year (Currie, Daley, & Richardson, 2010).

The COPDX guidelines report smoking cessation programmes have proven physiologically effective and financially beneficial for males and females and for persons of differing ethnic and cultural groups. The guidelines suggest a brief intervention approach is often effective and to produce maximal benefits, should be implemented at every patient contact (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009). Van der Meer, Wagena, Ostelo, Jacobs and Van Schayck (2009) suggest that smoking cessation intervention, involving physiological and psychosocial aspects, is the single most important consideration in the treatment of COPD, however to date, little research has been performed to assess the efficacy of interventions for the COPD patient group who appear to have been overlooked in comparison to the well smoking cohort (Van der Meer et al.,).

The incidence of COPD for those who concurrently smoke tobacco and marijuana is another area which also requires further research. A study of young male smokers with an average of 26 pack years of concurrent tobacco and marijuana use highlighted the lung tissue degradation (large bullae), cough, sputum production and wheeze evident for this patient group (Johnson, Smith, Morrison, Laszlo, & White, 2000). The authors suggest the harmful effects of tobacco smoking are well researched and documented however, the effects of marijuana smoking are somewhat lacking and less well researched or documented. The pulmonary symptoms as a result of marijuana smoking may be equal if not more severe than those evident for tobacco smokers

hence the need to undertake further study into the potential for pulmonary toxicity as a side effect of marijuana usage (Johnson et al., 2000). Figure 2.4 depicts predicted FEV₁ in smoking with curves demonstrating the rate of loss for a hypothetical susceptible smoker and the potential effects of smoking cessation.

Figure: 2.4: FEV₁ in smoking



From: “The natural history of chronic airflow obstruction,” by C. Fletcher and R. Peto, 1977, *British Medical Journal*, 1, p. 1646. 1977. Reprinted with permission.

2.8.4 Oxygen prescription

Oxygen is categorised as a drug used to treat varying degrees of hypoxemia which if used incorrectly and inappropriately, may prove to be ineffective and potentially lethal. Accurate oxygen prescription is essential to ensure efficacy of treatment, however research suggests that oxygen is often poorly prescribed (Dodd, et al., 2000). In many instances in acute medicine, oxygen therapy is governed by empirical applications and in some instances is given to patients based on subjective and presumptive need, rather than on objective measurements. The dangers inherent in this approach are the detrimental effects of under-oxygenation and in contrast hyperoxia, thus the prescription of oxygen therapy based on objective measurement and monitoring is deemed optimal and judicious management (Thomson, Webb, Maxwell, & Grant, 2002).

Oxygen is considered a medication and hence oxygen should be prescribed by the medical practitioner on the patient's medication sheet. Locally and within the Canterbury District Health Board, this patient medication chart is termed an MR4 and the oxygen prescription should include flow rate per minute, mode of delivery (acute mask, nasal cannula etc) and expected duration of delivery (Canterbury DHB, 2006). In reality and usual practice, a degree of laxity regarding adherence to protocol seems apparent and often the delivery of oxygenation is governed by the measurement of SpO₂ via pulse oximetry. For example, a medical order may be given within the clinical notes to ensure the patients SpO₂ is kept at a level equal to or greater than 90%. This directive seldom includes the flow rate or means of delivery of oxygenation and these decisions are often delegated to the attending nurse (M. Gluyas, personal communication,

October 12, 2009). This lack of adherence to guidelines for oxygen prescription is highlighted and reiterated in a study auditing the prescribing habits of junior doctors in a Scottish Hospital before and after the introduction of a prescription form. The study findings highlighted the high percentage (93%) of erroneous oxygen prescriptions prior to implementation of the medication chart (Dodd, et al., 2000).

One of the recommendations of the Sixth Oxygen Consensus Conference (1987) is that LTOT should be supplied on the prescription of a physician. The prescription should include aspects such as the source of oxygen delivery (concentrator, compressed oxygen in cylinders) and the most appropriate delivery device. This combination may ensure the patient receives the correct oxygen flow rate to avoid episodes of potentially life threatening hypoxemia. The authors suggest a standardised oxygen prescription form would ensure continuity and compliance by the prescribing physician, the supplier and potentially enhance patient understanding and compliance (Petty, et al., 2006).

2.8.5 Spirometry

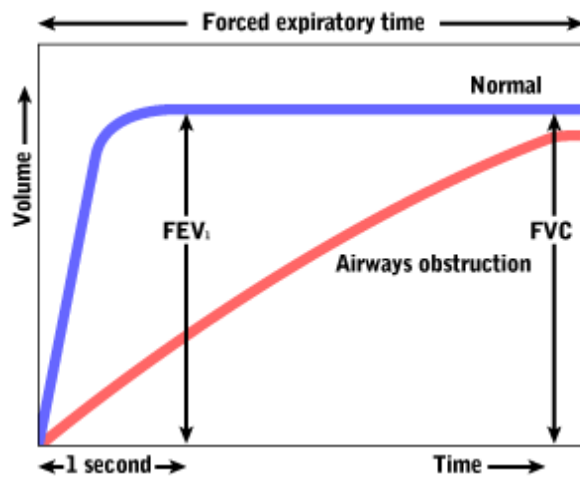
Spirometry is the most commonly implemented pulmonary function assessment test and is utilised for those patients who experience symptoms of respiratory illness and/or those who are at risk secondary to factors such as smoking, environmental exposures and familial or genetic predispositions. Spirometry may be performed in the respiratory laboratory setting, however since 1990 the accuracy of office spirometry units has enhanced the clinician's ability to

discover, monitor and diagnose restrictive airways disease, including asthma and COPD (Enright, 2009a).

Spirometry is often used to diagnose and monitor the progression of COPD and up to 65% of specialist physicians and pulmonologists utilise spirometry to assess bronchodilator responsiveness before diagnosing COPD (Enright, 2009a). Spirometry was utilised to monitor patient progress by up to 70% of medical professionals, nevertheless a lower utilisation of the procedure was highlighted for primary care physicians with an uptake of 43% (Barr, et al., 2005).

Spirometry is considered a low risk diagnostic procedure, however due to the exertion necessary to obtain accurate recordings, spirometry is not recommended for those patients with a recent myocardial infarction, unstable angina, pneumothorax and recent abdominal, neurological and ophthalmic surgery. Spirometry is performed with the patient in a seated position with the nares occluded manually or by the use of nose clips. The patient should be coached to take as deep a breath as possible prior to placement of the mouthpiece. Once the patient has taken the required deep inhalation, the mouthpiece is immediately placed between the patient's teeth and a tight seal with the lips is optimal to avoid the risk of air escape and subsequent erroneous measurements. The patient is then prompted to exhale sharply and to "blast" the exhaled breath into the spirometry machine's tubing and to continue the exhalation phase for at least six seconds. Up to three manoeuvres are usually performed and the addition of bronchodilators prior to the second or third manoeuvres may highlight a degree of bronchoconstriction reversibility if present (Enright, 2009b). Figure: 2.5 illustrates spirometric measurements of FVC and FEV₁.

Figure: 2.5: .Spirometric measurements of FVC and FEV₁



From: *What is COPD? Tests your doctor may perform*, by European Federation of Allergy and Airways Diseases Patients Association, 2011, Retrieved from http://www.efanet.org/copd/what_is_copd_tests.html. Reprinted with permission. isp. 1)

2.9 Experiences

Numerous studies have highlighted the psychosocial impact of LTOT on people with COPD, including a reduction in the ability to independently perform activities of daily living and an increased incidence of depression and feelings of helplessness and disabling anxiety. Denial of, or non-compliance concerning the use of LTOT appears to be another common theme which highlights implications for efficacy of therapeutic interventions (Bailey, 2004; Barnett, 2005; Doi, 2003; Ring & Danielson, 1997). The majority of literature suggests all patients with COPD experience some degree of lowered quality of life and a lessening of overall life satisfaction which is improved by the use of LTOT (Cornford, 2000; Cullen & Stiffler, 2009; Lynes & Kelly,

2009; Ring & Danielson, 1997). Interestingly and in contrast to previous and subsequent studies, a study undertaken in Sweden found patients using LTOT overwhelmingly experienced substantially lower levels of overall life satisfaction compared to those not on LTOT (Sturesson & Branholm, 2000).

This section reviews the qualitative literature on peoples' experiences of LTOT and will provide an overview of compliance and denial, education and knowledge including action planning and the functional status limitations imposed as a result of COPD and LTOT. The impact of the psychological aspects of living with COPD on LTOT will be explored with a focus on anxiety, panic, depression and dyspnoea.

2.9.1 Compliance and denial

Two large-scale studies (NOTT, 1980 and MRC, 1981) found the single most important factor in LTOT to achieve maximal benefit was the need to utilise the therapy for greater than 15 hours per day however, more recent evidence suggests the degree of patient non-compliance is limiting the degree of benefit experienced (Demirel, Demir, & Umut, 2003). In a study undertaken in Turkey in 2003, findings indicated a large percentage of the 86 participants underutilised their LTOT secondary to high noise levels produced by the concentrator. Thirty percent of the participants cited noise induced headache as a reason for underutilisation of LTOT. In 14% of those interviewed the reason proffered for non-compliance was the high cost of running the electrically driven concentrator and 21% of patients were not aware of their prescribed daily

usage durations. The authors concluded that ongoing patient education was important to achieve maximum compliance and associated health benefits for the recipients (Demirel, et al., 2003).

A large study undertaken in the United States of America enrolled 1023 patients and 1051 medical professionals. The study findings reported that up to 45% of the medical professionals interviewed reported issues gaining patient compliance with regard to adherence to the prescribed oxygenation, and a quarter of the study participants cited issues obtaining the necessary oxygen delivery devices due to a lack of supply (Barr, et al., 2005).

The prescription of LTOT may for some patients be a life-changing intervention, however the introduction of LTOT necessitates an acceptance by the patient as to their degree of disease severity and the limitations experienced as a result of this severity. Adherence to the LTOT prescription remains an issue and patients report numerous reasons for lack of compliance, including a perceived lack of dyspnoea and a fear of addiction to oxygen (20%), restricted freedom and autonomy (50%). Forty one percent of patients interviewed considered issues with the oxygen source and delivery device was the predominant cause of non-compliance. Some patients cited the duration of treatment as limiting (8%) and up to 38% of respondents felt a degree of shame and guilt associated with the use of long-term oxygenation. Of significance, some patients remained uncertain of the benefits of oxygenation and were concerned that in spite of their use of LTOT, their disease continued to progress. To date little is known or investigated to highlight strategies to promote patient adherence to LTOT and further qualitative research to elucidate the patient's experiences is recommended (Cullen & Stiffler, 2009).

2.9.2 Education and knowledge

Patient education is considered a pivotal and necessary aspect of COPD management and should be initiated at disease diagnosis and instigated at every patient contact point in an effort to maximise compliance and patient knowledge. Appropriate topics for ongoing education include advice regarding avoidance of risk factors, and basic and easily understood information about the pathophysiology of COPD. Education regarding medications (including the use of oxygen treatment), recognition of and action planning in exacerbations and strategies for managing dyspnoea are important areas of emphasis for patient and family education. In very severe or end-stage cases of COPD, education and discussion should be initiated with the patient and their family regarding their individual ceiling-of-care level and end-of-life decisions including a living will (Global Initiative for Chronic Obstructive Lung Disease, 2006; National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Education for the patient, their family, the associated community and hospital based health professionals is recommended to maximise the therapeutic benefit of LTOT and to minimise the physiological and financial burden incurred as a result of incorrect and sub-therapeutic usage and management. A comprehensive educational package is recommended and should include at a minimum the following aspects. The patient should be made aware of the ongoing cost of LTOT, including details of the supplier and those persons able to provide advice regarding maintenance

issues. The patient should be offered an easy to follow crisis plan which clearly details actions to take in the event of any emergency situation, such as a power failure or civil disaster. Patient and family education should highlight the importance of compliance to the oxygen prescription particularly the individual's recommended duration of therapy. Self-management planning is recommended to empower the patient and family to participate in their day-to-day management and monitoring of their current level of wellbeing. The patient should be provided with a written plan of actions (Appendix B) to take once they identify a deterioration in their physical functioning and who to contact for advice during a period of deterioration or in an emergency situation (Petty, et al., 2006).

Education for the patient and family may provide the motivation to promote adherence to the LTOT therapy and adjunct management, as advised by health professionals. This motivation to appropriately self-manage is especially important for those who experience chronic diseases such as COPD. Chronic disease management often necessitates and encompasses a multitude of aspects including LTOT, nebuliser therapy, correct spacer use and multiple medications which demand a high level of patient and family commitment. A lack of commitment may result in non-adherence which extends beyond the inappropriate use of prescribed medications to manifest as disempowerment and a lack of insight which may prove detrimental to the patient's wellbeing (Wykurz & Kelly, 2002).

2.9.3 Functional status limitations

Functional status is considered by many authors to be synonymous with activities of daily living [ADL] and for those patients with COPD their degree of dyspnoea limits some, or all, of these activities. ADL can be further divided into primary and secondary activities. Primary activities are considered the basics of existing and are often the last activities eliminated, even for those individuals severely affected. Primary activities most commonly associated with increased dyspnoea and fatigue include, walking, walking upstairs, bathing, showering, housework and meal preparation. The positive impact of pulmonary rehabilitation on the patient's ability to engage in primary activities has been highlighted. Optional activities, such as leisure activities, are often the first eliminated from the patient's life in an effort to decrease the degree of dyspnoea and fatigue experienced. The discontinuation of optional activities, once enjoyed by the patient, has the propensity to initiate feelings of isolation and a loss of independence and self-worth (Reardon, Lareau, & ZuWallack, 2006; Williams, Bruton, Ellis-Hill, & McPherson, 2007).

Literature reports a decrease in the patient's level of ADL functioning may be related to a loss of body image and negative perceptions related to the use of the LTOT concentrator, or the portable oxygen tank, used to increase the patient's ability to mobilise outside of the home environment (Doi, 2003). Doi found the use of the portable oxygen tank has the potential, for certain individuals, to be associated with a negative body image resulting in an avoidance of social interaction. Hence LTOT users may have a tendency to avoid performing ADLs such as shopping, walking and taking transportation in the public arena.

The maintenance of social participation and ADL external to the patient's home environment is hampered by the logistical arrangements necessary to manage portable oxygen systems. The

ambulatory oxygen systems currently available are heavy, cumbersome, conspicuous and lacking in aesthetic appeal. The ambulatory system currently widely available in New Zealand consists of a small oxygen cylinder which is only able to provide a maximum of three hours oxygenation, which limits the mobility and distance radius of the user. The logistical implications and difficulties involved with LTOT and airplane travel severely limits the accessibility of overseas destinations to those with COPD and on LTOT. A study undertaken by Williams et al., in 2007 highlighted the importance of travel to the majority of the LTOT patient group. A desire to undertake or continue to travel was a commonly recurring theme and a degree of compromise and ingenuity on behalf of the patient was necessary in order to achieve the desired holiday break. The ability to continue to drive was an important aspect of social mobility and maintenance of independence. For those who found their ability to walk limited by dyspnoea, driving provided a means to maintain ADLs and ensure freedom. Continuing to drive was especially important for those patients who had previously assumed the role of driver for others within the family unit. The transference of this responsibility to others created a loss of self esteem and role erosion for some patients (Williams, et al.).

2.9.4 Anxiety and depression

Clinical management of COPD encompasses optimisation of functioning and prevention of deterioration (including physiological complications such as polycythemia and cor pulmonale) and emphasis is placed on the importance of oxygenation in the reduction of morbidity and mortality for those patients with severe disease. Staging of COPD ranges from mild to severe and

the trajectory of the disease often includes periods of stability punctuated by exacerbations, frequently as a result of an infective process. The overriding treatment emphasis for stable disease is individualised symptom management with an ultimate aim of improvement in overall health related quality of life (National Institute for Clinical Excellence, 2004).

In the early 1980s, two large randomized controlled trials irrefutably demonstrated the decreased mortality rates for severe COPD in those who were prescribed and utilised LTOT either for greater than 12-15 hours per day or continuously over a period of one to three years. These early seminal studies focused primarily on the exactitude of the duration of oxygen delivery with a cursory acknowledgement of the psychosocial implications of COPD. Both trials highlighted the improvement in the patient's sense of wellbeing and quality of life once oxygen therapy was initiated, however due to the subjective nature of the patient reports, quantitative measurement was not undertaken (Medical Research Council Working Party, 1981; Nocturnal Oxygen Therapy Trial Group, 1980).

Most contemporary COPD management guidelines identify the importance of the psychosocial aspects of COPD and highlight the impact of depression and anxiety on the overall burden of COPD. The literature suggests therapeutic management of these aspects is essential to enhance the overall wellbeing and functioning of the patient. The management of the psychological aspects may meet the long-term goal of exacerbation prevention and reduced readmissions, as highlighted by all guidelines (American Thoracic Society & European Respiratory Society, 2004; Global Initiative for Chronic Obstructive Lung Disease, 2006; National Institute for

Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Increased levels of depression and anxiety are two important psychological issues commonly identified by COPD patients and previous research has identified the strong association between COPD and increased levels of anxiety (Eisner, et al., 2010; Hasson, et al., 2008). Bailey (2004) reports heightened levels of anxiety further exacerbate the degree of dyspnoea experienced by the individual that in turn leads to increased levels of anxiety and thus a spiralling effect eventuates. In actuality, the use of some medications including theophylline and steroids, which are commonly initiated in the treatment of all stages of COPD, have the propensity to potentiate the patient's degree of anxiety and anxiety induced dyspnoea (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009). The neuropsychiatric manifestations associated with theophylline and steroids are well documented and include agitation, restlessness and nervousness. In some instances corticosteroid induced psychosis has been documented (Brown & Chandler, 2001; Nair & Watson, 2005).

Rocker and colleagues (2007) suggest that symptoms of anxiety and depression are prevalent in advanced COPD and may affect up to 50% of people, however symptom recognition and treatment remains less than optimal (Rocker, Sinuff, Horton, & Hernandez, 2007). Dyspnoea is defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioural responses" (American Thoracic Society, 1999, p. 322). Dyspnoea

exists as a result of a multidimensional interplay of many factors and is ultimately a product of sensation and perception. Pharmacological and non-pharmacological therapies have been explored in the management of dyspnoea (Navigante, Cerchiotti, Castro, Lutteral, & Cabalar, 2006).

National and international guidelines highlight the importance of improvement in quality of life for those patients with COPD and state there is a well established and documented link between COPD and anxiety and depression. Heightened levels of anxiety increase the incidence of hospital readmissions which results in considerable financial, physical and psychological burden. The effective prevention and/or treatment of “COPD related panic disorder” should be a treatment and management priority. However the pharmacological management of depression, although equally important, may be adversely affected by side effects including sedation and respiratory depression (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Numerous studies have measured the COPD patients health related quality of life (HRQL) utilising proven measurement schedules such as the St George’s Respiratory Questionnaire and the degree of dyspnoea experienced by the patient has been found to be directly proportional to the patient’s perception of wellbeing (Jones, Quirk, & Baveystock, 1992). This finding is corroborated by another study which suggests the degree of dyspnoea experienced by the patient has a direct correlation to their health related quality of life and that a degree of dyspnoea is a persistent and sometimes very prominent feature of everyday living for those with COPD (Robinson, 2005). Other factors implicated in the perception of wellbeing include the presence

and incidence of exacerbations, particularly those requiring emergency admissions. Frequent emergency admissions (> 3 in 12 months) have been associated with decreased quality of life and increased mortality (de Miguel Diez, et al., 2003). Although useful, HRQL measurement schedules have their limitations in that they often fail to elucidate the broader aspects which impact on psychosocial functioning, including effective interpersonal and professional relationships (Alvarez-Gutierrez, et al., 2007).

Dyspnoea, cough and sputum production are common symptoms of COPD and some patients found these overtly visible signs of their disease problematic and embarrassing. These patients considered the visibility of their symptoms limited their socialisation and encouraged a degree of isolation and loneliness (Williams, et al., 2007). There appears to be a direct correlation between the degree of psychosomatic symptoms experienced by the individual and an increased tendency for lower life satisfaction, decreased ability to perform ADL's and an increased incidence of depression. As the patient's disease progresses and daily life becomes further restricted and increasingly more physically uncomfortable, the risk of decreased life satisfaction becomes greater and the incidence of depression increases. Previous studies undertaken in countries including Japan, United States of America and Canada reported between 34.5% and 75% of LTOT patients experience a significant level of depression and concern has arisen that in many incidences the depressive symptoms remain unrecognised and untreated (Doi, 2003; Lacasse, Series, Martin, & Maltais, 2007). Table 2.4 depicts the Modified Medical Research Council Dyspnoea Scale with grading from 1 to 5.

Table: 2.4 Modified Medical Research Council Dyspnoea Scale

Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying or walking up a slight hill
3	Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace
4	Stops for breath after walking about 100m or after a few minutes on the level
5	Too breathless to leave the house, or breathless when dressing or undressing

Source: (Medical Research Council Working Party, 1981, p. 682)

Anxiety in conjunction with depression impacts negatively on the patient's ability to self-manage and those who experienced incidences of severe and acute exacerbations demonstrated a markedly decreased ability to manage their level of anxiety (Dowson, Town, Frampton, & Mulder, 2004). In a study of 13 participants, all participants cited depression and anxiety as issues of importance in their day-to-day functioning. The participants' ability to function well was negatively impacted further by any "worry" about their future. Most participants conceded that they were reliant on prescribed medications to manage their symptoms of dyspnoea and anxiety (Hasson, et al., 2008).

In conclusion, to date there has been sparse research undertaken on several aspects of COPD. Research has sought to gain an understanding of the patient's experience of living with COPD and the impact on their life after the addition of LTOT. Researchers have failed to explore aspects of COPD patients' realities and few studies appear to have focused on a New Zealand

COPD participant group. Overall, there appears to be a paucity of research which highlights the combined aspects of experiences of LTOT and monitoring for the COPD population group.

CHAPTER THREE: Methodology and methods

3.1. Introduction

This chapter provides an outline of the chosen research methodology and the rationale for the selection of this particular methodological approach. The discussion includes an overview of the study's design and recruitment process. The development of the schedule for data collection is discussed in conjunction with an overview of the data collection and thematic analysis process. Finally, this chapter highlights ethical considerations and issues of rigour.

A qualitative approach was chosen on the basis of the extensive literature review undertaken at the commencement of the study which had highlighted a paucity of knowledge and poor understanding of the experience of LTOT. A qualitative research methodology was chosen for its ability to conceptualise, clearly define and identify the area of interest in an effort to maximise understanding through elucidation.

3.2 Methodology

In order to gain an understanding of the experiences and monitoring of the study's participants, thematic analysis was chosen as the preferred method by which to analyse the voluminous

quantity of raw data. Thematic analysis is described as a general inductive approach which provides a less complicated and efficient means by which to analyse qualitative data. The general inductive approach is utilised within research pertaining to the areas of health and social sciences and evolved from the desires of researchers who preferred to have their data analysis guided by a set of simple, clear and systematic procedural steps. In contrast to structured methodologies that may impose restraints and limits, inductive thematic analysis promotes the identification of key themes which may be obscured or remain undiscovered by the limitations inherent within the deductive methodology (Thomas, 2006).

Thematic analysis is a process whereby meaning and knowledge are extracted from the data and is a method of data analysis which lends itself as a process which may be employed with most qualitative methods. It is described as a way of seeing and encompasses a systematic observation and insight into the reality and way of being of a person or a group of persons, an interpersonal interaction, a situation, an organisation or a culture. Thematic analysis provides a means by which to understand and interpret that which appears initially to be unrelated and provides a basis on which to analyse qualitative data with a possibility of conversion into quantitative data if so desired. In essence, inductive thematic analysis may provide a bridge to negate the gap between differing methodologies and enhance the communication between the positivist and naturalistic paradigms. This degree of heightened understanding and insight provides the researcher, and others, with an opportunity to maximise their interpretive accuracy and sensitivity in an effort to fully understand the participant's reality. Thematic analysis is not without pitfalls, which may include the researcher's tendency to project their own conceptualisation onto the responding participant thus influencing the data obtained. Other

obstacles to sound research design include difficulties arising from sampling contamination and the potential for researcher fatigue, confusion and/or sensory overload (Boyatzis, 1998).

Thematic analysis provides a process which enables a systematic encoding of an expansive array of qualitative data culminating in the development of codes. Inductive coding is developed by the encoding of a group of themes derived from patterns highlighted within the raw data. At its minimum, inductive coding will describe and organise the possible observations, and at its maximum has the potential to interpret the area of interest (Boyatzis, 1998; Thomas, 2006).

This study employed the general inductive approach (Thomas, 2003, 2006) which is a qualitative methodology. Thomas's general inductive approach provided the theoretical and philosophical underpinning for this study. Thomas suggests the general inductive approach provides an easily understood, uncomplicated methodology and is an alternative to more traditional, and potentially more technical, methodologies. The general inductive approach possesses numerous similarities to other qualitative methodological approaches. Thomas defines the general inductive approach as a method which has the ability "to allow research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies" (Thomas, 2003, p. 2).

The general inductive approach is guided by several aims which most importantly are to encourage the findings of the research to materialise from narrative data. This inductive process ensures significant themes are not negated or overlooked. The risk of negation is a potential outcome of the limitations imposed by deductive approaches. The general inductive approach seeks to summarise raw data into a more manageable and informative structure. The resultant

summarised themes then provide an opportunity to develop and demonstrate unambiguous associations between the aims of the study and the inducted findings. The development of a model or theory derived from a study finding may then be possible and practicable (Thomas, 2003, 2006). The development of a model or theory was not an aim of this study due to the limitations of a master's thesis project.

A qualitative approach enabled the in-depth exploration of participants' experiences and maximised any opportunities to understand and elucidate the reality of living with COPD whilst on LTOT and the monitoring associated with LTOT. A single point of contact study approach was employed to minimise time, physical and logistical effort and financial expense whilst enabling the collection of large volumes of data which would be readily available for analysis (Wilson, 1987). The once-only interview was also to limit the physical and time commitment demanded of the study participants who experience moderate to severe COPD.

3.3 Methods

3.3.1 Recruitment

The 14 study participants were recruited from the LTOT patient lists of two respiratory outreach departments within the designated geographical region. It would not have been feasible to recruit the sample from the general population as patients are not permitted to utilise LTOT without the proviso of prescription, case management and follow-up.

Initially an approach in writing was sent to the general managers of each hospital (one secondary and one tertiary) and details of the study were supplied for the manager's perusal and acceptance. Once access was granted, a conversation with managers of each of the respiratory departments took place and they were provided with a description of the study, eligibility criteria, a sample participant information sheet, ethical approval confirmation and a sample of the proposed questionnaire. The department managers then met with their peers and permission was granted to access their patient populations to obtain the participants for this study. The department managers provided lists of patients who fitted the predetermined eligibility criteria and a mail out was undertaken. An invitation to participate (Appendix C) and a consent form (Appendix D) were posted to 20 potential participants who were selected randomly (by the researcher) from the lists provided by the respiratory departments. Ten people from each of two different areas within the defined geographical region formed the group of 20 potential participants.

The response rate was very encouraging with replies received from 19 people within the two mail-out groups. From these replies the final sample group was chosen by the researcher. Utilising a blind-draw process eight participants were chosen from one area and six from the other and these 14 people constituted the final study population group. A phone call was made to each participant and an interview date and time and place was arranged and any participant questions were addressed and answered during the initial phone contact. The five respondents who were not selected were contacted by phone by the researcher. Participants from two different geographical regions were sought and selected in an effort to minimise the impact on results which may have been manifest if one potentially under representative region was chosen

as the focus of the study. Each participant was masked numerically to reduce the risk of identification and further enhance confidentiality.

As all potential participants were under the care of a respiratory department, it was necessary to gain the support of the influential persons within the services, as a lack of support would have denied access to the most appropriate persons to inform this study. The gaining of permission in order to access participants who are deemed important sources of data involves the identification of individuals who are deemed “gatekeepers”. It is these “gatekeepers” or in the case of this study, general and departmental managers who have the ability to grant or deny access to the participant population, who have the potential to provide the rich data necessary to facilitate a qualitative study elucidating the phenomenon of interest (Polit, Beck, & Hungler, 2001).

The sample consisted of 14 people who identified as community based patients with COPD who had been on LTOT for a period of more than six months. The diagnosis of COPD did not rely on self-reports and was previously confirmed and recorded on the confidential patient files held by each institution. As such, the risk of erroneous self-diagnosis or diagnostic errors was negated by the limitations set by the eligibility criteria.

The study accessed a volunteer participant sample due to its convenience and economy and the ability to hand-pick the study participants who were deemed to be the most knowledgeable about the phenomenon of interest. The study design sought to minimise sampling bias, however due to the limitations of the eligibility criteria the target population required linkage to respiratory outreach services. This linkage could be considered more than perfunctory, and an expectation of

case management, in that the study sought to elucidate the patient's experiences of the services provided, and the outreach department's management of each participant.

3.3.2 Data collection

Data were collected over a two month period by conducting semi-structured interviews which were between 40-90 minutes in duration. The interviews were conducted at a venue identified by the participant and all respondents chose their own homes as the preferred venue for the interviews. This choice appeared to be overwhelmingly driven by the close proximity of the LTOT device and the participant's limited mobility however, the environmental setting provided a real-world view. The voice data was recorded with an Olympus digital voice recorder and a tape recorder as a backup device and each completed interview was then downloaded onto a code-locked personal computer system for safe storage, and transcribed to permit analysis.

The face-to-face semi-structured interview process provided the opportunity for the participants to verbally report experiences, perceptions, problems and any other information they deemed personally relevant in response to the study questions. The interview format acted as an invitation to the participant to narrate their experiences and, in essence, to tell their story to the researcher who was willing and able to listen, to comprehend, accurately record and reflect their story. The interview process allowed those participants who, for various reasons, were not able to express themselves in writing or numerically, the opportunity to be heard, thus limiting the potential for the risk of preconceived areas of importance by the interviewer. The semi-structured

interview design also afforded a degree of conformity in that all participants were asked the same questions in the same order and this may have enhanced the quantitative comparability of the study's findings. The "in the moment" design of the face-to-face interview also permitted clarification of any points where misunderstanding was possible and allowed the rephrasing of terminology or wording to enhance the participants' ability to relay rich in-depth data (Wilson, 1987).

A disadvantage of the interview approach included the sheer volume of data collected which necessitated a laborious phrase by phrase analysis and sorting. The perceived lack of anonymity may have influenced the participants' responses and they may have amended their answers. Whereas by comparison, the anonymity afforded by a mailed out questionnaire may have elicited differing responses to the same set of questions (Wilson, 1987).

The interview schedule (Appendix E) was utilised to guide the interviews and drew on the St George's Respiratory Questionnaire [SGRQ] which was developed and utilised by Jones et al. (1992) in their qualitative study (Appendix F). The SGRQ employs a self-administered exploration of 76 individual areas culminating in three domain scores and an overall score which highlights the impact of airways disease on the patient's health related quality of life. Areas of exploration include the impact of symptoms, effects of the respiratory disease on activity and overall effect on the individual's existence. Subsequent studies have reiterated the validity and reliability of the SGRQ in exploration of the impact of COPD and asthma on the wellbeing of the individual and suggest the questionnaire may provide additional information regarding the

patient's perception of clinical efficacy and overall quality of care afforded (Mahler & Mackowiak, 1995; Puhan, et al., 2007).

The adapted interview schedule included nine questions from the SGRQ in an effort to elucidate the experiences of those living with COPD on LTOT. To explore the patient's experiences of the monitoring associated with LTOT, it was necessary to formulate a new interview schedule comprising a total of 26 questions suitable for the intended patient population. The interview schedule included the patient's demographic data and current smoking status. The production of a new interview schedule was necessitated by a lack of generic schedules available to explore the areas of interest in this study. The Visual Simplified Respiratory Questionnaire, SGRQ, Quality of Well-being Scale, Sickness Impact Profile, Medical Research Council Dyspnoea Scale, and the Chronic Respiratory Questionnaire are some of the many examples of schedules currently available, however all appear to focus on the patient's health related quality of life with little or no exploration of the patient's experiences of monitoring (Jones, Lareau, & Mahler, 2009; Mahler & Mackowiak, 1995; Puhan, et al., 2007). To enable this study's ability to broaden the exploration of the patient experiences to encompass aspects of monitoring, modifications were necessary. The modifications included questions regarding aspects of monitoring including ABG assessment, spirometry, follow-up, action planning and rehabilitation.

The integration of content from another proven schedule is a common practice amongst researchers and the use of pretested material enhances the degree of reliability of the new schedule. The SGRQ is a well recognised and readily available schedule hence seeking permission to use portions of its content was not deemed necessary. The draft interview schedule

was reviewed by peers experienced in the management of patients with respiratory illness and each question was discussed and reviewed for clarity, content, logical sequencing and empathetic understanding and minimalistic impact on the respondent's psychological state. The modified interview schedule was then critiqued by colleagues recognised nationally and internationally for their academic and practical expertise and their expertise in the realm of health related research.

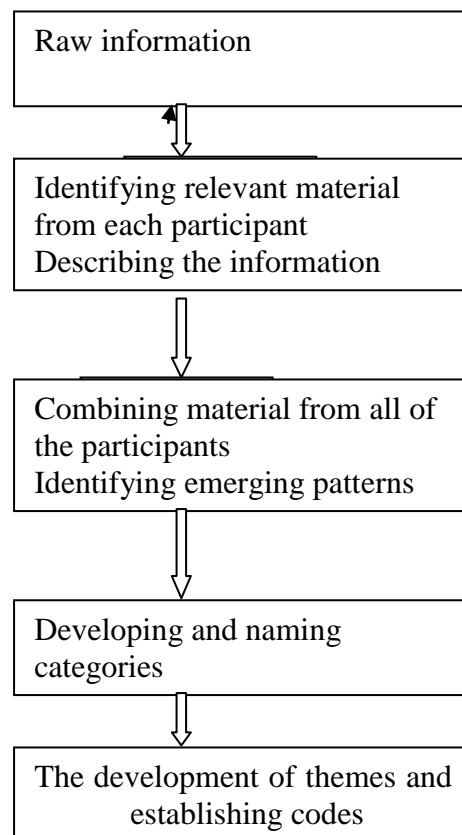
Participant candour and cooperation was assessed through the conduct of a two participant pilot study which also served to highlight the degree of comprehension elicited and the necessary time commitment in order to obtain rich data. During general conversations, several persons with COPD and on LTOT expressed an interest in this study and two offered to review the interview schedule to offer constructive critique. Critique and feedback was invited from the pilot study participants and the interview schedule gained their acceptance and approval after minor modifications. The conduct of a pilot study enables the researcher to gain insight and evidence upon which to base revisions, assess the study's feasibility and to make improvements (LoBiondo-Wood & Haber, 1998; Polit, et al., 2001).

The semi-structured interview schedule provided a beginning point, and a script to guide each participant through an exploration and narration of their reality of living with COPD and utilising LTOT and their experiences of monitoring. The majority of the questions were open-ended in order to elicit open dialogue and the semi-structured design ensured the focus remained on the areas of identified interest and deserving of investigation, due to a paucity of previous exploration.

3.3.3 Data analysis

In this study Thomas's (2003) general inductive approach underpins the study theoretically and Boyatzis's (1998) framework is utilised for analysing the data. Thematic analysis provides a method to analyse and interpret the data gathered and is composed of three overarching phases. The three phases are: i) recognising and consistently encoding a theme/codable moment, ii) code development, iii) the interpretation of the information and themes in the context of a theory or conceptual framework. Boyatzis (1998) describes five specific phases inherent within the inductive thematic analysis code development process. This process is illustrated in Figure 3.1

Figure 3.1: Boyatzis inductive thematic analysis code development process



The first stage of the process is termed “data cleaning” and involves preparation of the raw data into a consistent style ensuring format, grammar, and punctuation are equivalent across each interview transcript. During this phase it would also be prudent to ensure each interview is copied and stored securely. This preparation phase also includes the reading of the data and the addition of consistently documented researcher notes in the text margin whilst ensuring the integrity of the data remains intact.

The second phase encompasses the reading and rereading of the prepared text. It may be advantageous to listen repeatedly to the voice data recordings and to then repeatedly read each interview transcription. The aim of this phase is to ensure the researcher heeds the detail within each transcript and becomes very familiar with the content and developing themes. Recurrent and significant words and phrases should be highlighted in order to permit identification of patterns and themes within each individual participant’s transcript.

The third phase involves the creation of categories and the comparison of potential themes and experiential patterns across multiple participant transcripts which have been divided into subset groups. The ultimate aim of phase two and three is to capture and reduce the large quantity of data into smaller more manageable parcels whilst resisting the desire to prematurely commence the interpretation phase once preliminary themes have been discovered.

The fourth phase encompasses the creation of a code with an intention of creating between three to eight categories which fully capture the key experiences driving the themes obtained from the raw data. It should be noted that any one significant phrase may be coded into one or more

categories whilst a large quantity of data may remain uncoded due to perceived research aim irrelevance. Previously derived potential themes are reviewed across subsets and those themes appearing consistently and predominately are then coded (Boyatzis, 1998; Thomas, 2006).

To ensure each inductively derived thematic code captured and reflected the quality and richness of the area being studied, it was necessary to ensure each code included the following five rudiments as described by Boyatzis (1998):

1. A label
2. A definition or description of what the theme identified
3. A description of how to recognise when the theme occurs
4. A description of any qualifications or exclusions to the identification of the theme
5. Examples, both positive and negative, to eliminate possible confusion when searching for the theme.

The fifth and final phase involves checking the consistency or reliability of the application of the code. Each code should be validated by application across other subsets whilst ensuring that the code captures the essence of the raw data. At this point, a search was performed to highlight any opposing points of view and any new insights which may have been neglected. Once a thematic code has been identified this can be interpreted within the context of a theory or conceptual framework (Boyatzis, 1998).

3.3.4 Developing categories

The participants' transcripts were reviewed and significant, dominant and recurrent phrases were identified. These dominant/ significant phrases provided insights into the experiences and monitoring of the study participants and led to the identification of emerging patterns which were then categorised and named. Figure 3.2 provides an example of the categorisation and naming process by highlighting the emerging pattern of "the burden of LTOT" as a significant experience embedded within the participants' statements.

Figure 3.2: Deriving categories from patterns

<p>Emerging pattern</p> <p>“I realised that it was going to restrict me.” “I am afraid of falling over it.” “It was terribly noisy and was making a funny noise.”</p> <p>Category and name The burden of LTOT</p>

From these evolving categories, four themes emerged: i) ‘Smoking’, ii) ‘Oxygen therapy: The good the bad and the necessary’, iii) ‘The COPD journey’, and iv) ‘Feel the panic and breathe

anyway’ (psychological aspects of COPD). An example of the process involved in developing the theme; ‘Oxygen therapy, The good the bad and the necessary’, from the categories is illustrated in Figure 3.3

Figure 3.3: Deriving themes from the categories

Categories	Theme
<p>Positive aspects of LTOT (The good)</p> <ul style="list-style-type: none"> • Health benefits of LTOT • The reasons I wanted it • Patients as masters of their disease 	<p>Oxygen therapy: The good, the bad and the necessary</p>
<p>Negative aspects of LTOT (The bad)</p> <ul style="list-style-type: none"> • The burden of LTOT • The disease is the master 	
<p>Necessary aspects of LTOT (The necessary)</p> <ul style="list-style-type: none"> • Action planning • Spirometry and ABG • Adherence to LTOT prescription 	

3.3.5 Methodological rigour

The strength of the study is the inclusion of member checking as part of the research design. Study participants were supplied with verbatim transcripts of the interview and were afforded the opportunity to correct any information and add/or delete any part of the transcription as deemed

necessary. The preliminary findings were forwarded to the study participants in an effort to obtain participant reactions, including confirmation or denial of the findings. Member checking is considered the most important process in maximising the credibility of qualitative research data (Polit, et al., 2001).

Transferability was enhanced by the rich in-depth data collected which provided a view of the real-life contexts and experiences of the participants. The study participants represented differing cultural groups, however participants from indigenous and pacific cultures were not represented, which in turn may limit the transferability of the findings of the study. To further enhance the reader's confidence in the truth of the data, the researcher undertook prolonged engagement with the majority of the interviews lasting longer than 60 minutes. The prolonged engagement ensured sufficient time during the data collection phase to obtain an in-depth and rich understanding of the area of interest, with an ultimate aim of data saturation. Prolonged engagement also afforded an opportunity to establish rapport with the participants and to minimise the risk of misinformation. The use of primary sources rather than the inclusion of any secondary source data provided a first-hand account of the area of interest as experienced by the participant, without the risk of dilution or misinformation (LoBiondo-Wood & Haber, 1998).

The use of diverse informants from a wide geographical region provided a degree of data source triangulation and is another means by which to enhance the credibility of the study. Researcher credibility is another important consideration and it is essential that the participants possess belief and a conviction in the credentials of the researcher. This is important as in qualitative research the researcher is the data gathering schedule and the participants should be assured that

their experiences will be reported faithfully. Faithful reporting was maximised by the use of digital voice data recorders to record each interview. The interviews were then transcribed verbatim and member checked by the participants. The study's findings were derived wholly from participants' quotes and this maximised the confirmability of the findings (Polit, et al., 2001).

The inductive thematic analysis process has additional checks which may enhance the trustworthiness of the data analysis and thus in turn the findings. Formal and informal "Stakeholder checks" may be undertaken on the raw data, thematic analysis and code development and may enhance the credibility of the study findings by providing verification from parties with a vested interest. "Stakeholder checks" augment the member checking phase and can be implemented by allowing participants an opportunity to correct erroneous interpretations and by informal discussions with interested and qualified third parties (Thomas, 2006). At two stages during the data analysis phase the researcher sought the informal verification of interpretations from participants and a qualified third party.

3.3.6 Ethical considerations

Ethical approval was granted by the Upper South A Ethics committee on 18/August/2009 (Appendix G). Consultation was undertaken with the Otago University Research Coordinator for Maori to ensure ethical principles pertaining to Maori were considered and upheld. The research

proposal was forwarded to all interested parties (stakeholders) and unanimous consent and support for the study was extended.

Key ethical considerations relating to the research study include principles of beneficence, respect for human dignity, the participant's right to self-determination and full disclosure, and an assurance of justice. The study endeavoured to meet all expected ethical responsibilities and ensured the research design included ethics based aspects such as risk reduction, member checking, formal and informal debriefing, a cross sectional design and a heightened potential for benefit by elucidating areas of participant experiences not previously explored. An essential ethical responsibility of research is to acknowledge and disseminate significant findings in order to add to the body of knowledge and maximise the therapeutic management of patients (Polit, et al., 2001).

LoBiondo-Wood and Haber (1998) suggest that nurses, as consumers and producers of research, have a professional responsibility to disseminate research findings in an effort to improve client outcomes, whilst expanding the body of knowledge that guides evidence based best practice. Through an exploration of the participants' experiences, the study will seek to identify the positive and potentially negative aspects of current practice with a view to promoting therapeutically relevant change.

The potential participants were provided with a full description of the nature of the study, the responsibilities and credentials of the researcher and the possible benefits and risks of participation. These considerations meet the principle of beneficence which promotes the tenet

that research and the researcher should do no harm. Whilst physical harm is predominately overt, psychological harm has the potential to be less visible and more difficult to recognise or detect. The exclusion criteria ensured the most severely unwell potential participant group was excluded thus reducing the risk of physical discomfort (predominately breathlessness) (LoBiondo-Wood & Haber, 1998).

The semi-structured interview schedule lessened the requirement for the participant to divulge sensitive or potentially distressing personal information. Despite the parameters delineated by the more structured interview process, interviewing can be considered a form of therapeutic intervention. Any form of therapeutic intervention has the potential to affect the participant in some way however, the non-intrusive nature of the inquiry lessened the potential of negative impacts and possibly potentiated the positive aspect of feeling listened to. The interview process had the potential to be a cathartic experience which may have promoted healing and positively maximised the benefit to risk profile of the study (Patton, 2002). Although qualitative research is naturalistic and thus inherently more in-depth and personal than research based on a quantitative methodology, the inclusion of an open-ended time frame permitted adequate time for rest if required and the naturalistic setting ensured the participant was in a setting in which they felt safe and comfortable (Denzin & Lincoln, 2000).

Despite the inclusion of harm minimisation within the research design, the potential for physical and/or psychological distress remained a realistic consideration. Strategies to manage any potential harm included an assurance of interview termination if requested by the participant or deemed necessary by the researcher, based on subjective observations. Each participant had the

opportunity to debrief informally once the data recording was terminated and access to formal debriefing and/or therapeutic expertise was available through the services of appropriate medical clinicians, a social worker and a Maori Health professional (Polit, et al., 2001).

The participant's right to terminate their participation, ask questions, seek clarification and refuse to answer a particular question meets the principle of self-determination. The informed consent process was documented utilising an easily comprehensible consent form that clearly highlighted the voluntary aspect of participation and that non-participation would in no way prejudice future interrelationships. The information form and consent form clearly reiterate the purely voluntary aspect of participation and include the participant's right to choose to withdraw from the study at any point prior to the transcription of the interview. As a practising registered nurse, the possibility of role conflict exists. Polit, et al., (2001) suggest that there is a possibility that the participant may choose to be included in the study based on their knowledge of the researcher in their nursing role rather than their current role. The risk of role conflict was minimised by the addition of exclusion criteria which prevented any potential participant from taking part in the study if they had been nursed by the researcher within the past 12 month period. Role conflict was further negated by the conduction of interviews within the naturalistic setting, as chosen by the participant. Some authors would argue that despite the nurse being immersed in the role of a researcher, there is an ethical obligation to place patient advocacy before knowledge advancement, should any conflict arise (Polit, et al., 2001).

Participant confidentiality was ensured by the use of a cross sectional approach and the use of identification numbers in place of participant names and, if deemed necessary, information about

the participant's characteristics which could permit identification was withheld. Throughout the findings and discussion chapters a pseudonym was given to each participant in an effort to personalise the narrative data. The wide geographical region also helped ensure participant confidentiality by diluting the potential participant pool. Due to the fundamental methodology underlying qualitative research, anonymity was not assured and is not feasible in this study. Access to the data has been limited to the researcher and supervisors and when not in use, the data is stored under lock and key and in computer files identified by a numerical code with access limited to the researcher. The data will be destroyed once the research is complete and the researcher's academic qualification is awarded.

CHAPTER FOUR: Findings and analysis

4.1 Introduction

This chapter presents the socio-demographics and characteristics of the study participants and identifies the pseudonym utilised to personalise the study findings whilst maintaining confidentiality. The major themes and sub-themes and oxygen use of the study participants are highlighted. The findings of the study are presented within four major themes and an analysis is interwoven throughout the narrative data. At the end of each major theme a brief summary is presented. Finally an overall in-depth summary of the key findings within each major theme is presented.

4.2 Demographics

The study's participant group consisted of 14 people diagnosed with COPD who had utilised LTOT for a period greater than six months. The participants' overall average time on LTOT was 26.4 months. Table 4.1 outlines the socio-demographic details of the participants and Table 4.2 illustrates the characteristics of the participant sample group.

Table: 4.1 Socio-demographic details of the participants

	Gender	Age band	Marital status	Pseudonym
	male	80-84	widowed	Jock
	male	70-74	divorced	Bill
	male	65-69	married	Bruce
	male	65-69	married	Andy
	female	90-94	married	Jill
	female	70-74	divorced	Trina
	male	70-74	divorced	Tim
	female	75-79	widowed	Shelly
	male	65-69	widowed	Tom
	male	75-79	unknown	Trevor
	female	65-69	divorced	Ann
	female	65-69	widowed	Joan
	male	75-79	married	Spencer
	male	75-79	widowed	Rupert

All participants identified as Caucasian.

Table 4.2 details the characteristics of the participant sample group, including smoking status and length of time on LTOT.

Table: 4.2 Characteristics of the participant sample group

Pseudonym	smoking	Length of time on oxygen
Jock	Ex smoker	6 months
Bill	Ex smoker	18 months
Bruce	Ex smoker	18 months
Andy	Current smoker	7 months
Jill	Ex smoker	15 months
Trina	Current smoker	5 years
Tim	Current smoker	12 months
Shelly	Ex smoker	3 years
Tom	Current smoker	2.5 years
Trevor	Ex smoker	5 years
Ann	Ex smoker	3 years
Joan	Ex smoker	3 years
Spencer	Current smoker	18 months
Rupert	Ex smoker	18 months

4.3 Themes

The following four sections present the four major themes that emerged from the in-depth and comprehensive process of transcribing, systematisation, and encoding of the raw voice data obtained from the 14 interviews. Directed by the fourth step in Boyatzis's (1998) thematic analysis process; the creation of a thematic code, the resultant themes sought to grasp and

elucidate the experiences and monitoring of those people with COPD who received LTOT in an effort to improve their level of functioning and wellbeing.

Overall findings suggest the negative aspects of LTOT are outweighed by the benefits experienced by the participants. Findings were grouped into four main themes: ‘Smoking’; ‘Oxygen therapy: The good, the bad and the necessary’, ‘The COPD journey’ and ‘Feel the panic and breathe anyway’ (Psychological aspects of COPD). The first theme, ‘Smoking’ revealed the retrospective and current aspects of the impact of smoking for the COPD patient. The second theme, ‘Oxygen therapy, the good the bad and the necessary’ focussed on the participants’ experiences of LTOT and the necessary monitoring associated with its use.

The third theme, ‘The COPD journey’ focussed on participants’ knowledge of the disease and CO₂ retention. The needs and relationships identified as important by participants, and in one case, their spouse, were explored. The participants employed differing approaches to enhance their ability to cope with their disease and exploring these formed part of the content of this theme. The fourth theme, ‘Feel the panic and breathe anyway’ captured the psychological aspects of living with COPD and using LTOT. Table 4.3 depicts the themes that arose and the corresponding sub-themes.

Table: 4.3 The major themes and sub-themes

Theme	Sub-theme
<p>1. Smoking</p> <p>2. Oxygen therapy: The good the bad and the necessary</p> <p>3. The COPD journey</p> <p>4. Feel the panic and breathe anyway Psychological aspects of COPD</p>	<ul style="list-style-type: none"> • I've tried • I would have got it anyway • The smoking caused it <p>Positive aspects of LTOT The good</p> <ul style="list-style-type: none"> • Health benefits of LTOT • The reasons I wanted it • Patients as masters of their disease <p>Negative aspects of LTOT The bad</p> <ul style="list-style-type: none"> • The burden of LTOT • The disease is the master <p>Necessary aspects of LTOT The necessary</p> <ul style="list-style-type: none"> • Action planning • Spirometry and ABG analysis • Adherence to LTOT prescription <ul style="list-style-type: none"> • Knowledge of the disease and CO2 retention • Support systems • Coping <ul style="list-style-type: none"> • Panic • Depression, worthlessness and frustration • It's all my fault • How will I die

4.4 Smoking

This first section reveals the participants' experiences of smoking in relation to their diagnosis of COPD and their use of LTOT. International and national literature stipulates that before commencement of LTOT, the patient should have ceased smoking (Albert & Calverley, 2007; Canterbury DHB, 2006; Global Initiative for Chronic Lung Disease, 2006). This recommendation is firstly to reduce the safety risks associated with oxygen therapy and concurrent smoking, and secondly, to maximise the therapeutic effect of the LTOT. Despite the fact that all participants were fully aware of the risks (all had been provided with written information detailing safety considerations), Andy, Spencer, Trina, Tim and Tom continued to smoke whilst on LTOT.

I've tried

"I am still trying to give up. Oh Yeah I've cut right back. Something like back to about three a day, I thought what's the use?" (Spencer)

"Yes I have stopped, well I have stopped. I think I've stopped, but occasionally, very occasionally, maybe once a fortnight I will have a smoke. I will only have one or two and that's it. That will last me then for another two or three months." (Andy)

Nearly all of the participants highlighted the addictive nature of cigarettes and most had attempted to cease smoking more than once, often with minimal success.

Tom described a 12 month period of smoking cessation and his rapid return to the smoking habit once “tempted” to do so.

“Didn’t take much [to start smoking]” “It’s addictive but the thing is I think you can chuck it away alright, I mean you’re not doing nothing much it’s when it gets to you, well it does me. I mean you know it tempts you, so it’s normally when I have a cup of tea in the morning always got to have a smoke. Now might only have half of one and sometimes only a couple of puffs and then probably another one or two down the track I’ll have another couple of puffs just depends on how I am feeling.” (Tom)

All participants had a history of smoking of varying lengths and pack year duration, with the youngest age of commencement being five years old, but most began in their teenage years.

“I had my first cigarette probably at five. I don’t quite know but I was a full time smoker at 13.” (Rupert)

(Bill) had been smoking since the age of seven and stated “we used to pinch the old man’s tobacco and go down the river with it.”

I would have got it anyway

Several participants suggested smoking was not implicated as the probable cause of their COPD and/or appeared unaware of the health risks associated with smoking.

“Well there was nothing in tobacco in those days of course you know, and the stuff they put in them today is rubbish. They just put it in there to make you smoke.” (Bill)

Jock commenced smoking at the age of 12, encouraged by the availability of cigarettes and the influence of peers.

“Smoking was different then. Like everybody, everybody smoked and the dangers were just starting to come out at the time. Everybody smoked, war times you see. Cigarettes were then considered sweets, that was your rations.” (Jock)

Despite his smoking history, Jock was not convinced that smoking was connected to his diagnosis of COPD and implicated antibiotic eye drops as the causative factor.

“I can tell you now. I’ve got a scar on my left lung and nowhere else. It was way back to when I had pneumonia. I had eye drops that disagreed with me. I was taking them into my chest and they had antibiotics in them. And I am sure that’s what has caused the scarring.” (Jock)

Bruce had ceased smoking 20 years ago because of an illness which necessitated a doctor’s visit and was now convinced that his COPD was as a result of a genetic deficiency.

“He picked it up [respiratory specialist]. The one that I have got is genetic. I didn’t have much to do with it either. It’s actually interesting that [respiratory specialist] picked it up straight away when he saw the X-ray. Probably it’s [COPD] not caused by the smoking it’s the anti trip thing.” (Bruce)

Ann acknowledged the impact of her smoking history on her lung disease and then suggested that the doctors had implicated her “small lungs” and a one off exposure to smoke from a house fire as the predominant precursor of her COPD.

“Yeah after that [house fire] they didn’t seem to worry. I said what about the smoking does that cause it? Oh we [doctors] can tell you’re a smoker but no nothing to worry about. I thought it must have been all my smoking but no the doctors said I have got small lungs and breathing passages.” (Ann)

The smoking caused it

In contrast, approximately half of the participants considered their current situation and diagnosis was as a direct result of their smoking history and current smoking practices. (Tim) spoke of his ex wife’s concerns.

“I [Tim] gave up the booze 25 years ago and I should have smoked my bl..... self to death and I would have been gone by now. She [wife] said it wouldn’t have worked. You

already tried and it didn't work." "If you got to go back in time not much you can do about it. It's all my fault I am not blaming anyone else, it's all my fault yeah." (Tim)

"Yes, COPD should have told you that, only COPD's suffer and we've all been smokers. No, there's no quality of life now, I've got everything I really want and inner peace but it's all been ruined by the smoking. Everybody's done their best for me, respiratory outreach and everything brilliant." (Trevor)

"And when you think about the other thing [COPD] 99% of us have all been bl..... smokers, because when you started smoking back in our day they didn't tell you about this stuff and then when you try to get off them holy sh... worse than heroin." (Tom)

In summary, all of the participants had a smoking history prior to their diagnosis of COPD however, opinions were split equally as to the role of smoking in the development of their disease. Bruce, Andy, Trevor, Joan, Spencer and Rupert were unaware of the dangers of smoking in the early years of their use, with some describing cigarettes being distributed as rewards and portrayed as glamorous and normalised. Some of the participants commenced smoking at very young ages, with the youngest smoking at five years of age. Half the participants considered smoking was directly implicated in the development of their COPD, whilst the other participants blamed or implicated other precedents. Despite the well publicised risks and patient education offered, Andy, Spencer, Trina, Tim and Tom continued to smoke whilst utilising LTOT. All of the participants admitted that over the last decade they had been made aware of the health related risks associated with smoking. They had been offered smoking cessation support and received

education from several medical professionals including general practitioners, nurses and respiratory specialists. Despite the dangers associated with smoking whilst on LTOT none of the participants reported any adverse events.

4.5 Oxygen therapy: The good, the bad and the necessary

This second section describes the theme of: ‘Oxygen therapy, the good, the bad and the necessary’ and encompasses the positive and negative aspects of LTOT and provides an exploration of the participants’ experiences of the monitoring associated with LTOT use. Findings were explored under three sub themes: ‘The good’, ‘The bad’, and ‘The necessary’. Each of these sub themes is expanded further under separate headings.

4.5.1 The good

Most of the participants were readily able to verbalise and highlight the positive and beneficial aspects of LTOT. Most participants considered LTOT a form of medication which treated their COPD and maximised their physical wellbeing thus enabling a semblance of functional normality within the limits of their disease.

“I never thought nothing of it because I knew that I was needing something. I was needing a medicine of some kind. Yeah that sounds good, it’s true it’s a medicine.” (Jock)

The positive aspects of LTOT were grouped under the following three sub headings: i) The health benefits of LTOT, ii) The reasons I wanted it, and iii) Patients as masters of their disease.

The health benefits of LTOT

Most of the participants believed that the use of LTOT had positively influenced their physical wellbeing and lives overall. The most commonly referred to benefit was the relief obtained when the participant experienced disabling and frightening dyspnoea.

“Well it makes me breathe easier, makes me breathe a lot easier yeah, yeah so I don’t know what else I remember reading something about it. I feel better once I am on the oxygen because I’ve got to breathe hard even when I am not on it. That’s the only difference I find.” (Bill)

“Oh yes the difference it makes, yeah, it is, it is really, really, good you know, otherwise I’d be sitting on the chair and she’d [partner] say oh make a cup of tea. So I’d get up and make a cup of tea and by the time I’d have it boiled up I’d be a bit puffy and that. With the machine I can just go out and do it no trouble.” (Andy)

A metaphor of drowning was used by Tim to describe the dyspnoea he experienced and Tom described a lack of available air.

“I always feel I am quite happy about the oxygen as I used to feel like I was drowning. I was really scared about it one day, I said it’s like I am drowning and they [doctors] said yeah that’s it and I said to them it’s so hard to try and catch your breath.” (Tim)

“Well when I was at work I just couldn’t do nothing you know, run out of puff all the time yeah. So it got to the stage where they sent me home from work. Hardly getting any air.” (Tom)

Many participants spoke of the benefits of LTOT beyond the immediate relief of dyspnoea and considered LTOT had a wide-ranging benefit for the heart, lungs and the body as a whole.

“Well I think basically it is to help the rest of the organs in the body. Make sure they are functioning properly which helps your lungs or lung capacity. One doctor told me the most important organ oxygen would help was my heart, actually.” (Bruce)

An improvement in concentration and word finding was deemed an important aspect of LTOT for Trevor.

“I don’t talk sh.. and other things. I can tell when it’s [oxygen levels] going down because I can’t talk, I can’t concentrate and things just don’t go the right pace. It’s like playing the piano and then all of a sudden you’re getting old and I don’t, these [hands] don’t do what this [brain] wants. And so when I start to desaturate I am not as lucid, I

can't concentrate and I talk stupid, stupid and I know but I can't think of the words I was wanting. It comes up on you and I know the word but I can't think of it and I get all upset." (Trevor)

In some instances, the commencement of LTOT was viewed as a potential cure (panacea) for the participants' existing lung problems and breathing difficulties. The realisation that LTOT would provide respiratory support and not a cure soon became evident.

"They [medical personnel] said this thing [LTOT] will help you to cope but it's not going to take the place of your lungs. I just thought well I will be able to breathe naturally again. I had this naive idea that it was going to push this stuff into my lungs and I didn't have to do anything, but I learnt in a hurry that it doesn't work like that." (Tim)

Jill, Bill and Trina appeared to remain uncertain as to why they were prescribed LTOT initially and Shelly described a reduction in hours of therapy once on LTOT, which she interpreted as an improvement in her physical wellness.

"The doctor said to me I think you should go onto oxygen and I said why? And he said you would find it much better to live. And I said oh ok. I said I don't think I will bother and he [doctor] said right oh. So three years later when I was really quite bad and that same doctor said to me about it again and I said how long would I be on it. He said well for a start you will be on 24 hours a day. Oh goodness I said, oh well you will have to give up smoking so I did that and came home with oxygen. After six weeks I had to go

back to the hospital and he said you are doing fine, took an x-ray and he said well cut down to 16 hours a day and I have been on 16 ever since so I must have improved a little bit.” (Shelly)

Tom who was at the end-stage of his disease and requiring LTOT for up to 16 hours a day (with self-administered short-burst therapy intermittently throughout the day) spoke of reaching the magical number of 55² and once reached Tom could potentially discontinue his LTOT.

“And they [medical personnel] said I don’t know how to work it but if the thing [ABG] comes up to 55, whatever that is, I don’t know, but its good. Then he’ll [respiratory specialist] give us another maybe another year and say you’re still at 55 he might think about taking me off the oxygen. So that must be where the oxygen level is.” (Tom)

A few of the participants remained uncertain as to the actual and/or perceived benefits of LTOT. Some conceded they had experienced small gains on LTOT nevertheless, they were debating a cost/benefit rationale for continuation of the therapy.

“I can actually sit down and relax because I am quite busy most of the time. I try to be [busy] but I am starting to slow down awful quick now through shortness of breath you know. It’s [shortness of breath] not getting any better, it doesn’t appear to be. I don’t know if it has [LTOT] helped or not, I don’t know but I’d like to come off it [LTOT] just to like an experiment you know, but whether I should or not I don’t know. I can actually move around better without it.” (Spencer)

² 55mmHg (equal to or below) of oxygen is the objective measurement at which patients qualify for LTOT.

Jill felt disappointed that LTOT did not provide a marked improvement in her condition. Spencer expressed concern at the minimal impact LTOT had on his degree of dyspnoea.

“That’s hard to say I’ve been thinking about that one. I don’t feel wow, like I know I am better but I do feel it if I am off it [oxygen] a bit longer than I am usually, I get tired and I feel oh I can’t be bothered to do anything. But I’ve never been able to say, never sort of had this feeling where I put it [oxygen] on and think wow, wonderful. It’s just, I just carried on.” (Jill)

“I don’t know why they gave me it [oxygen] really. I don’t know to be honest. I was led to believe it was going to help me.”

Interviewer “has it helped.”

Participant “no not really.” (Spencer)

In summary, most of the participants were of the opinion that LTOT had provided a health benefit, particularly in the relief of dyspnoea. Dyspnoea was the most commonly referred to symptom and for all participants the most problematic. For the majority of participants LTOT provided some degree of symptomatic relief. Jock, Bruce, Trina and Rupert believed LTOT was prescribed to not only benefit the lungs, but also the heart and potentially the body as a whole. Trevor described an enhanced ability to concentrate when on LTOT. A small group of participants expressed disappointment at the lack of the “wow factor” and Jill, Tom and Spencer remained unconvinced of the benefits of LTOT. Some participants appeared unaware as to the

reasons they were prescribed LTOT and others held erroneous and unrealistic expectations regarding their potential for improvement. A few participants were of the understanding that LTOT would produce improvements in physical wellness to the degree they could cease their therapy.

Why I wanted oxygen

Interestingly, some participants expressed the view that they or their family members were the instigating force behind the prescription and supply of LTOT and highlighted a perceived reticence, on behalf of the medical fraternity, to initiate LTOT for their personal circumstances.

“Oh that was self explanatory because I knew what I wanted but the doctor over here said “you won’t get it you know, you won’t get oxygen. Very few people get it, the domiciliary oxygen”. But when I went and saw [respiratory specialist] and he said no you’ll be marginal, you don’t need oxygen. He said but well walk up these stairs about three or four steps and then he said don’t go any further. He [respiratory specialist] exaggerated it so I could qualify for the oxygen.” (Trevor)

More than one participant considered it was more cost effective to be supplied with LTOT in their own home than to continue spending time in hospital. On this basis, they suggested the prescription of LTOT for themselves, in order to lessen the burden on the health system.

“Um well actually, I was the one that suggested it, to come home with it [LTOT] because I thought by having it at home seeing as I was going into hospital losing oxygen spending three days four days in hospital on oxygen then being sent home. I thought it would be less expensive to have me at home than to have me in hospital all the time. Also the fact that if I’ve got that [LTOT] it’s going to keep me out of hospital longer.” (Joan)

“Three thousand dollars for the machine [concentrator], which keeps me out of hospital so that’s saving a thousand dollars, three thousand dollars a week for me not being in hospital having that machine at home.” (Joan)

Rupert spoke of his request to be supplied with LTOT because he had seen his friends and deceased wife undergoing LTOT. In his efforts to obtain LTOT Rupert had taken his request to the extent of offering to buy his own concentrator.

“I went and asked and I told them [medical personnel] I wanted it because I’d seen my friends go on to it. We [participant and family] almost forced the hospital by saying I will really buy one or give it [the hospital] about \$2000 I think towards the cost of one that’s about \$3000. Because they [the hospital] never had one over here and I use to tear in and out to hospital getting oxygen bottles for my wife because they wouldn’t give the hospital enough and we’d run out.” (Rupert)

Jill spoke of her son's influence in the prescription and supply of her LTOT. Jill wholly credits her son with the organisation of her LTOT, with an obvious exclusion of any consultation with medical personnel.

“One reason was because [son] kept on about it and said he reckoned that I should have it. I didn't know. Then he [son] comes home and takes me to see [respiratory specialist]. He [respiratory specialist] has always been busy when I have seen him and when I saw him first and was diagnosed I wasn't on oxygen. He [son] kept saying I think you should be on oxygen and somebody said you can hire oxygen in your home if you want it. So the next time I saw him [son] he kept on about it again, I think you should be on oxygen and this time I said yes ok that's fine. So he [son] organised it [LTOT] and that was that.”

(Jill)

A detailed description was narrated by Joan. This narration illustrated her perception of the indecision and differing opinions regarding LTOT prescription between two respiratory specialists and her “fight” to obtain LTOT.

“At the time I had Dr ... who was dead against it, because Dr ... was away and he was talking he actually had this silly sort of idea which I thought was rather silly. He [respiratory specialist] said you know they climb Mount Everest with no oxygen so why would you need oxygen at home. I looked at him for a minute and I said they don't have my lungs do they? And he sort of looked at me and I thought that was rather silly. I said if they had my lungs they wouldn't be climbing Mount Everest would they. He sort of

looked at me and went hmm yeah. We got on even though he didn't agree that I should have it at home but Dr ... did. And he was my doctor, he was my specialist, he was the one who came and the one I've seen ever since." (Joan)

In summary, an unexpectedly large group of participants described the steps they, and in some cases their families, deemed necessary to obtain LTOT. Jill, Rupert, Trevor and Joan described a perceived reticence and/or lack of agreement on the part of medical professionals regarding their suitability and qualification for LTOT. In their quest to be prescribed LTOT some of the participants rationalised their treatment on a cost basis. Rupert offered to buy his own concentrator, whilst others suggested the provision of LTOT would provide a monetary benefit to the health system when compared to the cost of their hospitalisations.

Patients as masters of their disease

Most of the participants considered the use of LTOT, in combination with the portable oxygen cylinders, enabled them to continue to live and enjoy aspects of life which may not have been possible without supplementary oxygenation.

"No, no, no, I don't go out in the wind when it gets like that no, no. I went down town and had the gas [portable oxygen] and all on the back. Went down to watch the motorbikes you know then went down and came back again, four of us yeah, yeah, really good but I had the gas with us on the back of the wheelchair." (Bill)

Tom enjoyed driving into the city on a weekly basis to get away from his usual surroundings and for a change of scenery. Depending on how well he felt on the day of the drive he would decide whether or not to take his portable oxygen supply.

“Yeah yeah sometimes if we go into town depending on how I feel when I leave I’ll decide whether I’m taking it [portable oxygen] or not then. If I don’t feel too good I take it and it’s there. I’ll take one, well if I’m not feeling too good I’ll take one, then again on the same token if I’m not feeling right I might not go either. It depends really on when I get out. I went into town last week just to get the h.... out of here.” (Tom)

“It keeps me more active I am able to still go out and do my things. I went out yesterday, um, went out to [shopping mall]; the girls pushed me around in a wheelchair. We took the oxygen with me. We went out about eleven o’clock and we didn’t get home until after two and I never put the oxygen back on until five o’clock. So I just do my own thing. You know we went out for a meal the other night and we took the portable [oxygen] we always take it with us, but sometimes leave it in the car. Yeah [partner] will go and get it if I need it but if I can get away without it, I won’t use it.” (Joan)

The use of the portable oxygen to enhance her mobility and participation in social activities outside the home was described perfunctorily by Shelly.

“If my son takes me anywhere he chucks one of the tanks [portable oxygen] in the car. Yes I have got wheels for it if I want it but if [son] takes me he just takes the tank and lays it on the back seat of the car and he will carry it and I just pop it on and he carries it.”
(Shelly)

Others highlighted the importance of the reassurance offered by the use of and/or close proximity of the portable cylinders. In some instances the portable cylinders provided a backup form of oxygenation in an emergency situation.

“I’ve got a couple in there, sometimes I’ve got one to hook it on to so you can run it out rather than use the bl..... power. I’ve always got one here but now I have to go on that [concentrator] we don’t always know when the powers coming back on.” (Tom)

“I have a small bottle in case the power goes off.” (Bruce)

Trevor had gone to great lengths to strategically position his portable oxygen cylinders around the house to ensure a readily available and easily accessed emergency supply was within close proximity.

“No, no, no, don’t be fooled, you only see what you’re meant to see, that is there. There’s one in the car, there’s one outside but in the lounge and in the bedrooms there’s the big pump [concentrator]. The bottles are placed same as these chairs and schedules, strategically in case I need to sit down. That’s how I am still here.” (Trevor)

In summary, for most of the participants portable oxygen provided a form of mastery/control over the participant's disease which in turn enabled a greater degree of security, mobility and freedom. This mastery afforded Jock, Bill, Bruce, Trina, Tim, Shelly Trevor Ann and Rupert an opportunity to maintain the social links and social mobility considered important. This degree of mastery and independence demanded a highly tuned and orchestrated performance in order to achieve the desired outcome and often involved the input and support of several individuals. For Bruce, Trina and Tom the portable oxygen cylinder provided an emergency oxygen backup system in case of power failure and was employed by most of the participants when experiencing an exacerbation of dyspnoea.

4.5.2 The Bad

Despite the predominately positive and enabling aspects of LTOT, lifestyle changes and adaptations were necessary to enable living within the LTOT regime and the limitations of the health status imposed on the participant by their concurrent COPD. The negative aspects of LTOT were grouped under the following two sub headings: i) The burden of LTOT and ii) The disease is the master.

The burden of LTOT

Some participants spoke of the embarrassment caused by the visibility of their disease and the LTOT utilised to maintain activities of daily living and quality of life. Andy and Jill refused to

use portable oxygenation in public, in an effort to limit the visibility of their disease and because they viewed the use of portable oxygenation as a sign of severe disease.

“No no that’s all I’ve got just the machine and I don’t want one [portable cylinder]. I don’t think I need them. I mean I’ve seen people carrying them along the street and that’s no, that’s not me at the moment. Not yet anyway not for a long time yet. It worried me a bit at first because I thought oh sh.. I thought it [LTOT] would be like scuba diver tanks you know. I thought oh h... carrying or pushing those around on a trolley.” (Andy)

“No I haven’t succumbed to that yet [portable oxygen]. Yes I have been told about that. I have got a wee bit of pride. I’d have to carry it around and yes well I wouldn’t want to go out with it that’s embarrassing.” (Jill)

Jill spoke of the logistical difficulties experienced with the use of LTOT, including the perceived dangers of falling over trailing oxygen tubing.

“I could sit here and I bring it [oxygen tubing] around here and then when I’m working in my room, which includes the bathroom I go and put it out there. If I go out there [lounge] in the afternoon which is what I do, I keep it on and I work with it but I don’t want to have it around the kitchen if I can help it. When I am getting a meal I am afraid of tripping over it. Because you know when you are moving around getting a meal it is trailing. It’s alright out there [lounge] because I am sort of stationary, but when I am

moving around the bedroom to other rooms or kitchen, I am afraid of falling over it.”

(Jill)

The partner of one participant relayed her experience with the logistical arrangements necessary for the LTOT within their home environment.

“Oh and then I went to pick it [concentrator] up and I said we have to go up stairs. They said well you can't you will have to take it up and down stairs very night and I said I can't physically do that. So they [respiratory outpatients] said you will need too much hose and that we couldn't have that much hose and then I told it was perfectly alright the amount of hose we have got. We have got one long bit with one short bit. But here they were telling me and our steps are quite steep so I would have to be carrying it up every night so I didn't think that was very good either.” (Bruce)

Others spoke of the logistical planning necessary to facilitate a journey or an outing and felt the rewards were not as worthwhile when taking into account the degree of planning necessary and the physiological impact.

“I have been out twice out of my flat and over here [hospital] twice. One was about a fortnight ago and one of the guys was turning 76. I was out for the afternoon for three hours and I had to go home. It was too bigger hassle to get one [portable oxygen] jacked up and then get me into the car and then put the oxygen in. Obviously it didn't happen because I got worse and then I said it's not

worth the hassle. I get puffed getting ready. I get puffed getting in the car and then I would settle down and stay there for two or three hours and then now I have to go home and it all starts all over again.” (Tim)

Many participants (who previously enjoyed travelling) found the thought of travelling with portable and concentrator oxygenation foreboding, essentially limiting their mobility and independence and enjoyment of life.

“I did use it [portable oxygen]. Took it down south in February last year. I went away for two days but I cut my hours down there. I think I only had 6 hours or something each night so that I didn’t exhaust it all on the first night. And I arrived back here and I still had a wee bit left. Yeah, yeah, I take it [concentrator] with me usually but this time I didn’t it was too much of a problem. Didn’t have enough room in the car because it takes up one space. It [concentrator] even has a dam seatbelt on to control it too. It’s like belt up and not injure itself.” (Rupert)

Tom found the newer concentrators more portable and transported his concentrator on the bus to Dunedin.

“Yeah, good I can pick it up and put it on the bus when I went down. Yeah and then plug it in, because I stayed at my sons down there and bobs your uncle.” (Tom)

Overseas travel had previously been an aspect of living enjoyed by some participants however, it now appeared that the participants need for LTOT had impeded their travel plans.

A Pacific Island cruise had been proposed by the son of one participant who had previously expressed a lifelong desire to travel by cruise ship.

“He [participant’s son] said we will take your big tank with you. I said blo.... lovely. I said sitting around on the deck with this [nasal cannula] stuck up me nose til 12 o’clock. I thought the thought was beautiful but actually I would feel so conspicuous with this thing stuck up me blo.... nose on the deck enjoying the sun and stuff.” (Shelly)

Andy had a daughter getting married overseas and was exploring the logistics involved with flying whilst requiring LTOT.

“Yeah, yeah, Well I want to go to Rarotonga next year so I’ve got to suss out about the oxygen now I suppose.” (Andy)

Bruce, Andy, Jill, Ann and Rupert highlighted the problems associated with the noise generated by the concentrator. In some instances it was the participant’s partner who found the noise generated by the concentrator irritating and imposing.

“Our original one was like a lawnmower going, I couldn’t sleep and I thought what am I going to do. I have got to have sleep. I mean even that one [new concentrator]. If I wake

at night it really annoys me. But the blue one is a lot better, but as I say, I can hear it now and I can certainly hear it from upstairs.” (Bruce’s partner)

One participant spoke of their delight when their “noisy” concentrator was taken away and replaced with a newer model which was quieter. The participant also relayed their concern when they thought the old concentrator may be returned to them.

“It was terribly noisy and was making a funny noise, so I rang up and I said my machine is making a funny noise. He [technician] said I will send somebody out. So a nice chappie came out and brought me this nice little blue one [concentrator] which is lovely. Hip, hip, hooray and I said good riddance. And so I got this nice little blue one.” (Jill)

“And for the weekend you know before we had the power. I had four [cylinders] just to keep me going it really was heaven because there was no noise but then I had no TV, no radio, nothing else. To have silence was quite nice.” (Trina)

The noise of the concentrator appeared to become more evident and more problematic for the participants as the concentrator neared the end of its useful life. Rupert used an analogy of “putting his concentrator down.”

“It was a rattly dam thing you know. You could tell when it was going, like an air conditioner. I could tell the machine was worn, it was rattling and banging. If it was a

car I would have sent it to the scrap yard, you know. If it was an animal you would have shot it or put it down, or something.” (Rupert)

“Yeah, although like he said when I came out, the thing [concentrator] I had was terrible made such a noise, it did, it was really, really loud and oh loud. But I had spoken to the specialist and they brought another one down from Dunedin.” (Ann)

In summary, although most of the participants found the portable oxygen somewhat liberating, a small group found the thought of being seen with oxygen tanks in public embarrassing. Others considered the use of portable oxygen (particularly in public) indicated the recipient experienced a more severe stage of the disease and as a result were reluctant to “succumb”. Logistical difficulties around the use of portable and concentrator supplied oxygenation were cited as problematic by half the participants. Most of the participants, and in some instances their family members, deemed the oxygen concentrator heavy, cumbersome, and in many instances too noisy to permit comfort within the home environment.

The disease is the master

All of the participants highlighted the limitations COPD and the use of LTOT imposed on their lives and the lives of their immediate and extended family and friends. Most participants had experienced several hospitalisations which increased in frequency, with an ever lessening time interval between hospitalisations as the disease progressed. All participants spoke of limitations

on their ability to participate in the activities of daily life and socialise outside of their home, with the ambient temperature³ and logistical arrangements for their LTOT paramount in their decision making process.

All the participants spoke of the breathlessness associated with the bending over necessary to complete activities of living and their desire to avoid the physical and psychological impacts of such situations.

“It’s just beyond me, I’ve never been much of a gardener anyway but with my back and everything I can’t kneel. I can’t bend, getting into the bottom cupboards; I can’t even get into them anymore. It’s just trying to bend down and breathe at the same time.” (Joan)

“More the bending over lass. Bending you know, it can be like that can get down but it’s a bit of a struggle but I don’t go looking for that shortness of breath. I try to tell myself I am not short of breath.” (Spencer)

For a participant, who usually has to use a wheelchair or mobility scooter for outings, the ability to walk independently and shop, with the physical support of a trolley, invoked a sense of achievement.

“But just lately I haven’t been far, but the other day, last week, we went down to the supermarket and I actually walked around the supermarket with the trolley.” (Joan)

³ Most participants expressed a preference for different ambient temperatures. Some preferred the heat whilst others preferred the cooler atmosphere.

“Oh yeah, well, I don’t walk there no, only supermarkets but I don’t even like walking. No. Nothing like you go around and look at the shops. Got to have a trolley when I walked because of my breathing, so I would rely on the trolley.” (Jock)

The physical support of a trolley enabled Andy to be involved in grocery shopping with his wife, which in turn offered a sense of contribution to household tasks.

“Yeah I push the trolley because it helps. I hang onto the trolley and the missus gets all the bits. Yeah I’ve got the trolley job.” (Andy)

In an effort to maintain the necessary activities of daily life, Jock, Trina, Tim, Shelly, Joan and Rupert had either formal home help assigned to them or informal support offered by their families. This support was particularly important when the participant desired a bath or shower. Nearly all of the participants cited bathing as their most problematic and breathlessness inducing activity and something they could no longer comfortably manage independently. In some instances, the partner of the participant had assumed the role of a personal care assistant.

“And I get frustrated because you get help from a [funded care service] once a week, there are things they can’t do and I can’t do it anymore.” (Joan)

The formal help was often allocated on particular days each week which meant the participant had to manage independently or enlist the help of informal helpers if necessary and/or available.

“I find dressing a pain. Three days a week of course I’ve got the girls [home helpers] to dress me because I have a shower. They come and shower me. They dress me but getting dressed and undressed ... phew. But never mind I’ve got nobody to answer to. I can take my time. See I get into pants, but not a skirt or something, then I have to breathe some oxygen for a little while then I will get into the rest of my clothes. I tried to get dressed on my own this morning and I put this top on back to front and I thought oh no got to start again.” (Shelly)

Jill (aged 93) enlisted the help of her husband to enable her to have a shower and get dressed and undressed each day.

“I get very breathless bathing. Not bathing it’s the rubbing you know rubbing dry. Yeah Mr [participant’s husband] helps me. We have got it worked out. He has started to rub my back down so that I don’t have to try and do it. So we have got over that one but I even when you know, when I have done a bath for the night just getting undressed and getting into bed I am pretty breathless. Any movement at all really.” (Jill)

Only a few of the participants received any form of personal care support hence the majority of participants managed to dress and bathe independently and all had ritualised systems in place to minimise the exertion required.

“Like I put my jersey or shirt on or whatever and you find you have got your arms in the wrong hole and you go, oh gees, I have to do this all again, sort of the right hole for the

right arm. Yeah, what I am inclined to do is get everything in a system so everything gets sorted while I'm sitting there and I can reach over and do the things you know and get dressed.” (Bruce)

*“Getting dressed in the morning I am quite capable but I am slow. I call it, what I call it, stabilising in the morning. In the afternoon, if I've been silly, I can't bend down to take my shoes off and things like this because I am too weak and I've got an electric bed.”
(Trevor)*

In summary, all of the participants highlighted issues with breathlessness (sometimes severe) when dressing and undressing. Dressing and undressing necessitated an orchestrated and finely tuned process in order to limit the degree of dyspnoea experienced by participants. A small number of the participants were recipients of personal care support. The ability to walk distances beyond 100 metres proved virtually impossible with only Andy reporting the ability to walk up to 200 metres. Most of the participants required wheelchairs for any outings. Overwhelmingly, the most common debilitating problem was the participants' (in most cases) severely limited ability to perform the essential functions of daily living. All but Jock reported frequent, and invariably, overwhelming issues with showering and dressing. Bending over was reported, by the majority of participants, as the most difficult manoeuvre to perform. The supermarket trolley became, for Andy, Jill, Trina, Ann and Joan, an important support to enable the participant to continue to grocery shop and to enhance mobility and independence.

4.5.3 The necessary

The necessary aspects of living with COPD, whilst utilising LTOT, involved several, multifaceted aspects of management. Management encompasses the promotion of self-efficacy via action planning and the formal measurements and monitoring necessary to assess the participant's response to treatment and to guide further interventions. Measurements, including spirometry and ABG, provide baseline figures on which to base LTOT qualification, the initial litreage and ongoing monitoring. The necessary aspects of LTOT are captured under the following three headings: i) Action planning, ii) Spirometry and ABG, and iii) Adherence to LTOT prescription.

Action planning

Action plans were considered an important schedule to promote and enable self-management and efficacy and to reduce hospital admissions (National Institute for Clinical Excellence, 2004).

Action plans describe strategies to manage escalating exacerbations of COPD including antibiotics and, in many instances, corticosteroids. Of the 14 participants only Bill, Bruce, Andy, Tim and Shelly utilised an action plan approach to self-management in the community. Despite all participants being on LTOT, no participant possessed an action plan which detailed their oxygen prescription.

Andy spoke of his reluctance to commence the antibiotic regime detailed on his action plan and his perception of the consequences as a result of his reticence.

“Yes, very short of breath. Like I sit on the end of the bed, even with the machine on I am still gasping and that’s my own fault because I get an infection and I don’t take my antibiotics quick enough.” (Andy)

Calling the doctor, or seeking medical assistance, as advised on the action plan was viewed by Tim as a weakness. Although Tim followed his action plan and knew the steps, the final phase of seeking help was difficult to achieve.

“I used to have to watch. The first thing was the colour of my sputum if it changed colour. Then I started to go to the doctor but unfortunately I didn’t and of course the action was mainly you know sort of a weakness, the way I sort of looked at it. You just go to the doctor. I know there was three colours. There was green, a yellow and see your doctor or you know. I sort of fudged the first two parts of the plan and by that time I got down to reading the third one it was too late. Yeah and the doctor used to growl at me. You just don’t push the button [personal alarm] quick enough. You don’t get help quick enough.” (Tim)

Nearly all of the participants considered the breathing technique education they had received formed part of their action plan. Several of the participants’ action plans were available for perusal and none detailed breathing techniques. Despite this absence of written instruction most participants considered these techniques part of an unwritten management plan.

“Yeah, yeah, but it was things I’m still doing now really. It’s [action plan] no different to what I’m doing now it’s just trying to get me to my feet. It’s taken a while to get that breathing going you know get myself organised to breathe properly yeah. Have to stop and think, yeah very hard what I am doing.” (Bill)

Joan had no formally documented action plan, however described her own individually organised management plan.

“No not really I don’t have one [action plan]. Usually but I haven’t got any at the moment. I haven’t got any antibiotics. Normally I do. I’ve got prednisone on me all the time and I would take it if I started getting really short of breath at nights like I did the other night.” (Joan)

In summary, the small number of patients who utilised their action plan possessed a moderate to poor understanding of the contents and the action plans stepwise progression, necessary for effective management. Most expressed reluctance to commence the medication regime detailed on their plan which often resulted in hospitalisation, as a result of an acute infective exacerbation. Most of the participants considered breathing techniques as an important unwritten aspect of their action plan and employed these techniques regularly throughout every day. Interestingly, no action plans highlighted or directed the duration and/or litreage of the participants LTOT. This is particularly pertinent as LTOT is potentially the most therapeutic and costly aspect of COPD management and lack of patient adherence is well documented.

Spirometry and ABG.

When describing their experiences of spirometry, the majority of the participants remained non-committal and, for the most part, ambivalent regarding the psychological and physical impacts of this procedure. All but Shelly recollected and described one or more instances of assessment, utilising spirometry, throughout the course of their disease. Overall, participants in the study group averaged three episodes of spirometric assessment over the duration of their disease.

The following statements are representative of the participants' overall experiences regarding undergoing spirometric assessment. Most of the descriptions were to the point and verbally sparse.

“Oh yeah, yeah, I’ve done that test. I’ve had it this time and once before.” (Jock)

“When I first came here to live I had to go. Might have had it twice but I think I might have had it once with [respiratory specialist].” (Andy)

Bruce, Trina and Rupert described a dislike of spirometry, however did not choose to elaborate extensively on their experiences, or the reason for their dislike of the procedure.

“I have had that done and I didn’t enjoy it that much.” (Bruce)

“Oh, yes, yes, I hate that thing, Yes, yes, I’ve had that every time I go and see [respiratory specialist].” (Trina)

“Well, not really, you just get that blo... exhausted, you can’t get the air in. It’s all for a good cause but it’s not enjoyable.” (Rupert)

Tim had experienced spirometry in the past, however due to the severity of his disease could no longer manage to complete the assessment. Tim expressed a feeling of futility as a result of the repeated attempts he was required to undertake.

“Oh yeah, no, the last two times they just sent me back again. It just doesn’t work. I couldn’t even move it. Yeah I used to do it. They used to have me there and then they would get out the inhalers and then wait half an hour and do it again, but the last, oh probably the last two years, they have wheeled me down there and as soon as we got there the girl [medical technician] said no. She said I’ve tried you before so they would come and take me away again because I couldn’t even register the thing.” (Tim)

In contrast, when describing their experiences regarding ABG all participants, other than Bill, were able to verbalise and portray their abhorrence and dread associated with this test. The degree of emotion exhibited when the participants’ described their experiences was palpable.

“No it blo.... hurts I know that. Down here somewhere and swabbed both arms and couldn’t get one there so she [doctor] had to go this side somewhere.” (Andy)

“They’re all painful. I went yesterday for that blood test that was quite painful because she couldn’t get it in anywhere but in here [indicated her inner wrist] and she was doing it with a big needle and it wasn’t a little needle, usually have a little needle that goes in but this one was a big one and she’s saying I’m sorry I’m sorry I’m hurting you and I said it’s not hurting it’s alright but I think that’s why I was a bit faint.” (Ann)

Others identified variances in skill level between medical personnel and the “relief” when a skilled clinician managed to complete the test successfully, quickly and with minimal discomfort.

“They use the oxygen in the blood test. They hurt, they do sometimes, depends on who does it. Um, I can remember one doctor when I went into A & E and she was digging and she couldn’t get it and when they can’t get it really hurts. You know it’s like on fire. I said you do that once more and I’m going to stick it in your vein. You know because it was getting to the stage where I knew, I said just get someone who knows what they’re doing. I said that really hurts and she was quite ratty. Then one of the people came from the blood thing [laboratory] and they got it in first pop. First pop you know I never felt it.” (Joan)

Rupert spoke of the after effects of multiple attempts by medical personnel to obtain a sample and although the use of local anaesthesia lessened the discomfort at the time of sampling he continued, to this day, to experience “severe after effects.”

“He [doctor] had five goes and they had to go and get somebody else to do it and I think it was, up my arm was blue and for months I couldn’t hardly bend my elbow even, that was worse I think. And I’ve had, I’ve had about five I think, very deep ones and every one I’ve had you know, weeks after I could still feel it. The last three I got her to give me a needle first but there are still the after effects down there even if you didn’t feel so much at the time. I get severe after effects from it.” (Rupert)

A number of participants from one regional locality spoke of their experiences of ABG sampling in conjunction with the use of a local anaesthetic pre-procedure. Their experiences suggest the use of local anaesthesia is more likely to produce a positive outcome for the participant.

“Sh.. well because they’d had quite a few goes at that, first stupid bu... couldn’t get anything in so had to have another bl.... joker he had a go and he got it first pop. I thought well that’s good first pop. Oh do you mind if we have a go at this arm. Yeah go for it, still didn’t get it anyway was still trying to. They did it without local that time when I was in there you see and they come out and shove it back in again. She [nurse] said haven’t they told you about the local anaesthetic. I said what local anaesthetic? She said you can get a local anaesthetic into your wrist and you don’t feel nothing. I said thank you very much. Some of those poor bug... suffer, why don’t they mention it? The blo.... doctor or whatever the hell she was, she wanted one [ABG] you know and I said oh well I’ll have a local. Oh won’t take long she said. I said I don’t give a sh.... I don’t care how long it takes but I said I’ll have a local before you take it or do it. She [doctor] said Oh I

haven't got time to do that. I said well bug... off then and so she went. The nurses had a go and got it and anyway never seen her [doctor] again.” (Tom)

“It's the most painful thing out. Putting the needle in yes I know that, that's quite common. I know what I want and I ask for it [local anaesthetic].” (Trevor)

Rupert had experienced such a traumatic episode during ABG sampling that he refused to allow any further tests without prior use of local anaesthetic.

“Yeah well I told them that the only condition they can take it is if I get a needle first or I'm not having that thing again. That is extremely painful.” (Rupert)

In summary, the prescription and management of LTOT necessitates objective measurement on which to base the LTOT prescription and to guide the ongoing management. Spirometry and ABG analysis are the mainstays of objective measurement and hence are widely and frequently utilised. Most of the participants remained nonplussed regarding spirometry with only Bruce and Trina expressing a dislike of the process and one participant who was physically no longer able to perform the test. In contrast, ABG analysis invoked unequivocal and graphic participant descriptions relaying the dread of the procedure. Every participant described sequelae ranging from pain and bruising to ongoing neurological symptoms. The use of a local anaesthetic prior to the procedure went some way to alleviate the degree of pain experienced by the individual. However, the implementation of local anaesthesia appears to differ within localities and is

dependent on clinician choice and patient demand. The skill of the clinician performing the procedure appears to have a direct impact on the participant's experience of the test.

Adherence to LTOT prescription.

Literature and prior research highlights the importance of provision of LTOT for at least 15 hours per day. Hence, patient adherence to the prescription is important to maximise the therapeutic benefits. The wide variance in oxygen usage and the degree to which patients adjusted and individualised their regimes was informative. Table 4.4 (see over) provides an overview of the participants' LTOT prescription and usage.

Table: 4.4 Oxygen use

Pseudonym	Actual LTOT prescription	Actual LTOT usage	Use of short-burst oxygen	Use of portable oxygen
Jock	16 – 18 hours per	15 hours per day	Yes on	Not used

	day		exertion	
Bill	Unknown	6 hours overnight	Yes on exertion “panic”	Yes
Bruce	15 – 16 “more than this is a waste of time”	15 hours per day	Yes on exertion “panic”	Used when going out
Andy	16 hours per day	12 hours overnight	Yes on exertion “panic”	No and not used in public
Jill	16 hours per day	10 to 16 hours variable evenings and overnight	No response	Yes and used in public
Trina	16 hours per day	16 hours overnight	Yes on exertion “churned up”	Not used
Tim	Unknown	Fits and starts	Yes “coping”	Not used
Shelly	16 hours per day initially 24 hours	12 to 16 hours overnight	No response	Used when going out
Tom	14 to 16 hours per day	12 to 16 hours overnight	Yes “panic” “have a puff”	Yes used at night
Trevor	18 to 20 hours per day	16 to 18 hours self adjusts litrage between 2 – 6 and then uses mask	Yes “strain”	Yes used to save power and as an emergency supply
Ann	16 hours per day	16 hours overnight	No	Not used
Joan	16 hours per day	Patient has made the decision to drop to 12 hours overnight	Yes on exertion	Yes and used in public
Spencer	16 hours per day	16 hours overnight “wouldn’t be under that”	No	Does not have a portable supply
Rupert	12 minimum to 16 maximum	12 hours per night “sometimes I don’t even manage that”	Yes	Yes

Most participants adjusted their LTOT to fit into their lifestyle and to create the least possible disruption to their daily schedule. Some of the participants suggested they had their doctors consent to adjust their daily usage.

“I count from six o’clock at night because it is easier. I might have it on six to eight pm or something like that. Sometimes it’s after six. I class the time from six o’clock until six o’clock the next night that I have my 16 hours because you have got the long time over the night and then I know I only need another hour or two hours during the day but

[respiratory specialist] says if you have 15 hours you are alright. He says don't worry about it if you are on it 15. He said and don't worry if you have 18." (Jock)

"Oh well, let's be honest about this. Sometimes I am watching something on television and I can't be bothered getting up and getting it [oxygen]. If someone takes me somewhere in the morning and I have to take it off early I have got a little tank [portable cylinder]. Like my girlfriend took me out quarter past ten the other morning, it was my suggestion that she take me at a time that suited her but when I got home at quarter to twelve I put it back on again to suit my 16 hours." (Shelly)

For many participants the use of LTOT imposed limitations on daily life and this sense of restriction had the potential to lessen the degree of adherence to the LTOT prescription.

"I didn't really mind. Although I realised that it was going to restrict me. But there was a benefit, so get on with it." (Jill)

"I can't see the sense of having it on for 16 hours if I feel alright in 12 [hours]. But I don't know whether I am doing the right thing or not." (Andy)

For Jock the thought that one day he may be able to discontinue his LTOT provided an incentive to adhere more closely, albeit not exactly, to his prescribed regime.

“I think everything seems to be stabling up though, you know what I mean. What I want to know is how long I’m going to be on oxygen for. How long do you think I will be on oxygen for?” (Jock)

Adherence to LTOT prescription is dependent on the cooperation of the recipient of the therapy. Andy, Trevor, and Shelly demonstrated a degree of determination that the LTOT would not impose any greater than minimal restrictions on their lifestyle.

“Yeah, yeah. No I don’t, the oxygen is not running my lifestyle, I’m running it’s life if you know what mean.” (Andy)

“It’s entirely what I’m doing, how I’m doing it I don’t want to be restricted by the oxygen so therefore I’m careful what I do so I don’t have to use it outside the normal times that I would but I go for a walk every day.” (Trevor)

In summary, the participant’s adherence to their oxygen prescription appeared variable with Bill and Tim apparently unaware of their prescription parameters. Nearly all the participants adjusted their daily LTOT regime to fit into their lifestyle in an attempt to limit the disruption to socialisation and social mobility and to enhance their overall enjoyment of life. Only Spencer, Ann, and Trina adhered strictly to their prescription and most of the participants utilised some form of short-burst therapy, either via the concentrator or portable cylinder, during periods of exertion. Some participants highlighted the restrictions imposed by LTOT, nevertheless were accepting of the restriction when the physical benefits were evident and experienced.

4.6 The COPD Journey

‘The COPD journey’, although individual for each participant, highlighted many areas of commonality and concern. The journey was influenced, and punctuated, by the severity of the individual’s illness, formal and informal support systems available for stable and acute periods, coping styles and mechanisms and knowledge of the disease. Common aspects of ‘The COPD journey’ are highlighted under the following three headings: i) Knowledge of the disease and CO₂ retention, ii) Support systems, and iii) Coping.

Knowledge of the disease and CO₂ retention

Despite the seemingly vast amount of readily available literature, and other forms of media, and resources providing information on COPD and LTOT, most of the participants demonstrated a lack of understanding and some misunderstandings regarding their disease. This misunderstanding was highlighted by Jill who appeared to have limited insight into the causative factors of COPD and the reason for her “lung trouble”.

“Yes I would like to know what caused it [COPD]. Yes I get annoyed when it affects my voice. I would very much like to know what caused it but was it anything I have done or what? I did ask [respiratory specialist] and he said they’re working on it. They are

working on it but of course it takes a long time these things. All that I have been told is somebody muttered something about scarring. That's all I know. What they mean by scarring I don't know." (Jill)

Most of the participants demonstrated limited knowledge of COPD and when asked if they had previously heard the term COPD, the responses varied from no obvious understanding to one participant who demonstrated an extensive understanding.

"Well not really, nobody's ever told me that's what I've had. Yeah I know that's what I'm like yeah but nobody's ever told me." (Bill)

(Rupert) "What's that?"

Interviewer "Haven't you heard of chronic airways disease."

(Rupert) "No, my wife died of emphysema. I was following the same pattern. I actually haven't had anyone tell me I've got emphysema no one. I would say they didn't tell me, it certainly didn't register."

"Yeah, yeah, they haven't spelt it out in so many words. Um, they're calling it dyspnoea which is just difficulty breathing." (Jock)

"Yes, well its emphysema and it's your lungs. You are all clogged up with this tar or whatever you like to call it." (Andy)

Shelly thought that acronym COPD stood for the episodes of croup she had experienced as a child.

“I always had croup when I was young and of course you can't breathe very well with croup and I always used to get hay fever, but back to the word go I have always had something wrong with my chest. Not so much wrong as how do you describe it. When I had croup and mum used to always have me in the kitchen and have the kettle boiling and pots boiling to keep steam up to me.” (Shelly)

Only Bruce and Tom were able to demonstrate a more than superficial understanding of their disease and diagnosis. When questioned about his understanding of the acronym COPD, Bruce provided a concise and relatively informed interpretation of COPD.

“The bronchial tubes and that sort of thing are stuffed up. The airways and things yeah.” (Bruce)

The participants' overall lack of knowledge regarding their individual propensity towards CO₂ retention, or not as the case may be, was somewhat surprising given the frequency of acute exacerbations described by the participants and the resultant emergency transportation to hospital for definitive treatment. When asked if they had heard the gas carbon dioxide, or CO₂, mentioned at any point, most participants simply replied “no”. Bruce had recently been taken into hospital by ambulance and mentioned that he was concerned that the ambulance officers had the oxygen up “too high”. Bruce provided a rationale for his concern.

“I think it was on more than 1, more than 1 litre I would say and I thought I was too busy thinking about other things then that I thought to myself no you’ve [ambulance officer] got it up too high anyway.” (Bruce)

Interestingly, this seemingly well-informed participant expressed a degree of surprise when questioned regarding CO₂ and CO₂ retention.

“You mean you can have too much of this [oxygen]. Someone did tell me that I shouldn’t have more than 1 [litre per minute] and if you put it up to 2 it upsets the balance but I don’t think they have ever told me about CO₂.” (Bruce)

Tim described an understanding of his risk of retaining CO₂ which was elicited by overhearing a conversation between medical personnel and, apparently, not directly conveyed to him.

“No, well, it was mentioned here the last time and yet I have never had any problems with it but I heard them [doctors] talking about it. I just gather there’s something about me not dealing with CO₂ or something. I didn’t go into it. I’ve got a bit blaze about it now. I just tell them [medical personnel] to put the pills in the thing and I will swallow them.” (Tim)

Tom and Joan were able to describe their knowledge of CO₂ retention and its implications relatively accurately.

“Yeah and they’ve told us you’re not allowed to alter [the oxygen litreage] don’t alter whatsoever and they [respiratory outreach] wired this [regulator] because being a CO₂ retainer. Yeah, well, I’m like on a knife edge and I can go one way or the other that’s what they say. He [respiratory nurse] said if you bug.... around with that you do more damage than you know.” (Tom)

“Well all I know is its carbon dioxide, Yeah so it’s just a pointless gas as far as I know and how much I retain or whatever I wouldn’t have a clue. Yeah when I retain it or why I can only probably guess it’s through smoking, carbon dioxide out of that and comes from that’s how I get it.” (Joan)

In summary, nearly all of the participants demonstrated limited knowledge of their disease and disease process, with some seemingly unclear as to their actual diagnosis. Most of the participants were unsure of the meaning of the term COPD and attributed their shortness of breath to numerous causes including childhood croup. Most of the participants had never heard of the term CO₂ and were unaware of their propensity, or not as the case may be, to retain CO₂. This highlights a need for disease education and the imparting of greater knowledge for patients with COPD and their families. This is particularly relevant for those participants at risk of CO₂ retention, particularly during an acute exacerbation of their disease when the risk is more pronounced.

Support systems

Friends and family provided much needed and valued support for many participants. Without the support provided many would have the potential to become increasingly housebound and socially limited. In many instances, friends, families and even neighbours, assumed the role of an informal caregiver and performed duties which included the set-up and transportation of the participant's portable oxygen. Shelly spoke of her enjoyment of country music and the support her friend had previously provided to enable her to attend and enjoy country music events.

"I had a very good friend. I still have a very good friend and she used to carry my oxygen into the pub and I would be sitting there like I don't know what with this little oxygen tank beside me and this [nasal cannula] bunged up my nose. I still go to country music but it's always in the afternoon and I've got that space of time that I don't need it [oxygen]."
(Shelly)

Many others relied on the support of obliging neighbours to accomplish the tasks of everyday living and for the occasional outing.

"I mean it's alright getting a taxi, my neighbour takes me up. But it's the getting around. It was alright when my neighbour was Mr he gets the chair and pushes me around in the chair and lets me get my breath back but I don't like being in that chair to be quite honest with you." (Bill)

“Yeah, I think the neighbourhood itself keeps an eye on you. What you can do I don’t think you could be as good as I am on your own. You need a back up. [district nurse] is [home support provider] the housework and everything is [home support provider] and cousin does the groceries and all, there’s plenty of inter-activity here.” (Trevor)

Formal support systems encompassed those community supports provided by the respiratory outreach teams including, in some localities, rehabilitation programmes. In many instances, depending on the participant’s locality, the district nurses provided ongoing support and daily management.

Bruce was the only participant who did not feel supported and informed by the systems in place during the commencement, setting up and, to an extent, the ongoing management of his LTOT. The participant (and his partner) was critical of the speed at which the acquisition and set up of LTOT proceeded and did not feel that particular medical personnel possessed sufficient knowledge of LTOT.

“There wasn’t much told about it [oxygen] at all really. We went and picked it up. It was all rush, rush, you gotta get this you gotta do that. I saw the doctor one day and we had to pick it up the same day wasn’t it? The district nurse came down and she was in a hurry and I thought gosh this isn’t very good. I can’t remember who came down but I just thought well, it just wasn’t very good PR I don’t think. In actual fact, she [district nurse] wasn’t even too sure how it was supposed to go, to be honest.” (Bruce)

Overwhelmingly participants could not speak highly enough of the services provided by the medical personnel in the hospital environment and the follow-up provided by the respiratory outreach teams, respiratory nurse specialists and district nurses.

“No there’s no quality of life now, I’ve got everything I really want and inner peace but it’s all been ruined by the smoking. Everybody’s done their best for me, [respiratory outreach] and everything brilliant. Oh they’ve been brilliant. I don’t think if it wasn’t able to get all those people then I’d be dead because they got me through. I am probably a good example of what they do because I’ve been very, very ill the last year and I’ve been as good as can ever be expected.” (Trevor)

Joan highlighted her reliance on the experience and knowledge of the nurses within the acute care setting and verbalised her disappointment and concern when moved to a hospital with a focus on rehabilitation.

“And she [nurse] said we can do this. I said no you can’t I said I need the nurses that know what they are doing. I said you girls are great but you are not what I need.” (Joan)

Although very complimentary regarding the community services and supports provided, some participants spoke of the isolation and loneliness surrounding the use of LTOT and the disease process of COPD. The participants suggested they would prefer more frequent interactions with medical personnel than the six monthly visits currently received.

“Sometimes I feel they could have a bit more of a home visit type thing. People are stuck at home a lot. Yeah like someone to come around and have a chat to you and like when you don’t get out and as I say my children have been very good but that one’s working. I don’t see as much of them as I used to, um and if I am not well, I don’t go anywhere and no one comes and sees me.” (Joan)

Despite most of the participants requiring concentrated formal and informal supports and experiencing frequent hospitalisations, only Joan had previously utilised respite care. Joan found the isolated locality, and distance from her family, impacted negatively on her overall experience of respite care.

“Then [son] came out later that day, that Sunday he came back you know so I was there [respite hospital] for the two weeks and I must admit it did me good. That was good I loved the hospital it’s just I wouldn’t go again, it was just too far out of town.” (Joan)

Palliative care is a comprehensive wrap around support package which includes respite care and is provided predominantly for those people who have a diagnosis of cancer and, to a lesser extent, other terminal diseases. Although COPD is essentially a terminal disease, only one of the participants identified as a recipient of palliative care support.

“No I am under palliative care. [palliative care specialist] yes that’s the man I see.” (Bill)

Nutritional support has been identified as important for people with COPD and is particularly important for those people who experience moderate to severe COPD. Only one participant mentioned the support of a dietician as part of their care package.

“Now I’ve got a dietician so I’m pretty well looked after.” (Jill)

Rehabilitation programmes are offered in some localities and not in others, due to funding constraints. All the participants had previously taken part in rehabilitation programmes and their perception of the benefits was variable. Half the participants would attend rehabilitation programmes if they were available and all the participants suggested the most valuable aspect of the programmes were the breathing exercises.

“I suppose exercises to help you breathe would be one good thing. I mean it’s alright doing as [respiratory nurse specialist] said. They give you a couple of tins of fruit and you go like this [demonstrating bicep curls] but its different sitting at home on your own. You know you think who wants to sit and hold these tins of fruit up. But you are with a group and you are all sort of doing that sort of thing, then it’s different.” (Andy)

“First one would be exercises like you know just exercises the arms and legs and things that were going to be, you know, just mobile and the next time we went we started lifting a few weights and peddling a bike and climbing up a set of steps. And the breathing exercises.” (Tom)

Trina was scathing of the rehabilitation programmes emphasis on inhaler use techniques and her perceived lack of focus on those persons on LTOT.

“We did that two years ago and it was a farce, don’t think very many were on oxygen. It was mainly to do with the inhalers you know and things like that and exercises and how to use them that we went to. Breathing exercises to help relax would be useful.” (Trina)

Despite her seemingly dismissive attitude towards the rehabilitation programme, when asked if she would attend a subsequent programme Trina answered.

“Yes I would.” (Trina)

Jill expressed a desire to avoid attending rehabilitation classes, due to her reluctance to participate within a public forum.

“Don’t think so. I am not very good at public things like that.” (Jill)

Others spoke of the logistical difficulties in attending rehabilitation programmes.

“No I was too old I didn’t want it, I didn’t want to go through this, also I knew that it was going to be difficult to get there. The logistics, the cold, the temperature can be controlled here but can’t there and there was no use for me. I could do it all at home or with someone else.” (Trevor)

Only one participant had not previously been offered the opportunity to attend COPD rehabilitation classes. Ann had decided that she would not attend in the future, due to her concern that any physical exertion may exacerbate her degree of breathlessness.

“No, only about once I started to do the exercises. I would be a bit frightened of them actually playing up with the actual breathing. You know what I mean.” (Ann)

In summary, all the participants identified support systems which encompassed family, friends and in some instances neighbours, who performed tasks including managing the participants portable oxygen. These informal support persons often impacted positively on the participant’s ability to function both within and outside of their own home environment. Formal support systems including district nurses, respiratory nurse specialists and in some instances outreach teams, provided the ongoing assessment and monitoring of the LTOT participants.

Overwhelmingly, the participants’ feedback was affirming and some considered this formal support was the main reason they were able to remain in their own homes. The participants’ views regarding rehabilitation programmes were variable with approximately half the group willing to attend ongoing classes, especially those with a focus on breathing exercises. Most participants had attended prior programmes and all reiterated the value and therapeutic benefits of education which focused on breathing techniques.

Coping

For the participants in this study coping meant different things to different people, in spite of this, all of the participants described, seemingly innocuous, things that made a difference to their lives. The partner of one participant spoke of her limited social interaction as a result of her husband's disease and his use of LTOT and her decision to continue to enjoy life and social interaction without her husband's company.

“He won't go out at night. I go by myself or I don't go. But now I have decided well I am going. As a couple we do nothing, yeah as I say as a couple we do nothing.” (Bruce's partner)

Verbal encouragement and positivity relayed by medical personnel enhanced some participant's ability to cope with their disease, disease management and its limitations.

“I'd been having a monthly blood test and they had been coming down from the laboratory to do it and [practice nurse] from the doctors surgery she rung me the other morning and she said it's alright love you won't be getting anymore blood tests until April of next year, you are doing fine. So that's quite good. That's very encouraging isn't it?” (Shelly)

Others found avoidance of certain things maximised their ability to cope and lessened the risk of experiencing a sense of depression. Shelly found her inability to reach 200 ml on her peak flow test depressing, hence decided to stop measuring her peak flows.

“150 [ml], it depressed me that I couldn’t get it over 200 [ml]. I am not really a depressing person but I think to myself Jesus Christ I had 150 [ml] that was as far as I could get. So I stopped doing it.” (Shelly)

Emergency management and planning recurred as a common theme in coping. The reassurance of the close proximity, and perceived readily available, ambulance service was deemed an important aspect of coping by many participants. Over half of the participants highlighted their reliance on the 111 emergency system and the ambulance service for definitive management in the acute phases of their disease.

“But if the power went off for any length of time I’d just ring an ambulance and go into hospital.” (Joan)

“But I mean what we’re saying is if I didn’t have my bottles and we had a power cut, no concentrator or the concentrator crapped out and I didn’t have bottles. Yeah, see the hospital would be the only one, because other than that would be to ring 111 and get the ambulance.” (Tom)

“Another thing too if I am really bad I just push my button [personal alarm] and the ambulance would be here before you can hardly turn around. It’s up there with the action plan and if I felt pretty bad I’d just push my button.” (Shelly)

Joan spoke of her use of the ambulance service in a period of acute exacerbation during which she feared for her life.

“I rang 111. She [district nurse] was supposed to be coming over but she said don’t bother telling me just ring the ambulance you know. By the time they came out I was really struggling to breathe and they got me into hospital. I actually thought I was going to go into another respiratory arrest, I really felt it was that bad.” (Joan)

In contrast, some participants were reluctant to seek emergency assistance in acute exacerbations and had been encouraged by medical personnel to do so.

“I sort of fudged the first two parts of the plan [action plan] and by the time I got down to reading the third one it was too late. Yeah and he [doctor] used to growl at me you just don’t push the button [personal alarm] quick enough, you don’t get help quick enough.” (Tim)

In summary, many participants, and/or their family members, employed various coping strategies, including avoidance of tests/monitoring which they found negative or distressing. Many participants appeared to grasp onto positive comments regarding their disease and found these remarks reassuring. During acute exacerbations of their disease, whether due to physical and/or psychological precedents, the use of the 111 system with an ambulance providing an emergency response was commonly reported. In some instances, participants viewed the

ambulance service as a backup system in case of mechanical or electrical failures which had the potential to adversely affect their supply of LTOT.

4.7 Feel the panic and breathe anyway (Psychological aspects of COPD)

The psychological impacts of COPD were wide ranging and overwhelmingly impacted negatively on the lives of the participants, and in some cases family and friends, in this study. All of the participants highlighted negative psychological aspects, with the most debilitating being their experiences of breathlessness and the associated level of heightened anxiety. All the participants were readily able to provide detailed descriptions of their experiences resulting in powerful and insightful narratives. The psychological aspects highlighted are grouped under the following four headings: i) Panic, ii) Depression, worthlessness and frustration, iii) It's all my fault, and iv) How will I die.

Panic

Panic was reported by every participant and was, in most cases, a daily occurrence which resulted in a substantial impact on the participant's everyday life. The participant's exacerbation of dyspnoea often increased the level of panic they experienced.

"I used to panic badly when I started to get this [oxygen], oh hell yeah. When I first started going over here [hospital] I would get worked up and then I'd be panicking and they [medical personnel] said no you are alright, calm down. But I thought I was really

dying you know, you know this was when it first happened. And I'd bl..... gasp it will come, but yeah I understand now. I've learnt to lie back and try and breathe through my nose." (Tim)

"Yeah, yeah and the doctor said I can have it [oxygen] turned down a bit. So at night time I'll panic a bit but I've always been the same I always panic on something and the oxygen takes me down quick if I panic too much, yeah." (Bill)

Many participants spoke of the importance of techniques to attempt to alleviate the panic experienced when they could not breathe. A breathing technique that the participants termed "smell the roses and blow out the candles" was utilised by many to enhance their ability to cope, and to relieve their dyspnoea.

"Yeah they had them [breathing exercise chart] on the wall when I was in the ward. A lot of people even lie still like that, because all you're doing is using this piece up here and this diaphragm down here they say is the thing that's got to do the work, you start breathing through your nose if you can and blow through your mouth. I do that at night time when I'm lying in bed. Sometimes I do it during the day." (Tom)

Specialist respiratory and general nurses provided the education necessary to teach the breathing techniques used by the participants to reduce their panic and respiratory distress.

“Breathe out, smell the roses, blow out the candles. Yes, yes, they [nurses] taught many people that. They taught me that at the hospital that was one of the first things the staff taught me, the breathing is important with so many people.” (Trevor)

“Yes, yes, yes, she’s [respiratory nurse] the one that taught me how to breathe, yeah, in through the nose and out through the mouth.” (Bill)

“It’s a safety thing, more so than having to use it [LTOT] but I get to that stage where rather than panic and start to panic which you can do I would rather have it there.” (Joan)

Depression, worthlessness and frustration

Depression, worthlessness and frustration were commonly identified emotions. Some of the participants were taking prescription medications, including antidepressants, to alleviate their psychological symptoms.

“Oh yeah and then everything just eases off. The breathlessness can frighten the hell out of you and so I take these funny tablets [antidepressants]. Yeah, that’s part of my day. They stop me having these panic attacks. Oh well, the doctor [respiratory specialist] when

I was staying in the hospital I was under him. It was depression this is the part of your brain yeah. If I didn't have them [antidepressants] probably be in there now." (Tom)

"Now you have [rural hospital] and [rural hospital] and another on way out. They are all way out now and as I say I had a really bad run with oxygen and I was really depressed. I think I was quite low. I got over that sadness and got over that. I think I was depressed from everything that had been going on and the lack of oxygen and of course then [son] had to take it [oxygen] to me and then we brought it home." (Joan)

Bill used the analogy of being discarded like refuse when describing his mood and feelings regarding his disease and his sense of self-worth.

"I would have been put in a dump probably." (Bill)

Others found the enforced need to take life more slowly particularly frustrating and limiting.

"Yeah, if I find something and I get a bit exasperated not bad tempered it's more I get frustrated, I do I get so frustrated I want to do something that I haven't tried to learn to put my hands down and try and take some breaths. It's all been a learning curve. Unfortunately too late but that's the way life is." (Tim)

Trevor found the company of his dog lessened his depression and encouraged him to participate in exercise and venture outside of the house.

“He’s [dog] non- demanding. With wonderful pets you come first, you can hold and talk to him, they sleep with you and share so you’re never alone. Oh, and when I was in hospital [sister] used to bring this one [indicating dog] into the ward.” (Trevor)

It’s all my fault

For some participants self blame for their current situation was evident. Half the participants considered they were wholly responsible for their disease and Bill and Trevor considered they deserved to be in their current situations.

“If you got to get back any luck there’s not much you can do about it, it’s all my fault. I am not blaming anyone else.” (Bill)

“And that’s [breathlessness] and part of the prostate cancer so there’s a lot of little mixed pieces in there, but we get by. We are not complaining I deserved it.” (Trevor)

How will I die

The end of life was a concern for some of the participants who expressed feelings of dread at what their death would be like.

“But I was talking to a lady in there [hospital] last time I was there. Her husband, before he died, was on it [LTOT]. She said ‘I hate to tell you this’ she said, don’t worry I know it’s not nice.” (Tim)

“It’s all up to me. I’ve been given the facilities and I am the master of my own destiny now for what’s left.” (Trevor)

In summary, there appears to be, to a degree, an acceptance of self infliction and stigmatisation for those who have COPD. This view, in the most part, appears related to the participant’s history of smoking and their belief that they have by smoking contributed to their disease. The psychological impacts of COPD are varied, nonetheless all participants highlighted the impact of the dyspnoea-panic-dyspnoea cycle and all employed breathing techniques in an attempt to lessen the impact. Depression appears to impact on the lives of half the participants with some utilising medication to alleviate and manage the symptoms. Some participants highlighted feelings of frustration at living within the limitations of their disease and others highlighted a degree of trepidation and foreboding around their disease trajectory towards the end of life.

4.8 Summary of key findings

The key findings from the study elucidated both the diversity and commonality of the participants’ experiences and provided a valuable insight into previously underexplored areas. The main findings are captured within each of the four major themes: i) ‘Smoking’, ii) ‘Oxygen

therapy the good the bad and the necessary', iii) 'The COPD journey', and iv) 'Feel the panic and breathe anyway' (Psychological aspects of COPD).

'Smoking' captured the participants' past and current smoking behaviours and the implications, including safety and efficacy, of these behaviours for LTOT. All participants had a past, or current smoking history, however not all accepted a link between smoking and their COPD diagnosis. All participants suggested in the early years of their smoking the dangers of smoking were either negated or not yet realised and that smoking was normalised and even glamorised. Half the participants perceived a direct causal relationship between COPD and smoking and all highlighted the addictive nature of the habit.

The theme, 'Oxygen therapy: The good, the bad and the necessary' highlighted the positive and negative aspects of living with LTOT and the participant's reality regarding ongoing assessment and monitoring. Overwhelmingly, the participants' experiences were positive and most viewed their LTOT as a medicine necessary to support their physical wellbeing and daily living.

Although the logistical implications of LTOT demanded a heightened degree of ingenuity and the support of others, most of the participants considered the negative aspects were ameliorated by the benefits they experienced. Monitoring included two differing modes of assessment namely, spirometry and ABG sampling. The participants were for the most ambivalent regarding the physical and psychological impacts of spirometry. On the other hand, the dread and emotion portrayed regarding ABG sampling was significant and the negative impact was clearly evident.

‘The COPD journey’ sought to investigate and describe the participant’s knowledge of their disease and their propensity to retain CO₂. Most of the participants possessed little, or no, understanding of the basic pathophysiology of COPD and some remained uncertain as to their actual diagnosis and the reason they were on LTOT. In an emergency situation (often as a result of an acute exacerbation of COPD) knowledge of CO₂ retention may prove to be lifesaving, despite this, most of the participants had either never heard of the term CO₂ retainer, or were unaware of their risk. Support systems highlighted the formal and informal systems utilised by the participants. All the participants received support which in many instances enhanced their ability to continue to live in their homes whilst maintaining a semblance of independence. The participants’ ability to cope with their disease and its limitations was often enhanced by positivity relayed by medical personnel and the conscious avoidance of tasks deemed depressing or negative. The rapid response of the ambulance service featured frequently as another avenue to maximise the participant’s ability to cope in times of crises.

‘Feel the panic and breathe anyway’ explored the psychological aspects of the participants’ reality and their everyday existence whilst living with COPD. Overwhelmingly, panic and feelings of breathlessness featured as the most debilitating emotions, with all participants highlighting the severity of their previous experiences. For nearly all the participants breathing exercises provided an effective self-management strategy to alleviate the degree of panic experienced. Many participants described depression, frustration and a sense of worthlessness as a direct result of living within the limitations of their disease. A small number of participants found medications went some way to alleviate their symptoms, however only a small percentage of the study’s participants had been offered symptomatic relief via pharmaceutical means. Some

of the participants expressed acceptance they were to blame for their current situation and considered they deserved to be on LTOT because they had smoked. Most participants avoided any discussion regarding the end of their life, conversely two spoke openly of their fear of death and the manner in which they would die.

CHAPTER FIVE: Discussion

5.1 Introduction

The findings of this study confirm that LTOT has the potential to impact profoundly, both negatively and positively, on the lives of those who have COPD. The findings highlight important areas in need of further elucidation and discussion. These areas include, amongst others, an underestimation of the psychological impacts of COPD and a high degree of non-

adherence to LTOT prescriptions. This study explored the experiences of 14 participants diagnosed with COPD who utilise LTOT. The principal aim of the study was to elucidate the participants' experiences of LTOT and to gain an insight into their experiences of aspects of monitoring, including spirometry and ABG sampling. Throughout this chapter, the major findings of the study are summarised and discussed through the lens of existing research. The implications for clinical practice are discussed and suggestions are proffered for future research directions and areas in need of further elucidation. The four major themes will be discussed individually under each of the previously mentioned four headings. Findings of this study will be discussed with reference to current and seminal literature.

5.2 Smoking

This study found that all participants had a history of smoking with some commencing smoking at a very young age. A history of smoking is consistent with statistical literature and previous studies which highlight between 85–90% of people with a diagnosis of COPD were, and in some cases still are, smokers (Broad & Jackson, 2003; Ministry of Health, 2008). Literature states that smoking remains the primary risk factor for development of COPD. Despite this, in up to 10% of cases risk factors other than smoking may include genetic influences and exposures to occupational and environmental dust, toxins and particulate matter (Broad & Jackson, 2003; National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Despite a plethora of literature, and advertising by public health advocates, highlighting the dangers of smoking, only half of this study's participants implicated smoking in their diagnosis of COPD. The participants who considered smoking had instigated their "lung problem" spoke of a sense of self-blame. Bill, Tim and Trevor considered they "deserved" to be in their current state of health as they had chosen to smoke and by smoking they had sealed their fate. This sense of defeat was highlighted by Spencer who had tried several times to cease smoking and had managed to "cut back" to three cigarettes a day. Spencer continued to persist with smoking cessation however, he questioned the health benefits he would gain and admitted to a degree of defeatism. Many identified other precedents including "small lungs", eye drops and alpha 1 antitripsin deficiency as the causes of their lung disease and some participants stated that their opinion was corroborated by the health professionals overseeing their care. These findings are similar to a study by Robinson (2005) in which some patients remained mystified as to how they acquired COPD, despite their smoking history.

Interestingly, male participants in my study highlighted the promotion of smoking as a treat or a reward and described the allocation of packets of cigarettes as part of their ration packs, around the period of the Second World War. The addition of cigarettes in the servicemen's ration packs resulted in males becoming the predominant group of tobacco users with a period of heightened uptake during and post the war periods. In the post-war years women began to take up smoking and now identify in numbers comparable to the male population⁴. None of the female participants identified as ex-servicewomen, nonetheless all had previously been smokers (Broad & Jackson, 2003).

⁴ The intervening years have seen marked social change. This change has resulted in a decreased incidence of the New Zealand population taking up cigarette smoking when compared to the decades 1940-1970.

Participants reported feeling encouraged to smoke by advertising material promoting the normalisation and glamorisation of smoking, however most had since either ceased smoking or had attempted several times to cease smoking. Bill and Jock admitted to a lack of awareness of the health related dangers of smoking during their early smoking years. Bill accused the cigarette manufacturers of recently altering the formulation of cigarettes to include “rubbish” which encouraged addiction. Interestingly, only two of the participants discussed the use of pharmaceutical smoking cessation assistance. Pharmacotherapy, in conjunction with brief interventional counselling, has been shown to be more effective than counselling alone and is recommended (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009). Participation in a smoking cessation programme was not highlighted by any of the participants. Several participants had attempted to stop smoking however none made mention of cessation counselling or the use of medication. Smoking cessation is considered to be one of the most important goals of COPD management with proven benefits including reducing the risk of developing COPD and minimising severity and progression of the disease. The efficacy of brief interventional approaches for every current smoker (in combination with pharmacotherapy) has been documented (O'Donnell, et al., 2008). In contrast, some authors found that despite intensive smoking cessation counselling and pharmacotherapeutic intervention for patients with, or at risk of developing COPD, the rate of smoking cessation amongst this population was dismal and discouraging (Gillissen, Wirtz, & Juergens, 2007).

Smoking whilst on LTOT was a practise employed by Andy, Trina, Tim, Tom and Spencer and all were aware that smoking cessation was a requirement prior to commencing LTOT. Despite

this awareness they did not appear to be cognisant of the dangers associated with smoking whilst on LTOT. The participants appeared to be more concerned that the research being undertaken would disclose their concurrent smoking and LTOT use. Andy, Trina, Tim, Tom and Spencer appeared more concerned about the potential to lose their LTOT than the associated safety risks. LTOT is not indicated for patients who continue to smoke due to safety concerns (including an increased fire risk) and secondarily, that continuation of smoking has the potential to offset the benefits conferred by LTOT (Beard, 2005; O'Donnell, et al., 2008).

Over the past ten years there appears to be an increasing incidence of burn injuries as a result of smoking whilst on LTOT (Lindford, Tehrani, Sassoon, & O'Neill, 2006). The increased notification of burn injuries may in part be due to the growing use of LTOT in the management of COPD. A recent audit undertaken in the United Kingdom, by the plastic surgery department of the Norfolk and Norwich University Hospitals, suggests between 14-51% of LTOT recipients continue to smoke despite the identified hazards (Lindford, et al.). These figures are congruent with the findings in this current study. In spite of the inherent risks of continuing to smoke whilst undergoing LTOT, participants in this study have not reported any injuries or burns. The absence of injuries within the participant group may be related to the small participant sample.

5.3 Oxygen therapy: The good, the bad, and the necessary

Various health-giving benefits of LTOT have been extensively documented. Most of the participants in this study considered LTOT promoted improvements in overall physical health

and enhanced a sense of wellbeing. A Swedish study of 10 patients with COPD highlighted many of the advantages for the body as a result of using LTOT. Patients highlighted their understanding of the body's requirements for oxygen and the life giving actions of oxygen. In this current study, participants' spoke of the effects of LTOT on the whole body, with benefits for the heart and cognition, culminating in improvements in concentration and word finding ability. An understanding of the holistic benefits of LTOT has been highlighted in several studies and appears to enhance the individual's acceptance of LTOT and endorse the connection between a sense of physical, psychological and social wellbeing and the use of LTOT (Earnest, 2002; Ring & Danielson, 1997).

The findings of this study are consistent with current literature, in that the majority of participants considered that LTOT had improved their physical and psychological wellbeing. Bruce, Andy, Shelly, Tom, Jock, Trevor and Rupert viewed their LTOT as a "medicine" which was prescribed to treat their COPD and as such were more accepting of its use. The participants' perception of the ability of LTOT to relieve dyspnoea was the most commonly identified benefit. All of the participants highlighted the impact of dyspnoea on their ability to maintain their usual ADL's, including showering and dressing. Barnett (2005) identified dyspnoea as the most problematic and disabling symptom experienced by the participants in her study. Barnett explored the impact of COPD and breathlessness on the individual's ability to maintain independence and the social linkages deemed important to the individual. Breathlessness impacted on all aspects of the individual's life and was often insidious in nature failing to be recognised by the individual and/or their families until well advanced.

LTOT's efficacy in the reduction of breathlessness has been challenged by a recent randomised controlled study and experts in the area of respiratory disease. Restrict (2009) found it is a commonly accepted misnomer, amongst clinicians and patients alike, that oxygen is able to treat breathlessness and there is a responsibility for clinicians to clearly identify that there is no evidence that LTOT will improve breathlessness. These findings are in direct contrast to the findings highlighted in this current study, where nearly all of the participants viewed LTOT and short-burst oxygenation as their mainstay and first line treatment for breathlessness. The findings in this study are congruent with those highlighted in an evidence based review. Roberts (2004) found self-administered short-burst oxygen was viewed by their recipients as "life-saving" nevertheless, Higginson (2010) reported the use of oxygen to treat non-hypoxic patients should be carefully considered. Higginson goes on to conclude that in light of the physical and psychological barriers and fiscal burden often incurred as a result of oxygen therapy, it should not be offered unless the patient is hypoxic ($\text{PaO}_2 < 7.3 \text{ kPa}$ or 55mmHg). To receive LTOT the participants in this current study met the criteria for prescription which includes a $\text{PaO}_2 < 7.3 \text{ kPa}$ or 55mmHg hence would be considered hypoxic.

A recent study has further fuelled the debate, and heightened awareness, around the supply of LTOT for the palliation of breathlessness. A randomised controlled trial of 239 patients with life-limiting illness, not hypoxic and with refractory dyspnoea, found that oxygen delivered via nasal cannula shows no significant therapeutic value when compared to nasally delivered room air. The authors conclude the high cost of providing LTOT to alleviate breathlessness in non-hypoxic patients is not warranted once a cost/benefit ratio is employed (Abernethy, et al., 2010). Any discussion regarding the treatment and/or palliation of breathlessness ought to be scrutinised with

an awareness of the paucity of objective scientific knowledge regarding the physical and psychological precursors. The exact mechanisms behind the patients' subjective experience of breathlessness and thus the maximal therapeutic intervention remain as yet not fully explored (Abernethy, et al., 2010; Navigante, Castro, & Cerchietti, 2010).

Interestingly, the supply of LTOT and the associated costs of its supply were a recurring theme in this study. An unexpectedly large group of participants requested LTOT and fought to obtain LTOT, apparently in some instances without the complete agreement of their attending physicians. Two of the participants rationalised their request for the supply of LTOT on a cost basis. Rupert and Joan considered it would be less burdensome on the health system if they were able to remain in their own homes and went to the extent of offering to buy their own concentrator unit. Despite an in-depth search of the literature this appears to be a previously unexplored finding, nonetheless the desire of the individual to remain within their own home and with their family is a universal finding frequently identified in other studies. The move to provide more clinical services in the patient's own home is a trend which appears to be borne out of the hospital at home and palliative care models and there appears to be a patient preference to remain at home as long as possible, even in some cases til death occurs (Dudgeon, 1995; Ojoo, et al., 2002).

The participants in my study indicated a strong preference to remain in their own homes until the time occurred when they were no longer able to "cope". Patient preference to live in their own homes may in some instances be the end result of a media focus on the burgeoning societal cost of managing chronic diseases such as COPD. Chronic diseases have been termed the "The health

care challenge of this Century” (Sheridan, Kenealy, Parsons, & Rea, 2009). COPD is a chronic disease which commands a disproportionate share of the New Zealand health dollar and often results in numerous complex hospital admissions. The COPD patient is unlikely to avoid the stigmatising attitudes and comments of some medical professionals and the media alike, and they are often acutely aware of the expense of the LTOT necessary to prolong their life (Higginson, 2010). This awareness of the societal burden of COPD was portrayed by participants in my study who offered to purchase their own concentrators in an effort to lessen the financial impact on the health system and/or to expedite the implementation of LTOT.

The potential for the inappropriate supply of LTOT has been explored, however this study focused on the supply of LTOT to patients who may not have met the qualification criteria, rather than the withholding of LTOT for those who do (Guell Rous, 2008). The patients’ perspective of medical management of COPD in the United States of America was explored and these surveys highlighted the potential for less than optimal management with a lack of physician adherence to guidelines. This lack of adherence may be as a result of a knowledge deficit and/or an enduring prejudice that COPD is a self-inflicted disease (Rozenbaum, 2008). No evidence of physician prejudice was divulged by any of the participants in this current study, nonetheless a study by Cornford (2000) found there may be a potential for “mismatch” in the supply of LTOT. Cornford concludes some inappropriate recipients are currently receiving LTOT, whilst others who have the potential to experience physical and psychological benefits have been overlooked.

Whilst some participants actively sought the supply of LTOT, others found aspects of LTOT burdensome. The burden of LTOT, as detailed by Bruce, Jill, Trina, Tim, Ann, Rupert and

Spencer, included the logistic arrangements necessary for managing LTOT and the noise generated by the concentrator. A study by Kampelmacher et al. (1998) highlighted the increased incidence of patient discontent around the use of LTOT. These authors found the majority of complaints were regarding the necessity to utilise a concentrator device to deliver LTOT. The authors highlight that use of a concentrator is associated with more problems than the use of oxygen cylinders. One ought to temper this statement with the admission that in most previous studies the complaints of LTOT patients have not been explored. Although the study by Kampelmacher et al. was undertaken thirteen years ago it possesses relevance to current practices and technologies. Since 1998 there have been few major technological advances to improve the delivery and acceptability of LTOT (Cornford, 2000). Kampelmacher et al's findings are congruent with the findings in this current study in which nearly all the participant complaints centred on the oxygen concentrator unit. Participants expressed concerns about its size and weight which limit portability and in turn the participant's ability to be socially and independently mobile.

The participants' ability to undertake national, and particularly international, travel is described as limited and made more difficult by LTOT, which limits the individual's ability to be independently mobile. A small minority of this study's participants expressed a desire to travel with Shelly and Andy wishing to undertake overseas travel. Guidelines suggest airline travel is possible for those COPD patients on LTOT, still most will require supplemental oxygenation in flight and flying should not be undertaken unless the patient is in a stable phase of their disease and meets certain criteria (American Thoracic Society & European Respiratory Society, 2004; National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The

Thoracic Society of Australia and New Zealand, 2009). Rozenbaum (2008) believes the use of LTOT, whilst in aircraft, is deserving of greater attention in the hope that this information may encourage more LTOT recipients to enjoy the freedom of travel by air.

Within the recipients' home environment the concentrator size, weight and limited portability is an issue. To increase the ability of the LTOT recipient to move relatively unfettered inside their dwelling, a long length of oxygen tubing is attached to the concentrator unit. The potential danger of falling over this trailing oxygen tubing was a concern for Jill. The noise generated by the concentrator was problematic for some of the participants in this current study. The restrictive nature of noisy and cumbersome concentrators was a recurring theme in other studies and necessitated lifestyle changes and alterations to the recipients routine in an effort to lessen the limitations imposed (Cornford, 2000).

Bill, Bruce, Trina, Shelly, Tom, Trevor, Joan and Rupert highlighted the benefits of portable oxygen cylinders as an adjunct in the delivery of LTOT. The participants enjoyed the flexibility and safety provided by the ready access to portable oxygen. Kampelmacher et al. (1998) argue that lightweight liquid oxygen systems may further enhance the ambulant recipient's ability to maintain their mobility and independence. Liquid oxygen systems are not commonly utilised in New Zealand, with no participants in this study using these systems or even appearing to be cognisant of their availability. Despite the enhanced transportability of oxygen cylinders, Andy and Jill refused to be seen in public with portable oxygen. They felt embarrassed by the visibility of their disease and viewed the need to utilise portable oxygen in public as sign of more severe COPD. This embarrassment and poor body image is highlighted in a Japanese study which

argued this reluctance and perceived stigma resulted in increased social isolation and an increased incidence of negative psychological impacts (Doi, 2003).

The inability to perform ADL was highlighted by most of the participants in this study, with showering and dressing the two most difficult and physically demanding activities. All but Jock found the exertion required to complete these tasks overwhelming at times, and most relied on self-administered short-burst oxygen therapy to initiate and complete the desired task. Showering and dressing necessitated a highly planned and orchestrated performance which in most instances took close to one hour to complete. Cornford (2000) discovered LTOT recipients found bathing and shaving two of the most difficult activities and most adapted their oxygenation delivery to suit their needs and to lessen their degree of distress. These “trial and error” practices permitted the recipient to obtain maximal individualised benefits from their LTOT.

Despite maximal benefits from LTOT, Andy, Jill, Trina, Tim and Rupert required some form of support, either formal or informal, to enable them to shower and dress. The remaining participants managed through ritualised processes to complete the desired task without additional supports. In some cases support was provided by family members who assumed the role of care givers. The husband of one elderly participant had taken on the role of a personal care giver providing assistance to bathe and dress. This reliance on family members for personal care support and assistance does not appear to be unique to New Zealand. A study undertaken in Ireland highlighted the variability in access to formal support services for COPD patients. Inconsistencies in patient access to support services necessitated increased inputs by close family

members, which in turn had the potential to increase levels of stress and detrimentally alter the dynamics of interpersonal relationships (Hasson, et al., 2008).

Self-management and enhanced independence is encouraged by the use of written action plans which guide the patient and significant others through a step wise system detailing medications, symptom alerts and the appropriate actions to take at each step. The value of self-management strategies, including action plans, has been highlighted by several COPD guidelines and several studies, with self-management of acute exacerbations deemed of utmost importance. Literature argues that those persons at risk of acute exacerbations should have a plan detailing the signs and symptoms which necessitate commencement of pharmacotherapeutics to lessen the severity of the exacerbation and thus the need for hospitalisation (National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Of the 14 participants only Bill, Bruce, Andy, Tim and Shelly described the use of action plans to guide their self-management and/or to guide the commencement of pharmacotherapeutics in instances of acute exacerbations. Andy described his reticence to commence the antibiotics and/or steroids, as detailed in the action plan. A study by Sridhar, Taylor, Dawson, Roberts and Partridge (2008) found a nurse initiated self-management plan was successful in encouraging patients to initiate the antibiotics and steroids detailed on their plans, resulting in a decreased incidence of mortality. Of the action plans currently utilised by the participants, none detailed the duration and literage of oxygen therapy. Bill and Tim appeared to have no knowledge of their oxygen prescription and as a result Tim described using his LTOT in “fits and starts”. Improved

patient education on the use of LTOT, including how and when to use it, was highlighted in a study of 25 patients recently discharged from hospital. The patients highlighted the value of individualised self-management plans including advice on how and when to seek medical advice and attention (Gruffydd-Jones, Langley-Johnson, Dyer, Badlan, & Ward, 2007).

Action plans form an important aspect of self-management, however to continue to receive maximum therapeutic benefits from LTOT the recipients' response to therapy requires continued monitoring and ongoing assessment by medical professionals. Prior to implementation of LTOT criteria need to be met, namely ABG measurement and spirometry, on which to base the LTOT prescription and on which to assess therapeutic benefit. The use of spirometry, in conjunction with ABG analysis, is considered the most informative measurement of the individual's disease severity and type. Both forms of measurement provide information which cannot be obtained by one form of testing in isolation (Shibel & Moser, 1970). Spirometry is considered the gold standard form of measurement and is employed to formally diagnose COPD. COPD exhibits evidence of airflow restriction which is not fully reversible and spirometry should be undertaken to provide diagnosis, assessment and enable ongoing monitoring (The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

In a study by Barr et al. (2005) the use of spirometry as a diagnostic procedure was reportedly common practice amongst the majority of doctors within secondary care settings. There is a drive to encourage more frequent adoption of spirometry within general practice. The use of spirometry in general practice is encouraged in an effort to maximise the rate of early detection and diagnosis of COPD, thus enabling earlier intervention (American Thoracic Society &

European Respiratory Society, 2004). Despite the importance placed on spirometry in primary care settings, none of the participants in this current study described spirometric assessment within a general practice or primary setting. All but Shelly had received spirometry, on more than one occasion, within secondary level institutions and the majority of participants remained unfazed and non-committal regarding the assessment.

The lack of emotion regarding spirometry is in direct contrast to the participant's descriptions of their experiences of ABG sampling. All of the participants expressed their absolute dislike and fear of ABG sampling, exemplified by the use of strong language to emphasize their abhorrence of the procedure. Despite an in-depth search of the literature, studies elucidating the patient's experience of ABG sampling are sparse. A study undertaken by Crawford (2004) found that prior to her study patients' experiences had not been explored. Crawford explored the experiences of 41 patients who were on LTOT and discovered that for the majority of the participants the ABG test had left a negative and indelible mark in their memory. Over half the patients reported moderate to severe levels of pain and discomfort and over half reported three or more attempts to obtain the necessary sample. These findings are congruent with the findings in this current study. Participants highlighted the pain and bruising associated with the procedure and described the negative impacts (physical and psychological) when the person performing the procedure was less than proficient and made multiple attempts to obtain the required sample.

The participants found the use of a local anaesthetic injected into the surrounding tissue prior to the procedure alleviated the discomfort experienced, to varying degrees. All the participants who previously had local anaesthesia administered prior to ABG sampling were adamant regarding its

continued use. The use of local anaesthesia appeared to be dependent on the patient's locality with patients from one region describing its use on a regular basis whilst others made no mention of any awareness or previous experience of local anaesthesia. These findings are similar to the study by Crawford (2004) who found only 5% of patients could recall the use of local anaesthesia and of this 5% all considered it effective to some degree. The use of local anaesthesia preceding arterial sampling is recommended by several studies (Dar, et al., 1995; Hudson, Dukes, & Reilly, 2006; Sado & Deakin, 2005).

The majority of the participants expressed concern that another method of measuring the parameters obtained from ABG sampling was not being utilised. Participants expressed the desire for an easier, less painful, means by which to measure their blood gases. Dar et al. (1995) found that due to the dread of arterial puncture some patients were avoiding presenting in acute exacerbations, resulting in an increased risk of morbidity and mortality. Researchers have been exploring the possibility of obtaining accurate measurements via less invasive and less painful arterialised earlobe sampling, however debate persists. A study of 40 patients revealed accurate correlations between earlobe and ABG sampling and recommended an increased uptake of this procedure (Pitkin, et al., 1994). In contrast, Yildizdas and colleague's study (undertaken in Turkey) does not consider capillary blood gas, or venous blood gas, accurately reflect the patients PO_2 (as measured by arterial methods) and hence do not recommend its substitution. Yildizdas, et al., employed a paediatric sample population so the findings should be viewed in this light (Yildizdas, et al., 2004). No participants reported any experiences of alternative sampling methods to assess their parameters, although all expressed a desire to experience an alternative, less traumatic technique.

Lack of adherence to medical directives is evident in non-compliance to LTOT prescriptions.

Only Trina, Ann and Spencer adhered strictly to their LTOT prescriptions. Kampelmacher et al. (1998) state the reasons for non-compliance to the prescription include, in some instances, fear of dependence and/or addiction to LTOT. In their study of 528 patients, approximately 20% of the respondents reported they did not adhere to their prescription due to difficulties with managing the aspects of their daily treatment, a perception of physical wellbeing (including an absence of breathlessness) and a fear of dependency. Males were more likely to be non-compliant and were more commonly non-compliant as a result of embarrassment regarding the increased visibility of their disease. In this current study embarrassment, particularly for the male participants, was identified and impacted negatively on adherence to LTOT prescription. The most obvious precursor to non-adherence appeared to be the participants' efforts to reduce the overall impact on socialisation, mobility and enjoyment of life. Participants adjusted their LTOT schedule to fit into their lives and to cause the least possible disruption to daily living. Most of participants also found the length of time on oxygen problematic and restricting and most participants used their LTOT whilst asleep to minimise its limitations. Fear of dependency was cursorily mentioned by Andy who could not rationalise 16 hours on LTOT if physical benefits could be achieved in less time. Only a few of the participants adhered strictly to their LTOT prescription with the majority under-utilising their LTOT to the degree that its therapeutic value was potentially lessened.

Adherence to LTOT prescription remains problematic for some patients particularly for those who do not consider their LTOT has provided their expected subjective benefits. A minority of participants spoke of a lack of improvement in their breathing and wondered if their LTOT was

effective or if their disease had worsened (Robinson, 2005). In this study findings are similar to those highlighted by Robinson. The subjective perception of physical benefits, particularly the relief of breathlessness, encourages the participant to adhere more closely to their LTOT prescription.

5.4 The COPD journey

Adherence to LTOT prescription has the potential to be enhanced with patient education and most participants expressed a desire for greater knowledge on several aspects of LTOT and COPD. The need for patient education is highlighted in several global guidelines and education is deemed an important aspect to promote adherence to treatment regimes and to enhance the patient's ability and interest in self-management (American Thoracic Society & European Respiratory Society, 2004; Global Initiative for Chronic Obstructive Lung Disease, 2006; National Institute for Clinical Excellence, 2004). Literature found that in some instances, patients had been offered up to three different names for their signs and symptoms, resulting in confusion and some degree of trepidation regarding the expected outcomes and disease trajectory (Scullion, 2008).

Scullion's (2008) findings exhibit congruity with those in this study. Participants appeared to possess little, if any, accurate information regarding their disease. Most were not certain of the meaning of the term COPD and Shelly thought the acronym stood for croup. Participants most often associated COPD with scarring, dyspnoea and emphysema however, in most cases they

had not received an official diagnosis. Scullion found up to 83% of COPD patients remain unaware of their diagnosis after the initial consultation and recommend further education to limit confusion and enhance patient understanding.

A degree of confusion and a lack of patient understanding regarding CO₂ appear evident. The COPD patient's knowledge of CO₂ retention and its potential dangers appears to be a sparsely researched area. Despite an extensive literature search there appears to be a dearth of studies which focus on the patient's awareness of CO₂ and its potential for associated health issues for those at risk. The studies reviewed appear to focus on the COPD patient's general knowledge rather than knowledge in specific areas. In this current study, only Tim and Tom exhibited any knowledge of the risks of CO₂ and one participant expressed genuine surprise that over-oxygenation had the potential to be dangerous for certain individuals. Bill gained knowledge of his propensity to CO₂ retention by overhearing a conversation between medical professionals, yet he has never received any information personally. Given that patients with moderate to severe COPD often experience increasing incidences of acute exacerbations (often requiring emergency oxygenation), it would appear pertinent that at risk patients have some knowledge so they may alert attending medical personnel. A study undertaken in an accident and emergency setting explored emergency nurses' knowledge of oxygen administration in acute exacerbations of COPD. The findings report that in some instances nurses fail to recognise the risks of CO₂ retention and the authors suggest maximising both the nurses and patients knowledge would greatly assist in ensuring the judicious use of oxygenation (Small & Barsby, 2000).

Booth et al. (2004) argue individualised assessment is essential to ensure each patient's oxygen therapy is optimal and within parameters considered safe. There is some evidence that for two participants in this current study delineation of parameters (to reduce the risk of CO₂ retention) may have been addressed to some degree. Bruce stated he was concerned about the high level of oxygen he was receiving during an ambulance transport, whilst Tom was aware to keep within his prescribed oxygen parameters due to his "knife edge" precariousness.

Whilst medical personnel provided one avenue of support for the participants in this study, several providers of formal and informal supports were frequently relied on. The participants highlighted their perception of the interplay of professional and lay people necessary to ensure they were able to continue to live within their chosen community and own home. Neighbours and friends were often employed to provide transport and in some instances acted as care givers, whilst assisting with the participant's oxygen supply. Leidy and Traver (1996) found daily life with COPD requires a degree of social resourcefulness and adaptation to find a means by which to continue living within the confines of the disease. To achieve this balance and maximise their social wellbeing and functioning, the individual may enlist the support of family, friends and the wider community. This degree of reliance on others for support has the potential to impact negatively on the individual's psychological wellbeing with an erosion of social roles and decreased self worth (Leidy & Traver, 1996). All of the participants in this current study relied on others for support. All of the participants received some degree of formal support, however in some instances this support consisted of a six monthly visit from the respiratory nurse educator.

Formal supports were overwhelmingly provided in the community by nurses and all but one of the participants in this current study were complimentary regarding the support and services they had previously received and continued to receive. Despite the high level of participant satisfaction identified in this study, a previous study which compared the formal supports offered to patients with end-stage COPD with those received by patients with cancer, uncovered some marked discrepancies. Patients with COPD received sporadic, uncoordinated support which in many cases failed to meet the individual's needs. In contrast, patients with cancer received a comprehensive multidisciplinary wrap-around package which included specialists, nurses, social workers and respite care opportunities (Gore, et al., 2000).

None of the participants interviewed mentioned contact with a social worker however, Jill was under the care of a dietician and Bill was under the auspices of the palliative care team. Joan had utilised two weeks of respite care, yet found the hospital's rural locality invoked a sense of loneliness, as her family lived approximately one hour away. Joan also spoke of the loneliness of living with COPD and suggested more frequent visits by community based nurses would augment her sense of wellbeing. The implementation of a "respiratory health worker" who visited and telephoned patients on a frequent and regular basis was explored by Gore, Brophy and Greenstone (2000) who found that this approach resulted in increased patient satisfaction, increased compliance and reduced mortality. The authors conclude that despite the recommendations of guidelines highlighting the value of "respiratory health workers", their optimal value and role is not yet defined.

COPD rehabilitation is another area which requires additional definition, delineation and further research. There appears to be limited consistency and uniformity as to the content delivered and the target COPD population group to which the programmes are directed. Gore et al. (2000) argue contemporary pulmonary rehabilitation is often directed at the moderate COPD population, with limited focus on those with more severe COPD. The benefits of pulmonary rehabilitation include, increased exercise capacity, increased knowledge, an improvement in quality of life and an enhanced ability to cope. However, due to financial and logistical limitations, the potential beneficiaries of the programmes often exceed enrolment limits and those with more severe COPD appear to lose out.

In this study opinions regarding pulmonary rehabilitation programmes were variable. All but Rupert had previously taken part in rehabilitation programmes, however only Bruce, Andy, Trina, Tim and Tom would attend a second time. The ability to attend a programme was restricted by locality, nevertheless at the time of writing, classes were being developed in regions previously not offering pulmonary rehabilitation. Pulmonary rehabilitation programmes addressed numerous aspects of living with COPD including breathing exercises. Participants were unanimous in their perception of the value of breathing exercises and all continued to utilise these techniques albeit adjusted to suit their individual needs.

Breathing exercises were one of the many techniques and strategies employed by the participants in this study to enhance their ability to cope with their disease. Other coping strategies utilised included avoidance of situations including particular tests, namely peak flow measurement, which they found depressing due to their inability to reach a goal figure. The support and

encouragement of medical professionals appeared important to most participants and most viewed positive comments, however seemingly insignificant, important in enhancing their ability to cope. The importance of supporting the patient to cope with their disease is highlighted by a New Zealand study of 84 acute admissions to Waikato hospital in 2004. The authors found that 35% of the admissions were as a result of social complications. Social complications consisted of “living alone, poor social support systems, no access to telephone/emergency contact, geographical remoteness and poor access to home-based health care” (Chang, et al., 2007 p. 238).

A degree of reliance on medical professionals was extended by some participants to include assistance from emergency services. For some of the participants coping was enhanced by their ability to rapidly summon help from the ambulance service. The participants viewed the ambulance service as a safety net system providing emergency care in acute exacerbations, emotional support and a backup system in instances of mechanical or electrical breakdowns. The frequent use of emergency services has been previously documented. Barr et al. (2005) found on average COPD patients reported six contacts with general practitioners per annum and over half had required emergency assistance within the last year. A multicentre study undertaken in 2007 suggests whilst the majority of patients with COPD tend to underestimate the severity of their disease, most reported frequent contacts with medical services and the use of emergency services was commonplace (Alvarez-Gutierrez, et al., 2007).

5.5 Feel the panic and breathe anyway (Psychological aspects of COPD)

Sturesson and Branholm (2000) highlighted the decreased levels of life satisfaction experienced by those patients with COPD and in many instances, their families. The COPD patient's reliance on others to perform ADL, including leisure activities and outings, may have impacted on the findings with the LTOT patients reporting the lowest levels of life satisfaction. This is potentially due to the logistical arrangements and restrictions imposed by the LTOT equipment and portable cylinders. Decreased levels of life satisfaction have implications for patients with COPD who frequently exhibit high levels of depression and anxiety. Participants were able to clearly portray the psychological impacts of their disease. Panic was reported by every participant, with the majority reporting episodes of panic during which they perceived death was inevitable. Panic created a spiralling effect which further exacerbated the participant's degree of dyspnoea, resulting in increased levels of panic. Most of the participants utilised breathing techniques in an attempt to lessen their degree of panic. The technique commonly referred to was "smell the roses and blow out the candles" and involved a gentle inhalation phase with a pursed lip exhalation. Despite an extensive literature search the origins of this technique remain obscure.

A study by Bailey (2004) argues rather than anxiety exacerbating the patient's level of dyspnoea, anxiety may actually occur earlier as a symptom of worsening respiratory function and demands greater recognition as a warning sign. This increased focus on the patient's experiences may serve to highlight the role of anxiety in the dyspnoea cycle. Previously held assumptions suggest that anxiety precedes dyspnoea, which in turn exacerbates the patient's level of anxiety. A qualitative study exploring the patient's experiences of dyspnoea and anxiety argues this assumption demands further research and proffers the patient's level of anxiety may in fact be an important

symptom of worsening respiratory status. The authors propose a dyspnoea-anxiety-dyspnoea cycle rather than the commonly accepted anxiety-dyspnoea-anxiety cycle and reiterate the importance of attaching greater significance to the subjective reports of the patient (Bailey, 2004).

Several studies have reported on the high incidence and morbidity associated with anxiety and panic within the COPD patient population and many consider the psychological effects of COPD remain unrecognised and undertreated (Bailey, 2004; Doi, 2003; Dowson, et al., 2004; Gruffydd-Jones, et al., 2007; Ring & Danielson, 1997; Robinson, 2005). The psychological impact of COPD is well documented with anxiety and depression considered common and frequently manifesting as feelings of despair and often associated with a lowered opinion of self worth (Barnett, 2005). Gore et al. (2000) argue that despite the ready availability of screening processes and schedules which identify the COPD patient's high incidence of anxiety and depression, a very small percentage of patients receive treatment. The authors conclude this may in some part be due to the belief that the psychological sequelae of chronic disease are inescapable and have the potential to be resistant to pharmacotherapeutic intervention.

Despite their reports of depression, anxiety, worthlessness and frustration, of the 14 participants in this current study, only a few were taking any form of medication to alleviate their symptoms. The majority relied on LTOT in the form of short-burst therapy, rather than medication, to alleviate their panic and breathlessness whilst others enjoyed the company of animals, which they considered highly therapeutic. The high incidence of psychological sequelae of COPD is highlighted by several guidelines and all mention the importance of treating symptoms such as depression and disabling anxiety. Depression is common in chronic disease and the high

prevalence of panic disorders which further exacerbate dyspnoea remain treatment priorities (American Thoracic Society & European Respiratory Society, 2004; Global Initiative for Chronic Obstructive Lung Disease, 2006; National Institute for Clinical Excellence, 2004; The Australian Lung Foundation and The Thoracic Society of Australia and New Zealand, 2009).

Although this study did not actively seek to elucidate the participants' thoughts regarding their end of life and the process of dying, several of the participants touched, albeit briefly, on the subject. Several participants offered unsolicited information and thoughts and Tim and Trevor were open and descriptive regarding their fear and trepidation. Tim had discussed death, as a result of end-stage COPD, with the partner of a recently deceased COPD patient and been vividly informed of the horrific process it had been. Tim had then decided he would no longer seek information as the reality was too terrible to contemplate. Gore et al. (2000) report this denial is common amongst the COPD population. Many of the participants identified a desire for greater information regarding their disease, however very few wished to be offered detailed information regarding the morbid trajectory of their disease as they found the reality distressing.

Study limitations

The current study highlights and describes the views of 14 participants with COPD who volunteered to be interviewed about their experiences of LTOT and its associated monitoring. Within the qualitative paradigm 14 participants is a sufficient number by which to achieve richness of data, with an ultimate aim of elucidating the area of interest (LoBiondo-Wood &

Haber, 1998). The recruitment strategy ensured an even and widespread sample population was obtained and recruitment from two geographical regions ensured an enhanced degree of robustness. Due to a lack of sample randomisation the participant population may have failed to identify experiences that may have been atypical of those elucidated in the study. Despite measures to enhance validity several important limitations of this study need to be highlighted and the study findings need to be viewed under the lens of these limitations (Polit, et al., 2001).

Firstly, it would be erroneous of this current study to state that the findings are representative of the experiences of all persons with COPD using LTOT. The findings may have failed to capture the experiences of those people who may have been unable for various reasons including a communication deficit, cultural barrier or a fear of repercussions to speak freely of their experiences. Although criteria excluded any participants who had been nursed by the author within the past 12 months, some people may have refrained from participating in the study for fear that their responses may impact adversely on their care, or the care of their families. Those people who use LTOT with no complaints or issues may not have felt the need to relay their experiences and others may have held the perception that they could divulge nothing of value, thus declined to respond. In anticipation of the prolonged interview process, and the need to participate in conversation, some participants may have deemed the research too physically and psychologically demanding, thus potentially limiting the diversity of the information obtained (LoBiondo-Wood & Haber, 1998).

Secondly, the adapted interview schedule was pilot tested on two participants to ensure clarity, content, sequencing and to minimise the risks of physical and psychological impacts. A more

formalised pilot study, with a larger participant sample, may have ensured the reliability of the interview schedule and maximised the transferability and credibility of the study's findings. To assist reliability, the adapted interview schedule could have been pretested on a non-LTOT COPD population and the results compared to those obtained from the LTOT COPD sample. Evidence of differences between the two groups would have assisted credibility and enhanced the transferability of the study's findings (Wilson, 1987).

Thirdly, whilst the study findings add to the body of knowledge regarding the experiences of people with COPD whilst utilising LTOT and provides valuable insights into sparsely explored areas of interest pertinent to this study's participant population, there are limitations. Other aspects of the participants' experiences such as the impact of culture, financial stability and the impact of the participants' experience on their significant others have not been directly explored in this current study. Literature argues the impacts and types of psychosocial influences evident for those on LTOT is poorly defined and poorly researched, potentially limiting the discovery of effective therapeutic interventions (Cullen & Stiffler, 2009).

Fourthly, the qualitative paradigm has the ability to explore an area of interest in which knowledge deficits prevail, hence the qualitative paradigm succeeded in meeting the aims of the study. The qualitative paradigm is particularly valuable when utilised to gain insights into the participants' experiences of health, as in this study. Despite this suitability the qualitative paradigm has its limitations including a potential for bias. As the researcher becomes the data collection schedule it is important that the researcher interprets and analyses the narrative data accurately in order to produce findings which truly reflect the participant's experiences. The

presence of the researcher throughout the interview process has the potential to affect the participants' responses and the quality of the research is dependent on the skill of the researcher. The data collection, thematic analysis and interpretation of findings were all undertaken by the author who was not qualified or previously experienced as a researcher, hence the study's findings need to be viewed in this light (Polit, et al., 2001).

Implications and recommendations

The findings of this study highlight the experiences of those people with COPD utilising LTOT and reveal a high degree of impact on their lives and the lives of others within their personal and wider social circle. Overwhelmingly LTOT impacts positively on the physical wellness of the patient, nevertheless this comes with associated negative impacts which remain largely under investigated. These findings highlight important implications for the multidisciplinary health professionals employed in the area of chronic care management. Health professionals, their ancillary services and personnel across diverse clinical settings, have the opportunity and expertise to instigate positive change to current practices. A skilled multidisciplinary review of accepted practice has the potential to reduce the degree to which COPD and LTOT negatively impacts the lives of the patient and their significant others. A reduction in personal and familial burden may in turn lessen the societal burden of COPD.

To impact positively on the life of the COPD patient, health professionals require a broad and in-depth knowledge of the physical, psychological, social and spiritual impacts of the disease and

the implications of the addition of LTOT. COPD falls within the spectrum of chronic disease and has a growing global burden which will necessitate the increasing utilisation of LTOT. To be truly effective health professionals require not only a broad knowledge of the pathophysiology of COPD, they should have an in-depth understanding of the physiology and technical management of LTOT. Important aspects of technical management include spirometry and ABG, both of which have the potential to impact negatively on the experiences of the LTOT recipient. The findings of this current study highlight the need to ensure that the medical professionals undertaking these procedures (particularly ABG sampling) are skilled and thus able to perform the procedure with minimal, or no, negative sequelae. It is vitally important that medical professionals acknowledge the therapeutic (physical and psychological) value of the use of local anaesthesia prior to arterial punctures. It is a recommendation that COPD be afforded the recognition it commands as a complex chronic disease which exerts substantial multifactorial impacts on all involved. COPD deserves the same funding and resource allocation as other end of life diseases including cancers. The value of the palliative approach to the management of cancer is proven and should be extended to enhance the holistic management of COPD.

Bailey, Colella and Mossey (2004) found nurses with limited knowledge fail to fully individualise holistic care for the COPD patient resulting in an uninformed adherence to an inappropriate management plan with less than optimal results. The authors suggest greater overall knowledge, in conjunction with experiential learning informed by the patient themselves, will enable the attending health professional to revise erroneous and inaccurate practices. Despite COPD being termed the “Cinderella” of chronic diseases it is essential that health professionals possess a broad understanding and knowledge of all aspects of the disease and this expertise necessitates ongoing revision and reassessment through continued education. The importance of

the LTOT patients' experiences is becoming increasingly recognised as an essential aspect in effective management and in the development of a therapeutic relationship and as a source of valuable knowledge (Robinson, 2005). The findings of this current study reinforce the recommendation that medical professionals need to place greater recognition on the benefits of extending knowledge through advanced education which includes learning opportunities offered by patients and their families.

The maximal therapeutic value of LTOT would be further enhanced by a well informed health professional who has the potential to encourage greater adherence to LTOT prescription through patient education. Greater adherence to prescription and smoking cessation is the cornerstone to effective LTOT and a knowledgeable professional may have the effect of encouraging patient compliance within the therapeutic relationship. It is a recommendation that an increased focus is placed on the therapeutic benefits of smoking cessation for all COPD patient populations and this focus should include those patients with end-stage COPD. The dangers associated with smoking whilst on LTOT demand greater recognition and an enhanced focus. It is the responsibility of health professionals to ensure the patient is aware of the inherent risks and potential implications of continuing to smoke prior to, or during, LTOT. The health professional is in a valuable and influential position and is able to highlight and reinforce the positive aspects of LTOT therapy, whilst implementing supports and interventions to lessen the negative aspects (Eastwood, O'Connell, Gardener, & Considine, 2008). It is a recommendation that therapeutic management of COPD should place greater emphasis on the value of greater implementation and adherence to action planning. Action plans have the ability to enhance the patient's adherence to their LTOT prescription by defining its parameters in print. Therefore it is recommended that all LTOT

recipients are given an individualised action plan which clearly outlines the period of oxygenation (including start and stop times) and the literage of the flow. Action plans guide self-management, promote self-efficacy and include a stepwise plan to enhance the patient's ability to cope in an emergency situation.

Until health professionals fully understand the negative aspects of LTOT patients' experiences they cannot hope to fully comprehend the burden experienced by the individual and their significant others and provide the interventions and supports to alleviate this burden. It is therefore imperative that therapeutic interventions and care planning is developed within a collaborative framework encompassing the needs and views of most importantly the patient, their significant others and other stakeholders (Robinson, 2005).

An exploration and greater understanding of patient's positive experiences of LTOT provides another avenue by which to gain valuable insights into effective management strategies. To enhance the medical professionals understanding they need to invite and empower the patient to be an educator. The patient is the ultimate teacher and informant and an acceptance or acknowledgement of the value of this tacit expertise is somewhat negated historically. A study undertaken in 2002 highlighted the obvious benefits of involving patients in the education of medical professionals. Patients undertaking a more visible and active role in education enhances knowledge and skill acquisition and has the additional value of promoting positive attitudinal change (Wykurz & Kelly, 2002). This current study highlighted the COPD patients' degree of expertise acquired through decades of living with COPD whilst using LTOT. To enhance COPD management it is recommended that medical professionals accept that the patient is the expert of

their own disease and able to accurately assess treatment efficacy. The patients' experiences in this study highlighted the individuality of their COPD journey and the value of recognising the educational opportunities afforded by encouraging the patient to become the teacher.

Encouraging the patient to become an expert authority will require an overdue and essential attitudinal shift. Barr et al. (2005) highlighted a degree of reluctance on the part of clinicians to adhere to COPD guidelines and this reluctance was particularly evident in the management of patients who continued to smoke. It is a recommendation of my study that clinicians recognise the expertise and therapeutic value of guidelines and adhere more closely to research based management protocols.

An attitudinal change is necessary to recognise, and effectively treat, the psychological impacts of COPD which have the potential to be exacerbated by the addition of LTOT. Underestimation of the burden of the psychological aspects of COPD and LTOT is well documented and must become a therapeutic priority for all health professionals. The incidence of disabling anxiety and overwhelming depression amongst the LTOT population is recognised and treatment, including pharmacotherapy and counselling, is recommended to reduce the impact on the individual's quality of life and ability to continue living within their chosen community. Reducing the patient's psychological burden will in turn have positive outcomes for their significant others and may reduce the reliance on support persons (Global Initiative for Chronic Obstructive Lung Disease, 2006; Ring & Danielson, 1997; Robinson, 2005).

Medical professionals have the necessary ability and resources to investigate and implement formal and informal support networks in an effort to reduce the burden experienced by the

families of LTOT patients. This multidisciplinary approach to management and support is deemed advantageous for all concerned with the effect of diluting the burden experienced by any one individual. This supportive approach encompasses a package of care and support which may include aspects of hospital at home management and a greater involvement of community outreach professionals. In end-stage COPD a palliative support package may prove beneficial in providing a care package to meet the medical and psychosocial needs of the patient and their families (Gruffydd-Jones, et al., 2007). It is a recommendation that health professionals recognise the value of nurse led respiratory outreach services, dieticians, social workers, caregivers and others in the COPD patient's network of support. The enhancement of a multidisciplinary, multifaceted palliative approach to patient management has the potential to encourage the greater collaboration of health professionals, resulting in a less fragmented, dynamic and more responsive care package for the patient and their families.

Future research

Despite the fact that patients with COPD on LTOT is a well researched population, gaps in knowledge remain evident and in need of further exploration. The focus of existing research has to date largely centred around quantitative studies on adherence to LTOT prescription and the experiences of COPD and LTOT patients. There has been very little qualitative exploration of the complaints of patient utilising LTOT, or of management strategies which may promote adherence to prescription and minimise these complaints. The discussion in this current study

highlights areas in need of further research, including areas of continuing, or newly identified, contrasting expert opinions. There is a need to explore these aspects of the patient's experience utilising high quality qualitative methodology, in order to augment the body of existing knowledge, by allowing the patient to tell their story and to be the educator.

Allowing the patient to be the teacher may assist health professionals to revisit and produce an informed review of previously held knowledge, including alternative measures of disease severity, and a reassessment of those who may or may not benefit from LTOT. Croxton and Bailey (2006) found several areas of knowledge and management for the COPD patient on LTOT are deserving of further research. These areas include the efficacy and safety of LTOT for those patients who continue to smoke, increased monitoring of the patient's daily LTOT duration and the reasons for some patients limited adherence to prescription, and the use of short-burst oxygen therapy during periods of increased physical activity. Controversially, Croxton and Bailey consider since the two groundbreaking trials (NOTT and MRC) there has been no new research to confirm the optimal duration and timing of LTOT and overall survival benefit. They promote a greater research focus on the patient's subjective reports of factors such as quality of life, psychological impacts including mood and cognitive functioning and overall sense of wellbeing.

This increased focus on the patients' experiences may serve to highlight the role of anxiety in the dyspnoea cycle. Previously held assumptions argue that anxiety precedes dyspnoea, which in turn exacerbates the patient's level of anxiety. Subjective patient reports in this current study, and numerous others, unequivocally highlight the value of oxygen in the symptomatic relief of

panic and breathlessness (Bailey, 2004; Barnett, 2005; Earnest, 2002; Robinson, 2005). Debate persists regarding the efficacy of oxygen in the relief of breathlessness and a study by Abernethy et al. (2010) argue that oxygen is no more effective than nasally delivered room air in relieving breathlessness. Due to the degree of disability experienced as a result of breathlessness, the role of oxygenation, pharmacotherapy and other treatment adjuncts in the relief of dyspnoea in hypoxic COPD patients is deserving of greater exploration. There is a highlighted paucity of knowledge regarding the physiological mechanisms driving the patient's subjective perception of breathlessness and scientific exploration is deemed essential. A greater understanding of the physiological basis of dyspnoea will also serve to enhance therapeutic management, resulting in improved patient outcomes and a decreased fiscal burden (Abernethy, et al., 2010).

To improve patient outcomes there is a need to explore and improve the technological aspects of LTOT delivery and monitoring. As highlighted previously, over the past decade there have been minimal technological advancements in the design of concentrators and/or portable oxygen delivery systems. This lack of design revision and improvement has resulted in ongoing patient complaints and non-compliance, resulting in ineffective LTOT. Design revision, resulting in more portable LTOT delivery devices, may promote the mobility of the LTOT recipient resulting in an increased enjoyment of national and international travel. The efficacy of ABG analysis in comparison to capillary sampling is deserving of greater research, as is the provision of spirometric assessment in the primary setting. The ease and comfort of capillary sampling has the potential to lessen the negative and traumatic impacts of blood gas analysis and spirometry in the primary setting would improve the physicians' and patients' access to this important aspect of diagnostic measurement.

To maximise this exploration a high quality qualitative methodology would be appropriate, however the addition of aspects of quantitative control and the analysis of objective data would be considered of value. Rich in-depth qualitative data gathered through face-to-face interviews could be enhanced by the addition of objective data gathered through the use of structured quantitative schedules and measurement scales. The additional use of quantitative measurement could assist the acquisition of data suitable for analysis by statistical methods thus enhancing the validity of the results. The integration of qualitative and quantitative data may have the unexpected result of highlighting incongruencies in data consistency prompting further research into areas of inconsistency. The value of this outcome would be the ability of the research to add to, or change, the existing body of knowledge, through extending the boundaries of current research and exploration (Polit, et al., 2001).

The inclusion of a control, or comparison group, of COPD patients not utilising LTOT may serve to enhance the credibility of this current study's findings. The competent researcher's use of a comparison group could provide a basis against which to compare the experiences of the group of interest, namely those patients with COPD on LTOT. The use of a comparison group may elucidate commonalities and incongruencies which may prove important and instructive (Polit, et al., 2001).

Conclusion

Due to the knowledge, and to a degree an acceptance, that COPD is largely a self-inflicted disease, it is possible that COPD is not considered a high profile or high priority disease by health professionals or the general population. COPD has been termed the “Cinderella” of life-limiting diseases and despite the growing personal and fiscal burden, COPD has been the recipient of limited resources and continuing stigmatisation. In order to positively affect the lives of the LTOT patient and their families change is essential and COPD needs to be recognised as a global health priority. COPD patients on LTOT deserve the same resource input and recognition as that offered to other end-stage diseases, such as cancers. This increased focus on effective interdisciplinary management should encourage the patient to become increasingly involved in their care planning, resulting in a more coordinated, individualised and therapeutic package.

The provision of a therapeutic, cost-effective and individualised management plan necessitates an exploration of the patients’ and their families’ experiences. Greater recognition of the importance of the patients’ experiences is considered essential for those health professionals involved in the care of patients on LTOT, researchers and those who develop policies, guidelines and direct fiscal expenditure. The subjective experiences of participants provide unequivocal self-reported evidence of the positive and negative impacts of living with COPD whilst utilising LTOT. The participants’ positive experiences assumed great importance in maximising their ability to benefit physically and psychologically from the therapeutic interventions provided and to identify which interventions they find efficacious and those less effective. There is a requirement for health professionals to continually explore aspects of the LTOT patient’s reality and to facilitate qualitative changes in management and therapeutics in an effort to maximise the

positive aspects of the patient's experiences and to lessen the impact and quantity of negative experiences.

The acquisition of knowledge would enhance the health professional's ability to fully comprehend the importance and implications of the LTOT patient's experiences and to provide insightful and innovative management. To accomplish this aim education for health professionals should include a comprehensive understanding of the pathophysiology of COPD and the therapeutic and technical aspects of LTOT. This knowledge should then be disseminated to others including patients and their families. This enhanced knowledge and open communication may serve to maximise the patient's motivation to effectively manage their disease and their ability to cope within its limitations.

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