

**Patients' and Healthcare Professionals' Perceptions
of Oxygen Therapy: An Interpretative
Phenomenological Analysis**

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Doctor of Philosophy, Edge Hill University**

Declaration

This thesis is entirely my own work and has not been submitted, in full, or part, for the award of a higher degree at any other educational institution. Sections of the thesis have already been published, presented at conference, or are under consideration for publication, details are listed below:

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Dedication

I would like to dedicate this thesis to the memory of my nephew, Chris, who died aged 17 with cystic fibrosis, and whose creativity, humour, optimism, love and courage, continues to inspire me to try to improve the lives and care of individuals with respiratory disease.

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PREFACE

I started nurse training in 1980, a year before my nephew Christopher, then aged 2, was diagnosed with Cystic Fibrosis. Chris spent more than half of his seventeen years of life on oxygen, a therapy that dominated both his home care and acute episodes spent in hospital. He had chronic hypoxaemia, the severity of which increased during acute exacerbations of his illness.

I was with him when he died; a Respiratory Nurse Specialist of two years by then. As I entered the room, Chris had a mask over his face delivering a very noisy high flow of oxygen. The humidifier had run empty and the spluttering, as a consequence, amplified the noise to the point where it was difficult for the family to talk to Chris or each other. The pulse oximeter was on the bedside cabinet alarming, unremittingly – his oxygen saturations recording 70% – Chris's breathing was laboured. I removed the pulse oximeter probe and asked for the oxygen delivery device to be changed. We played music – Chris loved music – the sound soothed us all. Chris died shortly afterwards, surrounded by a loving family, at peace at last; his final stage of life, in my opinion, unnecessarily distressing for all concerned and dominated by oxygen.

My involvement and interest in oxygen was formed from these early experiences. My previous role as a Respiratory Nurse Specialist involved the assessment, support and continued monitoring of respiratory patients receiving domiciliary oxygen. I was also involved in teaching respiratory care to acute care professionals, an experience that highlighted inconsistencies and poor practice that were sometimes detrimental to patients. After leaving clinical practice and pursuing a career in teaching, the focus on respiratory care continued and my interest in oxygen grew. When I undertook an MA in Professional Education the focus for my dissertation was on whether specialist respiratory education makes a difference to healthcare professionals in practice. The findings supported that, in particular, knowledge and understanding concerning oxygen therapy was profoundly lacking, confirming anecdotal classroom evidence.

When considering undertaking this PhD, my thoughts immediately went to oxygen therapy, and my interest and curiosity in the unrelenting prevalence of poor understanding and resultant poor practice. There was little in the literature to enlighten this phenomenon, although a growing acknowledgement that, perhaps, cultural issues were existent. With an interest in education of healthcare

professionals, I realised how important it was, in order to influence practice, to try to expose any existent beliefs, misconceptions and culture, detrimental to practice, that may exist. In order to do this, and in the absence of existing evidence, I chose to explore perceptions of oxygen therapy in detail. I felt it important to consider both patients and healthcare professionals in this particular context, taking into consideration the often inseparable interactions between the two groups.

The PhD journey commenced and the thesis took form, primarily in the outline of the research question: how do patients and healthcare professionals perceive oxygen therapy? To me the obvious approach was qualitative research but in order to try to be more representative, attain generalisability and make the research more *acceptable* to the medical community, the initial plan was to undertake a mixed methods study, allowing the first phenomenological phase to influence and inform the second: a questionnaire to survey a larger sample.

At the point of transfer to PhD registration, it was apparent that the study thus far had generated very rich, complex and extensive data. Upon advice and recommendation from the External Examiner at the transfer viva voce examination, the research was directed to a single method. It was felt that this would ensure a sincere application of qualitative research philosophy, and give justice to the data and participants.

The exiguous literature available further directed the structure of the thesis and choosing a methodological approach to reviewing the literature that was systematic in nature, but could include published empirical work from diverse sources, was a challenge. In addition, a suggestion from a supervisor directed me towards examination of historical literature. The findings of which I found were much more significant than first anticipated, and progressed to form a valuable chapter of the thesis. This did not however negate the literature review, and therefore the decision to incorporate both literature chapters into the thesis was made.

The literature utilised to support the study therefore comes from a wide base, in the absence of anything pertaining directly to the research question. Because oxygen is such a complex and multidimensional therapeutic intervention, it was considered that the reader would need to be familiar with a wide range of issues, in order to appreciate the context of the arguments presented, and the significance of the findings. Thus the background incorporates diverse clinical contexts and issues.

My previous experience, both personal and professional, therefore can be seen to have both influenced and directed this thesis. At the outset I tried to discard any preconceived ideas regarding oxygen that I personally held. But as I progressed with the development of arguments I realised that I didn't really hold any firm ideas and that the nuances of oxygen therapy, despite my depth of knowledge and understanding, were as much an enigma to me as to others. This self-revelation allowed fluidity of my thoughts and analyses, as data was transformed into findings and recommendations. Recommendations which I hope will serve to highlight and unravel the complexities of oxygen, and reveal what, how and, to some extent, why, fallacies exist.

ABSTRACT

Background: Despite common usage of oxygen as a therapeutic intervention, audit suggests the existence of poor prescribing and administration practices. Contemporary studies and guidelines propose an influencing culture whereby oxygen is given to alleviate breathlessness and to most acute clinical presentations, with disregard for potential drawbacks; but there is no evidence supporting this claim. The problem self-perpetuates as erroneous beliefs are passed to patients, their carers and the general public.

Aim: To explore healthcare professionals' (HCPs) and patients' perceptions of oxygen therapy.

Method: Semi-structured interviews were undertaken with 28 patients and 34 HCPs (including nurses, paramedics, pharmacists and general practitioners). Self-reported beliefs and behaviours were recorded, transcribed verbatim and analysed iteratively using interpretative phenomenological analysis (IPA).

Results: Three master themes were identified: *oxygen as a panacea, the burden of oxygen, and antecedents to beliefs*. Sub-themes under these constants differed between HCPs and patients, but fundamentally both groups viewed oxygen as an innocuous therapy with numerous benefits. Patients used oxygen for *breathlessness* and as an *enabler*; they were *grateful to the oxygen* and accepted it as *part of the disease*. HCPs used oxygen because *it helps patients; it works!; it makes HCPs feel better*, and also out of *compassion*. But oxygen is not benign and a burden is evident, for patients it *makes the disease visible* and carries *associated costs*. For HCPs there is an *awareness of the dangers* and *the patients' burden*, which often results in clinical *dilemmas* and an emotional cost to caring. The study exposed patients' potential antecedents to beliefs as *faith in HCPs* and *past experiences*; for HCPs these were *entrenched culture* and *expectations*. Patients appeared *not to think* about oxygen and understanding was poor. All HCPs believed they had not received enough education specific to oxygen, and an approach of *DIY education* prevailed.

Summary: These findings suggest that a set of fixed beliefs regarding oxygen therapy exist, influenced by several impacting factors. The overwhelming perception that oxygen is a universal remedy prevails, but is, at times, contradictory, when benefits are countered by adverse effects of oxygen. These adverse effects, additional to physiological dangers, included psychosocial and emotional costs. This is the first time that perceptions of oxygen therapy have been reported and will be an important contribution to knowledge, supporting strategies to raise awareness of entrenched cultures, influence future educational and research strategies, and inform policy.

What is already known on this topic:

- Oxygen is commonly used in acute clinical scenarios and for the management of dyspnoea.
- Administering oxygen therapy can pose dangers and drawbacks for patients.
- Despite evidence based guidelines poor and resistant practice regarding oxygen therapy persists.

What this study adds:

- Patients and HCPs regard oxygen as a panacea.
- Oxygen has psychological and social burdens for patients and HCPs.
- For HCPs this presents dilemmas in practice
- An emotional cost to decision making with regards to oxygen is apparent.
- Patients' beliefs are influenced by their faith in HCPs and past experiences.
- An entrenched culture exists fuelled by expectations.
- Education regarding oxygen is lacking for both patients and HCPs.

Key words: Oxygen therapy, perceptions, respiratory patients, healthcare professionals, interpretative phenomenological analysis.

CHAPTER 1 – INTRODUCTION AND BACKGROUND

This chapter introduces the research question and provides underpinning rationale for the study. It will summarise the evident problems regarding oxygen therapy, together with some of the potential adverse consequences, and why it is deemed necessary to identify and uncover perceptions of oxygen. Thereafter follows an outline of physiological principles related to oxygen as a therapeutic intervention and elaboration of apparent issues, highlighting common uses for which oxygen is prescribed and administered, drawing on available literature to portray the current landscape in order to inform the research question further.

1.1 INTRODUCTION

Oxygen therapy is one of the most common therapeutic interventions in modern day healthcare, worldwide, particularly for the treatment and management of respiratory conditions, both acute and chronic. When administered as a therapeutic intervention oxygen is regarded as a drug and with the exception of emergency situations, should always be prescribed (British National Formulary [BNF], 2014). Oxygen can save lives through correction and prevention of hypoxaemia (low levels of oxygen in the blood), but there is also potential for serious harm, and even death, if it is not administered and managed appropriately. In the United Kingdom (UK) contemporary guidelines offer criteria and directives for administration and prescription of oxygen, dependant on the patient's condition, acuity and care setting (British Thoracic Society [BTS], 2008; BTS, 2014; Joint Royal Colleges Ambulances Liaison Committee [JRCALC], 2013).

Despite universal use, it is nonetheless apparent that oxygen is often prescribed and administered injudiciously (Denniston et al., 2002; Durrington et al.,

2005; New, 2006; Wallace et al., 2010; O'Driscoll et al., 2011; Cameron et al., 2012; Pilcher et al., 2013; Roberts et al., 2013), potentially resulting in worse outcomes for patients, including increased mortality. This is particularly relevant to pre-hospital and emergency settings where liberal use of high flow oxygen is widespread (Austin et al., 2010; Perrin et al., 2011; Wijesinghe et al., 2012; Hollier et al., 2014).

In addition to issues of increased mortality and morbidity consequential to incorrect use of oxygen therapy in respiratory patients, inappropriate use across numerous other medical conditions is now being highlighted (BTS, 2008). With a growing evidence base, deep-seated and traditional practice is being challenged (Cabello et al., 2013; Godlee, 2012; Pountain and Roffe, 2012; Shuvy et al., 2013), but with the potential to exacerbate growing confusion amongst patients and healthcare professionals alike.

Although widely available and commonly used, 24% of all hospital in-patients received oxygen in one hospital audit (Eastwood et al., 2011), 34% of patients received oxygen during emergency ambulance transfer (Hale et al, 2008), and 82% of COPD (chronic obstructive pulmonary disease) patients presenting with an acute exacerbation (Considine et al., 2012). It has long been recognised that oxygen is often poorly prescribed (Bell, 1995; Bateman and Leach, 1998), an observation endorsed in numerous audits in acute settings (Dodd et al., 2000; Howell, 2001; Hickey, 2007; Wijesinghe et al., 2010; Sundaram et al., 20013). In particular, a national audit in 2008 of 99 UK hospitals found that only 10% of patients receiving oxygen had a correct prescription. Following publication of national emergency oxygen guidelines in 2008 (BTS) this figure increased to 52% by 2012, demonstrating that, despite specific guidance, just under half of patients still did not have a safe prescription (O'Driscoll, 2014). The same issue is evident within an

international context (Boyle and Wong, 2006; Brokalaki et al., 2004; Neves et al., 2012).

In juxtaposition to emergency oxygen issues, similar problems exist with provision and management of home oxygen services. A report produced by the Royal College of Physicians (RCP, 1999), in response to spiralling costs of domiciliary oxygen, uncovered similar poor prescribing practices and follow-up of patients. This led to major changes in prescription and supply of home oxygen in England and Wales, principally the provision of clinical standards for initial assessment and subsequent patient management (BTS, 2006). Despite implementation of these changes, problems persist (Davidson et al., 2011; Lee et al., 2013), again, not just confined to the UK but a recurring problem in the developed world (Guyatt et al., 2000; Jones et al., 2007; Venduri et al., 2014). Yet despite the pervasiveness of these problems, it is unclear what factors contribute to persistent poor practice, which, despite the introduction of guidelines, appears resolute.

This whole issue regarding problematic prescribing of oxygen in the UK heralded directives from the National Patient Safety Agency (NPSA, 2009) as a result of receiving 281 reports of serious incidents (up to June 2009) related to inappropriate administration and management of oxygen. Of these incidents, poor oxygen management appears to have directly caused 9 patient deaths and possibly contributed to a further 35. How many incidents go unreported cannot be assessed.

Recently, the focus on oxygen therapy in the context of both safety and cost efficiency has taken a higher profile. The use of oxygen in both acute and chronic settings has been recognised as a major area for improvement within An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England (Department of Health [DH], 2011), and further endorsed by the National

Institute of Clinical Effectiveness Guidance on COPD (NICE, 2010). Guidelines (BTS, 2008; BTS, 2014) form a comprehensive agenda, seeking to standardise clinical practice and enhance quality, but poor practice persists, proving that implementation is difficult; the reasons why remain elusive.

The British Thoracic Society (BTS) suggest that a high proportion of medical oxygen is possibly administered because most clinicians believe that oxygen can alleviate breathlessness (BTS, 2008). There is scant evidence supporting this claim, although Abernethy et al. (2005), in an e-mail survey, found that 70% of clinicians would prescribe oxygen for dyspnoea despite normal oxygen saturations. The use of oxygen in palliative care settings is increasingly contentious, evident through opinion within professional publications (Booth et al., 2004; Davidson and Johnson, 2011; Johnson et al., 2013; Currow et al., 2013).

It is further suggested that a major problem contributing to poor prescribing practices is that healthcare professionals often receive conflicting information and advice about oxygen therapy during their training and clinical careers; many are confused about the entire area of oxygen prescription and use (BTS, 2008). However there is little empirical evidence to support this assertion.

The problem appears to become self-perpetuating as anecdotal evidence suggests that erroneous beliefs are portrayed to individuals receiving oxygen therapy, their carers and the general public. Subsequently this may lead to unrealistic expectations and poor adherence to prescribed oxygen therapy negating benefits (Walshaw et al., 1990).

One final, major issue and incentive for adherence to guidelines and judicious use of oxygen therapy is superfluous cost. As governments and healthcare providers strive to ensure equitable and safe access to health services according to the most

cost-effective and evidence-based manner, the potential for efficiency savings in this sub-optimal area of care provides tremendous incentive for cost-conscious healthcare providers. Direct savings in the region of £130,000 (Deeming et al., 2008) to £150,000 (Fielding et al., 2012), per year, per primary care trust, have been demonstrated. The potential savings for improved prescribing practices overall is unknown. In the current financial climate, ways of managing waste rather than cutting services may be a more appealing strategy in responding to imposed budget reductions.

Despite the growing acknowledgment of issues surrounding oxygen therapy, with regard to prescription and administration practices, it is not clear from the literature where the roots of these fallacies lie, and indeed whether this is a result of tradition, lack of knowledge regarding the indications and use of oxygen therapy by healthcare professionals, or misunderstanding of the basic physiological principles of oxygen *per se*. Burls et al. (2010), in an on-line survey of 524 healthcare professionals' beliefs and practices concerning the use of oxygen in acute myocardial infarction, contrary to current guidelines, found 98.3% said they always, or usually, used oxygen, and 55% thought oxygen definitely, or probably, significantly reduced the risk of death. This widespread belief in oxygen appears to persist despite increasing evidence of potentially detrimental effects, suggesting that its usage is so embedded in clinical practice that it is generally assumed to be safe.

Essentially, the main existing issue, and the justification for the current study, is that practice has been found to be stubbornly contrary to oxygen therapy guidelines, and patients are dying as a result. As emerging evidence increasingly highlights the detrimental use of high flow oxygen in common emergency medical presentations, it is possible that confusion amongst healthcare professionals has been amplified. Additionally, the use of oxygen to relieve dyspnoea is growing increasingly

controversial, exacerbated by a lack of clear guidance and consensus. In order to improve practice, safety, efficacy and cost-effectiveness of oxygen therapy, potential beliefs, practices, cultures and possible origins of practice that may be fuelling discordance need to be exposed and challenged. Thus the current study aimed to explore perceptions of oxygen in order to consider what influences are permeating contemporary healthcare. Highlighting these issues could help identify fallacies, and allow healthcare practitioners to confront the poor practice that is continuing to harm patients.

The research question therefore was: “What are the perceptions of oxygen therapy within selected healthcare professional groups and an identified patient population?”

1.2 RESEARCH AIM AND OBJECTIVES

1.2.1 Research Aim

The aim of this study is to explore perceptions of oxygen therapy from both respiratory patients’ and healthcare professionals’ perspectives in order to identify and analyse the features and idiosyncrasies of oxygen therapy in modern day healthcare, thereby helping to direct future clinical practice and research in this fundamental area of health.

1.2.2 Research Objectives

1. To explore perceptions of oxygen therapy within a selected group of respiratory patients.
2. To explore perceptions of oxygen therapy from selected healthcare professionals.

3. To identify key themes which govern and influence both patients' and HCPs' perceptions of oxygen therapy and therefore clinical reality.
4. To inform future clinical, educational and research agendas for therapeutic oxygen.

1.3 DEFINITION OF TERMS

For the purpose of this study a 'health care professional' is a registered health professional and 'patients' are adults with chronic respiratory disease who have experienced, at some time in their disease trajectory, administration of oxygen as a therapeutic intervention.

Perception – *a belief or opinion, often held by many people and based on how things seem (Cambridge Dictionary, 2010).*

1.4 BACKGROUND

This background sets out to contextualise the therapeutic use of oxygen and to make the reader aware of wider issues that may need to be considered. The literature is consulted to substantiate the research problem and to position the phenomenon under investigation. Initially an overview of related and relevant physiology is summarised.

1.4.1 Related Physiology

Oxygen is a colourless, odourless and tasteless chemical element (O). As a therapeutic intervention it is more commonly the diatomic molecule, dioxygen (O₂), that is commonly referred to as oxygen; the name itself a misnomer. Oxygen is present as 20.8% of the volume of air at atmospheric pressure. It is essential for cell

metabolism in all humans and most other forms of life; delivery at cellular level is dependent upon numerous mechanisms including ventilation, diffusion, and carriage.

The respiratory system is one of the major systems of the body and primarily consists of two lungs. Its main function is to facilitate gas exchange through ventilation (the process of breathing) and respiration. Respiration can be expressed in two ways: internal respiration and external respiration. External respiration refers to exchange of gases at alveolar (terminal air sacs)/capillary level, whereby oxygen enters the blood and carbon dioxide leaves to be excreted through exhalation. Internal respiration refers to metabolism at cell level where oxygen is combined with carbohydrates to produce energy; carbon dioxide is a waste product of this process. As is evident, external respiration is essential to maintain internal respiration and therefore preserve life.

The process of external respiration involves the movement of gases across the alveolar/capillary membrane, this movement of gases occurs through the process of diffusion. Gases such as oxygen and carbon dioxide diffuse along their partial pressure gradient: that is gases move from areas of high pressure to areas of low pressure. Thus oxygen moves from the alveoli to the blood stream where oxygen levels are lower. Once this diffusion has occurred oxygen needs to be transported to the tissues and vital organs in order that internal respiration can occur.

The major source of transport for oxygen therapy is haemoglobin (Hb), contained in red blood cells. Because there is a fixed amount of Hb circulating in the blood, the amount of oxygen carried is often referred to in terms of saturation of Hb, termed SaO_2 ; if measured from a pulse oximeter (a simple non-invasive estimation of blood oxygen content) this is termed SpO_2 . Alternatively the partial pressure of

oxygen in the blood can be measured directly in kilopascals (kPa) through blood gas analysis, the normal range being 12.0-14.6 kPa; this is a sensitive indicator of levels of blood oxygen, Hb saturation, blood carbon dioxide and pH.

Haemoglobin, because of its structure, has four binding sites and the amount of oxygen carried in the blood depends on how many of these sites are occupied. If all sites are occupied the molecule is said to be fully saturated. There is a defined relationship between the partial pressure of oxygen and the percentage of saturated haemoglobin, represented by the oxyhaemoglobin dissociation curve. Importantly this curve is not linear but sigmoid in shape: a unique property that influences saturation and desaturation (Figure 1) and therefore facilitating uptake and release of oxygen under normal circumstances.

Figure 1: The Oxyhaemoglobin Dissociation Curve

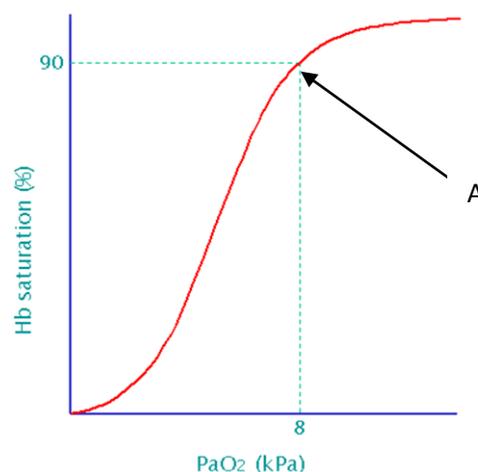


Figure 1, point A, illustrates a clinically critical point on the curve; this is the point, 8 kPa/90% saturation, below which respiratory failure is defined. Above this point it can be seen that the curve plateaus demonstrating that with further considerable increases in arterial oxygen tension relatively small gains in saturation

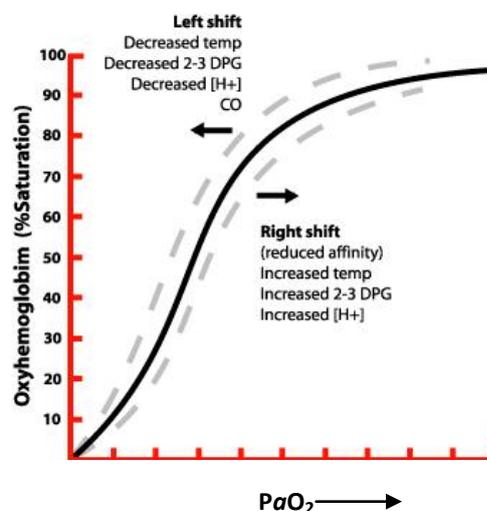
will result. Contrary to this, if the arterial oxygen tension falls below 8 kPa the saturation of the haemoglobin falls rapidly.

The affinity of haemoglobin for oxygen, and hence the position of the dissociation curve, varies with local conditions (Figure 2). A reduced oxygen affinity, represented as a right shift in the curve, can be caused by any of four factors:

- Fall in pH (scale of values denoting acidity/alkalinity of the body)
- Rise in PCO_2 (the Bohr effect)
- Increased 2-3 DPG (2-3-diphosphoglycerate, an inorganic phosphate produced in red cells to control the movement of oxygen across cellular beds)
- Increased temperature.

The effect of the shifting curve is to enable the release of oxygen to active tissues, for example exercising muscle. In the lungs, oxygen uptake is aided by increasing affinity of haemoglobin for oxygen, caused by a falling $PaCO_2$, temperature and increased pH and reflected by a left shift of the curve.

Figure 2: Influences of right and left shifts of the curve



Within the lungs transfer of oxygen to the blood is rapid and efficient, but it is dependent upon the pressure exerted by the gas. This pressure itself is dependent upon the concentration of oxygen as a proportion of ventilated air. It is this relationship between oxygen and haemoglobin that informs certain clinical principles. For instance, at normal atmospheric pressure (approx. 21% oxygen) haemoglobin will saturate at 96-98%. There is no physiological rationale, or benefit, therefore to increase the percentage of oxygen available to the lungs if the haemoglobin is already fully saturated. In certain circumstances diffusion defects can occur: such as a thickening or destruction of the alveolar/capillary barrier through disease; an impairment of blood flow into the pulmonary circulatory system; poor ventilation of the lungs which can be caused by several factors including disease such as asthma or pneumonia or (respiratory) muscular fatigue. In these situations blood oxygen levels can be affected and hypoxaemia (a deficiency of oxygen in the blood) may result. Correction of hypoxaemia by administration of supplemental oxygen in these clinical situations can ensure that enough oxygen, through increased partial pressure, is available to the tissues and vital organs, therefore preventing hypoxia and cell death.

An additional vital aspect of physiology that governs transport and supply of oxygen to the tissues is that of 'hypoxic vasoconstriction'. This is the lung's ability to divert blood flow away from areas which are poorly ventilated to areas that are better ventilated in order to maximise ventilation with perfusion (blood supply). This mechanism is unique to the lungs. Response to hypoxia in other major organs (such as the brain, heart and kidneys) is to vasodilate in order to facilitate circulation and blood flow to areas starved of oxygen. This natural mechanism is important as the body constantly strives, in both health and disease, to maximise ventilation and

perfusion matching. Any mismatch can impair external respiration and impede the supply of oxygen and removal of carbon dioxide.

So, because of the physiological properties of oxygen, namely its binding and carriage, there is little, if any, benefit in giving oxygen exceeding normal levels; indeed the administration of an inappropriate concentration of oxygen can have serious or even fatal consequences (BNF, 2014). The consequences can be as a result of either hypoxaemia or hyperoxaemia (high levels of oxygen in the blood).

Hypoxaemia, as previously defined, refers to low partial pressure of oxygen in the blood. Hypoxia is a deficiency in the amount of oxygen reaching the body's tissues and vital organs; this may be caused as a result of a deficiency of oxygen in the ventilated air or as a result of hypoxaemia. The precise level at which a patient becomes hypoxic is debateable, though it is generally accepted that the physiological defining level of respiratory failure and hypoxaemia ($\text{PaO}_2 \leq 8\text{kPa}$, generally equating to $\text{SaO}_2 \leq 90\%$) will apply to most individuals and that there is no known risk of hypoxic tissue injury above this level (BTS, 2008).

Hyperoxaemia is caused by over administration of oxygen therapy, often with detrimental consequences. Physiologically $\text{PaO}_2 \geq 16\text{kPa}$ saturates the Hb at 100% and obviously cannot increase from this. Yet the effects of further increases in PaO_2 may be important in certain conditions as the blood serum, additionally, becomes flooded with oxygen. These consequences include hypercapnia (high carbon dioxide blood level) with potential resultant acidosis (low blood pH), particularly in high risk patient groups (e.g. COPD, severe chronic asthma, bronchiectasis, cystic fibrosis, chest wall disease and obesity hypoventilation) (BTS, 2008).

This injudicious use of high-flow oxygen, and consequential hypercapnia, often observed in emergency settings, has been attributed to a number of mechanisms:

- Worsening of ventilation perfusion matching (Robinson et al., 2000; New, 2006; Kane et al., 2011; Abdo and Heunks, 2012) – through release of pulmonary vasoconstriction.
- Increase in dead space (the volume of air during ventilation which does not take part in the gas exchange) – as a result of worsened mis-match.
- Worsening hypercapnia and respiratory acidosis – as a result of increased dead space.
- Rebound hypoxaemia -hypoxaemia which is more severe following removal of supplementary oxygen than that which was present before oxygen was administered (Kane et al., 2011).
- Absorption atelectasis (collapse of part of the lung) (Downs, 2003).
- The Haldane effect - oxygenated blood has a reduced capacity for carbon dioxide carriage and therefore diminishes excretion
- Reduced cardiac output
- Damage from oxygen free radicals (discussed further in Chapter 2)
- Increased systemic vascular resistance (BTS, 2008).

Increasing awareness of these potential detrimental effects of oxygen (Singhal, 2006; Shuvy et al., 2013) have heralded recent changes in the UK for first response management of other clinical conditions such as stroke and cardiac ischaemia (JRCALC, 20013).

Other side effects resulting from over-oxygenation may include pulmonary oxygen toxicity (explored further in Chapter 2), with possible progression to ARDS (acute respiratory distress syndrome) and other less serious, but nonetheless uncomfortable, effects such as dry mucosal areas and pressure sores from administration equipment. Additionally, the prescription of home oxygen can result in an over-riding feeling of anxiety for patients with COPD and their families (Mehta et al., 2011).

Principles of the oxyhaemoglobin dissociation curve and risks of both hypoxaemia and hyperoxaemia govern the rationale for the titration of oxygen to within set ranges according to the presenting clinical condition (Figure 3) (BTS, 2008). That is, there is little benefit to be gained through increasing available oxygen when haemoglobin is saturating at normal levels (94-98%). For some patients with chronic respiratory disease however, oxygen saturation levels may routinely fall below 90%, and patients with chronic hypercapnic respiratory failure may be at risk of exacerbating carbon dioxide retention with high blood oxygen levels, thus the recommendation is to keep saturations between 88-92%, maintaining adequate oxygenation without the risk of worsening retention of carbon dioxide.

Figure 3: Recommended target saturations

TARGET SATURATION	PATIENT GROUP
94-98%	Most patients
88-92%	COPD or CO ₂ retaining patients: Chronic hypoxic lung disease (e.g. COPD, severe chronic asthma, bronchiectasis, cystic fibrosis) Chest wall disease (e.g. kyphoscoliosis, thoracoplasty, neuromuscular disease, obesity hypoventilation)

1.4.2 Therapeutic Oxygen

When administered as a therapeutic intervention oxygen should be regarded as a drug (BNF, 2014). In the context of respiratory care, oxygen is generally prescribed for hypoxaemia, either acute or chronic. The condition being treated would normally determine the concentration and duration of oxygen administered. Presented below is the context of oxygen as a therapeutic agent.

The medical administration of oxygen can generally be divided into three main categories: emergency, domiciliary, and palliative. These categories, the evidence base, and current guidance will be discussed briefly to provide background. Detail of historical origins and related evidence base will be covered in Chapter 2.

Emergency Use of Oxygen Therapy

The use of emergency oxygen therapy appears to be enigmatic in the majority of healthcare settings with frequent reports of poor prescribing practices (Dodd et al., 2000; Howell, 2001; Boyle and Wong, 2006; Kbar and Campbell, 2006), critical incidents (NPSA, 2009) and poor knowledge base (Considine et al., 2005; Considine and Botti, 2006; Considine et al., 2007; Kelly, 2010).

Oxygen as a drug is frequently indicated for hypoxaemic patients to increase alveolar oxygen tension and decrease the work of breathing. Although principally lifesaving, in certain circumstances it can prove lethal if prescribed and/or administered incorrectly (BNF, 2014). Despite this seemingly clear rationale for the use of oxygen, confusion still exists about its administration, particularly when treating respiratory, and in particular COPD patients (Drummond, 2007; Roberts, 2004; Troosters, 2004; Calverley, 2000; New, 2006). Not confined to respiratory care

however, the same level of confusion and lack of implementation of evidence-based guidance has been reported in other areas: cardiology and stroke services (Thomson et al., 2002); oxygen in neonates and maternal care (Tin, 2000); treatment of cluster headaches (Bennett et al., 2009). In many of these clinical circumstances imprudent use of oxygen and failure to monitor treatment may have serious consequences.

It is against this backdrop that the British Thoracic Society (BTS) compiled the first Guidelines for Emergency Oxygen use in Adult Patients (BTS, 2008). Previous UK guidance on emergency oxygen came from a generic perspective, namely the Resuscitation Council and the UK Ambulance Service. Based on work in the North West of England (Murphy et al., 2001) the guidelines developed into a national agenda which has been subsequently endorsed and adopted internationally. The guidelines are currently being updated and are due to be published in 2015.

Essentially the guidelines give direction for assessment, administration and ongoing monitoring of emergency oxygen for all patients, but, importantly, specific guidance regarding those patients 'at risk' of the injudicious use of oxygen is considered. The guidelines acknowledge that early recognition of the need for oxygen can be difficult as clinical features are often non-specific, including altered mental state, dyspnoea (shortness of breath), cyanosis (blue tinge due to deficiency of oxygen in the blood), tachypnoea (fast breathing rate), cardiac arrhythmias (disturbance of the heart's rhythm) and coma (unconscious state). Thus to enable assessment of the patient's oxygen status, specific investigations are required, such as blood gas analysis and pulse oximetry (BTS, 2008).

Assessment, and indeed on-going monitoring, of the patient is therefore considered essential to ensure adequate oxygenation of the tissues and vital organs during an acute situation. The major risk for the majority of patients is giving too little oxygen (Murphy et al., 2001), leading to cardiac arrhythmias, tissue injury, damage to vital organs and ultimately death. Emergency care will often require delivery of high concentrations of oxygen (40-60%) as most patients who are acutely short of breath will have potentially life-threatening conditions.

It is conceivable, in these situations, to appreciate the emergency care approach of administering high percentages of oxygen therapy routinely. Anecdotal evidence suggests that often oxygen is administered indiscriminately to any patient who appears breathless, and that this practice then continues into on-going care, even after the patient has been assessed as normoxaemic (normal oxygen levels). This not only provides a hazard for certain patients who are at risk of the effects of hyperoxaemia, but also results in administration of oxygen to patients when there is no clear physiological need, or theoretically no potential physiological benefit. This backdrop has ultimately led to guidance that treatment should be based on achieving target arterial oxygen tensions and saturations, rather than on giving predetermined concentrations or flow rates of inspired oxygen (BTS, 2008).

Evidence is now highlighting the detrimental use of high flow oxygen and hyperoxaemia in patients with acute respiratory presentations. Austin (2010), in a prehospital setting in Tasmania in a randomised controlled trial assessed the effect on mortality of high flow versus titrated oxygen in a population of 405 presumed COPD patients with an acute exacerbation. Overall mortality was 9% in the high flow arm compared with 4% in the titrated arm. In a sub group of patients with confirmed COPD the mortality was 9% in the high flow arm compared with 2% in the titrated

arm. This represented a reduced mortality of 58% for all patients and 78% for patients with confirmed COPD as a result of titration of oxygen.

In a similar study in New Zealand, Perrin et al. (2011) recorded the effect of high concentration oxygen therapy on 106 asthma patients in the emergency department. Through transcutaneous monitoring of CO₂ (PtcO₂) blood levels, the researchers set out to estimate the proportion of patients with a clinically significant rise in PtcO₂. In patients in the high concentration oxygen group the rise in PtcO₂ of \geq 4mm Hg at 60 minutes was 44% versus 19% in the titrated arm; thus further supporting the use of titrated oxygen in patients presenting with acute severe asthma.

The evidence continues; in patients with suspected CAP (community acquired pneumonia) those given high concentration oxygen showed a clinically significant rise in PtcO₂: 50% with high flow oxygen compared with 14.7% in the titrated arm (Wijesinghe et al., 2012). Amongst the patients with confirmed (radiological) CAP the PtcO₂ rise was 57.1% (high flow) versus 12.8% (titrated). This suggests that patients with any respiratory disorder involving abnormal gas exchange risk increasing hypercapnia with high concentrations of oxygen. In OHS (obesity hypoventilation syndrome) a similar message supports the use of oxygen titrated to saturations. Hollier et al. (2014), in a double-blind, randomised, crossover study with 28 OHS patients, showed that breathing a moderate concentration of supplemental oxygen in stable OHS both worsened hypercapnia and induced acidaemia, as a result of worsening hypoventilation and dead space to tidal volume ratio, highlighting the risks of using oxygen in this population.

Traditionally, then, caution has been exercised regarding ‘high-risk’ patient groups, namely those at risk of hypercapnic respiratory failure in respect of over-oxygenation. Additionally, a growing body of evidence is highlighting potential dangers of over-oxygenation in several other patient groups for whom high flow oxygen was traditionally standard treatment (Austin et al., 2010; Perrin et al., 2011; Wijesinghe et al., 2012; Hollier et al., 2014; Shuvy et al., 2013; Godlee, 2012; Pountain and Roffe, 2012) and will be discussed further in Chapter 2.

This emerging evidence has further underpinned recommendations for judicious use of oxygen and rationale for titration according to blood levels (RCP, 2011; JRCALC, 2013; BTS, 2008). Indeed the evidence is so convincing now, that anaesthetists, a clinical group traditionally renowned for advocating high flow oxygen irrespective of blood oxygen levels, are being persuaded when it comes to shrewd use of oxygen (Martin and Grocott, 2013).

Domiciliary Oxygen Therapy

Domiciliary oxygen therapy refers to provision of oxygen in the home. It comes in various forms, principally Long Term Oxygen Therapy (LTOT), ambulatory and short burst oxygen therapy (SBOT). An overview of the indications and a short summary of the evidence base for each is offered here with a more elaborate examination of the historical perspectives available in Chapter 2.

Long Term Oxygen Therapy

Long Term Oxygen Therapy (LTOT) is indicated for chronic hypoxaemia, which may result from a number of different conditions including COPD, cystic fibrosis, chronic heart failure, or nocturnal hypoventilation resulting from obesity,

chest wall disease or sleep apnoea. The primary objective is to correct hypoxaemia, achieving a blood gas tension of at least 8.0 kPa at rest and/or an oxygen saturation of at least 90% (BTS, 2014).

The evidence base for LTOT dates back to two landmark studies conducted in the 1970s (NOTT, 1980; MRC, 1981). Both randomised controlled trials (RCT) demonstrated that in COPD patients with chronic hypoxaemia, long term oxygen therapy increased survival. The results of these studies defined the need for oxygen for at least 15 hours per day; however survival improved when it was used for more than 20 hours per day.

Oxygen therapy administered in the foregoing manner preserves vital organ function, reduces pulmonary hypertension (and subsequently cor pulmonale – right sided heart failure that may result as a consequence of chronic lung disease) and secondary polycythaemia (an increase in red blood cells that can occur as a result of chronic hypoxaemia, which in turn increases blood viscosity leading to an increased risk of embolus – abnormal blood clot); these benefits, in turn, may reduce morbidity and mortality. A comprehensive assessment of the patient, to include blood gas analysis, when stable on at least two occasions, determines the need for LTOT.

Despite the existent evidence base and strict criteria for assessment, patients are often inappropriately prescribed domiciliary oxygen; the National COPD Audit (RCP and BTS, 2008) reported that 25% of patients following an acute exacerbation are discharged from hospital with oxygen despite guidance which recommends patients are assessed and prescribed LTOT in the chronic stable state.

Ambulatory Oxygen Therapy

Ambulatory oxygen therapy refers to use of oxygen during exercise and activities of daily living (BTS, 2014), delivered by equipment that can be carried by most patients. The need for ambulatory oxygen therapy is governed by the patient's oxygen levels at rest and on exercise, and by their requirement to leave the home. This method of supplementary oxygen therapy is indicated for patients who are hypoxaemic and already receiving LTOT, or those patients not fulfilling the criteria for LTOT but who desaturate (haemoglobin releases oxygen causing low saturation levels) with exercise (BNF, 2014). This therapy should only be prescribed following a full assessment of the patient's blood gases, and of their abilities and willingness to accept the therapy.

Mechanisms and physiological benefits of supplementary oxygen therapy during exercise in COPD patients who desaturate have been documented. These include reduction of dynamic hyperinflation, reduction of respiratory drive via decreased aortic/carotid chemoreceptor stimulation, improved blood oxygen content leading to increased oxygen uptake by peripheral muscles and possible prevention of hypoxic bronchoconstriction (Snider, 2002).

A systematic review suggests that ambulatory oxygen therapy does improve exercise performance in patients with COPD, but results may be affected by publication bias and small sample sizes in included RCTs (Bradley and O'Neill, 2005); its role in exercise training is still to be determined (Nonoyama et al., 2007). A more recent systematic review concluded that there was not enough evidence to recommend ambulatory oxygen therapy in patients with COPD who are not hypoxaemic at rest, though some improvements in dyspnoea and fatigue post-

exercise were evident (Ameer et al., 2014). The current consensus is that more rigorous RCTs are needed.

Short Burst Oxygen Therapy

Short burst oxygen therapy (SBOT) refers to intermittent, occasional use of supplemental oxygen at home. It has been traditionally prescribed to relieve dyspnoea or to provide oxygen before and/or after exercise. The use of short term oxygen in this way is widespread and as a consequence expensive. There is little evidence to support the prescription in patients who are not chronically hypoxic at rest or who demonstrate desaturation during exercise (Stevenson and Calverley 2004), though, anecdotally, patients often report subjective benefit.

SBOT may reduce dyspnoea via similar mechanisms to those described above for ambulatory oxygen after exercise (Lewis et al., 2003); oxygen delivered post exercise has been reported to reduce dynamic hyperinflation but there are no reported benefits for dyspnoea of using oxygen rather than air (Stevenson and Calverley, 2002). It may be the mechanism of reduced rate of ventilation and oxygen cost (rate at which respiratory muscles consume oxygen as they ventilate the lungs) that minimise the sensation of dyspnoea (O'Donnell et al., 1997). This suggests that factors other than lung mechanics may be important, such as facial cooling Schwartzstein et al. (1987).

Liss and Grant (1988) reported no difference in dyspnoea comparing air to oxygen in eight hypoxic subjects, although when topical anaesthesia was applied to nasal passages all participants were significantly more dyspnoeic during administration of both gases. This role of non-specific stimulation of nasal receptors

by gas flow in the modulation of dyspnoea, together with flow of gas across the face, could explain the placebo effect of air and oxygen in various studies.

A Cochrane review of oxygen for non-hypoxaemic COPD patients, including 28 trials, did acknowledge a reduction of dyspnoea, though heterogeneity of studies prevented any firm recommendations other than assessing individuals on an individual basis whilst awaiting completion of large RCTs (Uronis et al., 2011).

Palliative Oxygen Therapy

This final category of therapeutic oxygen outlines its use for palliation of dyspnoea, a practice prevalent in contemporary clinical care settings. Dyspnoea is a common distressing symptom in many terminal conditions and one for which oxygen is often prescribed. The symptom itself, contributing factors, assessment and treatment are further outlined later in this Chapter (page 25).

With regards to the use of oxygen for palliation of dyspnoea, a report from the Association of Palliative Medicine following a review of the (limited) research concluded that there is some evidence that oxygen can have a useful role in palliation of dyspnoea in selected patients with advanced cancer, COPD and in some neurological conditions such as MND (motor neurone disease) (Booth et al., 2004; Bausewein, 2008).

Caution with any palliative approach is necessary to prevent introducing new symptoms, for example exacerbation of hypercapnia in susceptible individuals, which could induce drowsiness or headaches. As with short burst oxygen therapy there appears to be no physiological rationale for administering oxygen to patients with normal blood oxygen levels, and patients who experience relief are probably

experiencing a placebo effect from facial cooling and relief of anxiety (Schwartzstein, 1987; Muers, 2005; Booth et al., 2005).

This placebo effect, however, should not be underestimated (Goldacre, 2009; Spiegel and Harrington, 2008; Godlee, 2008) and may even be advocated in palliative care. Dyspnoea and anxiety have been inextricably linked (Bailey, 2004) and in order to break the vicious cycle it may be necessary to treat both; oxygen therapy could well play an important role in this respect. Yet drawbacks are apparent as it can potentially cause patients physical, psychological, emotional and social discomfort (Booth and Dudgeon, 2006). Oxygen can also, by reinforcing the placebo dimension, cause a challenge to healthcare professionals, patients and families in managing the palliative and terminal phase of illness (Davidson and Johnson, 2011). Despite these considerations oxygen continues to be recommended for use in the palliation of dyspnoea in patients who are normoxaemic and not relieved by other treatments (NICE, 2010; BNF, 2014). This remains a controversial issue in palliative care that probably adds to some of the erroneous beliefs which lead to the inappropriate use of oxygen therapy.

This précis of therapeutic usage of oxygen has outlined key considerations and it is clear that evidence is lacking and much clinical practice appears to be based on tradition and ritual. How this manifests into perceptions is unclear, but it is a dimension that may well illuminate recurring and persistent practice.

In order to appreciate why oxygen therapy is often the default treatment for breathlessness, both in emergency and palliative care, it is important to outline the symptom, its causes, impact on individuals and available options for effective management.

1.4.3 Dyspnoea

The American Thoracic Society Statement defines dyspnoea as “*a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity*” (Parshall et al., 2012: 436). Booth (2005) describes it as a complex and distressing experience of both body and mind; it has also been identified as a potent predictor of mortality and use of healthcare resources (Parshall et al., 2012). Breathlessness has been discussed with regards to detection and signalling of real or impending threat to existence (Gracely et al., 2007) thus the gravity of the phenomenon cannot be underestimated in relation to patients’ subjective experience.

It should not be overlooked that breathlessness in itself is a normal familiar sensation that occurs with physical exertion and is related to physical fitness. In the presence of pathology the threshold of breathlessness is lowered and refractory dyspnoea is that which persists at rest, or with minimal activity, despite optimal therapy of the underlying condition (Mahler, 2013). Dyspnoea therefore can be described as a heightened level of awareness of the uncomfortable sensation of feeling breathless.

Causes

Dyspnoea is a common symptom affecting up to 50% of all patients in acute care and 25% of patients in ambulatory settings (Parshall et al., 2012). The symptom may be experienced as a consequence of a wide range of diseases commonly, but not exclusively, cardiopulmonary and neuromuscular. In addition it may be seen as a manifestation of poor cardiovascular fitness or obesity, both of which can pre-exist with clinical conditions serving to exacerbate the symptom. This is particularly

common in COPD patients where a fear of breathlessness itself contributes to a sedentary lifestyle, which in turn results in a loss of muscle mass and functioning. The ultimate consequence is general physical deconditioning which necessitates increased work of breathing: this further enhances the sensation of dyspnoea (BTS, 2013). Overlaid with fear and anxiety of mortal danger, a vicious cycle of worsening dyspnoea ensues which is extremely difficult to break or control. An emotional response to dyspnoea often manifests in panic which can be responsible for increased healthcare utilisation, and a negative impact on quality of life (Bailey, 2004).

Mechanisms

Respiration itself is visceral (involuntary control) but the act of breathing is somatic (voluntary control) (Martini and Bartholomew, 2007). Despite this voluntary nature it is the least optional of all skeletal muscle activity, such that demands made cannot be evaded by unconsciousness, or voluntarily suppressed for prolonged periods. Essentially, mechanisms that contribute to dyspnoea are complex and diverse, involving sensory information relayed to the higher brain centres where respiratory related signals are combined with contextual, cognitive and behavioural influences.

Breathing itself is normally an unconscious activity but when normal mechanisms are disturbed it can reach consciousness, especially if the sensation is unpleasant and/or distressing. Many uncertainties and questions remain regarding the exact mechanisms that contribute to dyspnoea (Mahler et al., 2010) and much of what is currently understood is derived from studies of young, healthy subjects and the relevance to pathologic dyspnoea is uncertain. Although these doubts exist there

is consensus within the literature regarding the intricacy of the phenomenon, and reference is made to dyspnoea being a synthetic sensation resulting from complex interactions of signals from within the central nervous system and a variety of both chemical and motor receptors (Manning and Schwartzstein, 1995). It is thought that seldom will dyspnoea result from only one of these mechanisms (Manning and Schwartzstein, 1995).

Fundamentally, the key mechanisms appear to be chemoreceptors, mechanoreceptors, respiratory muscles and emotional cognitive and behavioural processes. Not all factors necessarily contribute always and during exercise all of the mechanisms described are amplified with additional stimulus from peripheral muscles.

Chemoreceptors: Primary mechanisms include stimulation of chemoreceptors capable of sensing changes in blood oxygen, carbon dioxide and pH levels. Therefore any deviations from normal in arterial blood gas levels and pH will contribute to the perception of dyspnoea. Following from this there are some contradictions regarding the impact of hypercapnia on dyspnoea *per se*, with studies suggesting those who retain carbon dioxide are less breathless (Peters and O'Donnell, 2006). Additionally the relationship between hypoxia and dyspnoea appears even more complex and a poor correlation has been found to exist in patients with COPD (Manning and Schwartzstein, 1995; Clemens et al., 2009).

Mechanoreceptors: Respiratory mechanoreceptors, namely stretch receptors, irritant receptors and juxtapulmonary (or J) receptors, are stimulated by mechanical and chemical stimuli and almost all signals are carried to the brainstem via the vagus nerve. Again it is currently poorly understood what contribution these make to

dyspnoea, and studies both blocking and stimulating mechanoreceptors have shown inconclusive results (Peters and O'Donnell, 2006). Nonetheless it has been found that stimulation of these receptors, through chest wall expansion, will reduce dyspnoea despite subsequent falls in PaO_2 (Peters and O'Donnell, 2006) and therefore a contributory role is apparent.

Respiratory muscle function: Increased effort of breathing is associated with increased physiological dead space, particularly produced by hyperinflation as greater ventilation and respiratory effort is required to maintain adequate gas exchange. Hyperinflation further contributes to altered lung mechanics causing ventilation to occur at a less compliant region of the pressure-volume curve which further reduces inspiratory muscle strength. It seems likely that resultant increase in work and discomfort of breathing, close to total lung capacity, will impact upon the sensation of dyspnoea (BTS, 2013). In addition increased airway resistance (as in COPD) will also affect the work required in order to provide adequate ventilation.

Afferent Mismatch: First proposed by Campbell and Howell in 1963 as 'length-tension inappropriateness' the theory of neuromechanical dissociation, or uncoupling, refers to a mismatch between the drive to breathe and the ability to perform it (Schwartzstein et al., 1989). Based on the fact that no single afferent or efferent signal is solely responsible for dyspnoea, the hypothesis suggests a mismatch between efferent motor signals (determined in part by metabolic requirements such as oxygen need, carbon dioxide production and respiratory muscle function) and afferent feedback (an amalgam of sensory information related to respiratory pressures, lung and chest wall motion and airflow). The theory itself is popular and provides a useful concept for management of dyspnoea, such as reducing central drive, improving mechanical muscular response, or both.

Importantly this theory does not consider the emotional, cognitive and behavioural process that may either ensue from experiencing dyspnoea or contribute to the sensation.

Emotional and cognitive processes: Dyspnoea is a subjective experience and therefore it can be influenced by both emotional and cognitive processes. Once the symptom is perceived the individual evaluates personal meaning and behaviour is modified accordingly. Contributing to this evaluation will be previous experiences, knowledge and understanding, together with pre-existing anxiety and depression (Parshall et al., 2012); this effect is greater amongst patients with lower functional capacity (Doyle et al., 2013) and important when considering dyspnoea in those with chronic lung disease who often reduce activities in order to avoid exertional dyspnoea.

The perception of dyspnoea itself has been described as a 'sensory gating system' involving attentional modulation of gating (changing of cognitive state in order to concentrate their attention on ventilation), affective awareness, and evaluation (Davenport, 2007). In other words, the individual, in order to experience breathlessness, needs to be aware of ventilation and decide whether it is comfortable or not; this awareness in itself is crucial to any attempts at voluntary compensation.

Ultimately the complex social and environmental situations that patients live in will influence their perception and reaction to dyspnoea, affecting their awareness of capabilities and self-concepts. Loneliness or presence of friends and families has also been found to impact on these behavioural responses in addition to patients' expectations (Parshall et al., 2012).

Assessment of Dyspnoea

Dyspnoea has been described as several qualitatively distinctive sensations including a shortness of breath, an urge to breathe, air hunger, feeling of suffocation and an increased effort of breathing (Yernault, 2000; Parshall et al., 2012). Assessment is by an individual's verbal description and numerous validated tools exist that can be utilised in the clinical environment to try to measure, in an objective manner, this subjective phenomenon (Parshall et al., 2012). There have been recent attempts to make this measurement more sophisticated by categorising, for example, impact on performance or what breathing feels like, or the various patterns of dyspnoea (Simon et al., 2013; Currow et al., 2013). This work may help to target therapies and management strategies in future, but measurement of breathlessness remains complex and further advances are needed.

Treatment of Dyspnoea

Diagnosis and treatment of underlying pathologic causes of dyspnoea is recommended to ameliorate the symptom (Parshall et al., 2012). But for many patients the cause may not be known or dyspnoea becomes refractory, persisting despite optimal treatment of the underlying condition. These are often the patients who are most challenging when trying to improve the symptom (Elkington et al., 2005).

Treatment strategies are generally divided into pharmacological and non-pharmacological, but as breathlessness is a multidimensional symptom, intervention should involve a combination of approaches.

Pharmacological: The use of opioids for pharmacological management of dyspnoea has the strongest evidence base (Mahler, 2013), although some questions still remain regarding its long term use (Booth, 2013). Opioids, primarily morphine, work by modulating perception of dyspnoea and there may be some decrease in respiratory drive and anxiety (Mahler, 2013). Yet despite reassurance from limited evidence regarding the safety of using opioids, fear of overdosing and development of significant respiratory depression persists amongst healthcare professionals (Mahler et al., 2010; Kamal et al., 2012; Hallenbeck, 2012).

Other classes of drugs, such as antidepressants, also have limited application for long term use. A systematic review of evidence concerning use of benzodiazepines, which are commonly used in management of dyspnoea, concluded that there was no evidence of any beneficial effect and this class of drug should only be used if other first line treatment such as opioids and non-pharmacological interventions have been tried (Simon et al., 2010).

The use of supplemental oxygen for amelioration of dyspnoea is common clinical practice in both chronic lung disease (in the form of SBOT) and palliative care. The prescription of oxygen for patients with underlying hypoxia is grounded in sound clinical trials and pathologic evidence, and seldom disputed. However, when a patient's blood oxygen level remains normal an argument presents itself which leads to contention and confusion in practice.

Non-pharmacological: Booth (2013) suggests three non-pharmacological intervention groupings: firstly those that affect *breathing*, for example fan therapy, breathing exercises and neuromuscular electrical stimulation. Secondly, those that affect *thinking*, that is targeting central perception of breathlessness, for example

education, relaxation techniques, cognitive behavioural therapy and active listening. And thirdly, interventions that affect *functioning*, for example exercise programmes, mobility aids and pacing skills. It would seem that given the complexity of dyspnoea incorporation of one, or several, of these approaches to management is essential. Evidence base remains scant but is emerging.

To summarise this overview of dyspnoea management: ideally treatments need to be individually tailored to meet patients' concerns and priorities; the inclusion of family and carers in these needs is deemed an integral part of supportive care; an 'n of 1' trial is often necessitated in order to assess efficacy on an individual basis.

Dyspnoea is clearly a complex phenomenon that impacts on morbidity, mortality and healthcare utilisation. Whilst physiological mechanisms are important it is also clear that psychological, social and environmental factors are also pivotal in the way that dyspnoea is experienced and controlled. Secondary physiological and behavioural responses often result from this complex phenomenon; but only the person experiencing dyspnoea can perceive it *per se*.

So whether a patient with underlying respiratory disease experiences dyspnoea on exertion as a result of increased metabolism, increased airway resistance, mechanically disadvantaged ventilatory muscles, or changes in arterial blood gases is unclear (Manning and Schwartzstein, 1995). Whatever the cause, there is little doubt that dyspnoea is extremely uncomfortable and has a profound negative impact on quality of life (Francésa et al., 2008). As major indicators for administering and/or prescribing oxygen therapy, these aspects of dyspnoea will be important to consider within the thesis.

The final section of this background considers oxygen in the wider social arena. As both HCPs' and patients' perceptions may be influenced by a variety of dimensions, including cognitive and social, it is important to consider the role, influence and status of oxygen in society.

1.4.4 Non-clinical Uses of Oxygen Therapy

The remit of the study is to consider perceptions of oxygen therapy in both individual patients and healthcare professionals in an attempt to investigate and expose the thinking behind the use of oxygen therapy in modern day healthcare. To some degree the source of these perceptions, or at least some of the influences, may direct strategies to improve practice in the future. Apart from being patients and healthcare professionals these individuals are also members of the general public, and as such, will be influenced by images of oxygen portrayed by media and popular culture. To this end it is also necessary, therefore, to consider the use of oxygen as a recreational drug.

The notion of oxygen as a recreational drug is contemporary. Most UK music festivals throughout the summer months, with the majority of attendees ranging between 16 and 26 years of age, offer oxygen for a fee of £3.50-£5 for a 5 minute session and are called 'Oxygen Rehab Bars' (Festival Forum, 2010). The idea of taking oxygen recreationally seems to be gaining momentum from a craze that originated in Japan and the US and is now commonly advertised in many European countries including the UK (Bubble Oxygen Bars, 2014). Oxygen as a commodity therefore can be seen as a potential area of growth, particularly with younger age groups. Bar-based parties offer guests the opportunity to sit and breathe pure oxygen through flavoured liquids or alcoholic mixtures; a three to five minute session claiming

to 'revitalise and uplift' (Bubble Oxygen Bars, 2014) and assertions are made that they are the 'pubs of the future' (Festival Forum, 2010). One alarming aspect of the advertisements that are abundant on the Worldwide Web is claims such as '*there is also no danger from using these oxygen machines*' (Fantasia, 2014). And there are further claims: creams; oils; toothpastes; powders; shampoos; various drinks and nutritional supplements, are just some of the products proclaiming beneficial effects from their oxygen content.

Advertising of oxygen as a commodity is not confined to youth websites and audiences. The British Lung Foundation (BLF) is a registered charity that aims to improve treatment, care and support for people affected by lung disease (BLF, 2014). This support is primarily delivered by Breathe Easy, the patient support arm of the BLF. Together with local and national networks of people dedicated to supporting patients with lung disease, Breathe Easy also publishes a quarterly members' magazine. In addition to providing some useful and informative articles aimed at patients and their carers the magazine also contains advertisements. And whilst most of these advertisements are objective and innocuous, others herald the virtues of oxygen drinks and the availability of oxygen in cans (Breathe Easy, 2008). These advertisements claim that products such as OGO® *Oxygen* are ideal for use when breathless (at £5.95 per canister which lasts for two minutes or 30 gulps).

Another public perspective worth considering is the use of hyperbaric oxygen as an aid to promote recovery from acute injury. This is a therapy which was endorsed during past world cup football tournaments with high profile cases sleeping in oxygen tents to regain fitness (Telegraph, 2010). Whilst there may be some evidence in animal models (Best et al., 1998) and its use in acute injury is depicted

(Gill and Bell, 2004), hyperbaric oxygen for muscle and soft tissue injury as a means to speed recovery has been found, in a Cochrane systematic review, to lack substantial evidence (Bennett et al., 2005). Despite this lack of evidence, the use of oxygen to treat sports injury is still given high profile in the media and continues to influence the general public's perception of oxygen and its powers.

Finally, the portrayal of oxygen as a medical necessity in mass media such as popular television series cannot be overlooked. Programmes such as 'Casualty' and 'Holby City' seem to revolve around the patient receiving oxygen to the point where oxygen and emergency care are seen as synonymous. The impact of such high profile images and intimations needs to be considered in the context of popular social perceptions of oxygen.

1.5 SUMMARY

This opening chapter has aimed to position the research question and to justify the current study. In addition it has served to place the identified clinical problem in context by providing key background information upon which the thesis has been built. The following two chapters aim to interrogate available literature in order to further position the research question and provide a platform for synthesis with findings from the study. Chapter 2 will consider the historical origins of oxygen as a therapeutic intervention, analysing the roots of clinical practice to explore potential antecedents that have permeated into today's clinical environment. Chapter 3 will review published evidence regarding both patients' and HCPs' perceptions of oxygen therapy.

CHAPTER 2 – HISTORICAL REVIEW OF OXYGEN

'History is who we are and why we are the way we are.' David McCullough, Historian

'To know where we're going, we need to know where we've been.' Anon.

Stories can reach out from history to inspire and guide future progress. Thus this historical chapter seeks to analyse established beliefs regarding oxygen, and consider possible influences and relationships of this knowledge within the current thesis. The aim is to address the history of oxygen, from its originating presence in the Earth's atmosphere and its relationship with evolution, to the discovery of oxygen in the 17th century and consideration of the historical perspective of oxygen as a therapeutic intervention.

A search of the literature was undertaken in CINAHL and PubMed using the search terms 'history' and 'oxygen'; the importance of the Boolean 'and' ensured a focused search to locate only historical reviews. The strategy located 193 papers of which 63 were retrieved for full consideration following review of the title and abstract: of these 31 were later discounted, though consideration of the reference lists of remaining papers identified a further 29 studies of value that were then incorporated. The review was not intended to be systematic, therefore strict inclusion and exclusion criteria were not applied: papers were chosen for relevance and originality. A total of 64 papers are therefore synthesised into this narrative review.

2.1 THE NATURAL HISTORY OF OXYGEN

To understand the full character of oxygen it is beneficial to overview the natural history in relation to its derivation, contribution to the atmosphere and role in the origins of life.

Oxygen is a colourless, odourless and tasteless diatomic molecule (O_2). It is present as 20.8% of the volume of air, comprises 49.2% of the Earth's crust and 88.8% by mass of the world's oceans (Biddle, 2008). Oxygen is the third most abundant element in the cosmos, behind hydrogen and helium, and is the most abundant element in the Earth's crust. Yet many theories exist suggesting that oxygen was probably not present at all in Earth's early atmosphere (Dole, 1965). Relative to this is the notion that there was a close connection between the origins of life on planet Earth and growth in the abundance of atmospheric oxygen (Berkner and Marshall, 1964). Oxygen is essential for cell metabolism in all humans and most forms of terrestrial life (Lane, 2002).

To substantiate the conjecture that oxygen was once absent from Earth it is necessary to examine the theorems that support this notion.

Oxygen is believed to have been formed as part of hydrogen-burning nuclear reactions in which hydrogen is converted to helium (Dole, 1965). If true, it is hypothesised that at zero time (the creation of the universe – 5 billion years ago) hydrogen was essentially pure because very few nuclear reactions produce hydrogen. As a star is created the reaction converts hydrogen to helium, a process that radiates energy and is dependent on temperature. As hydrogen is further consumed in the core of the star to form helium, known as the helium fusion process, the temperature increases allowing further nuclear transformations to take place: one of these is the formation of carbon. In the presence of sufficient carbon, oxygen is formed through the exothermic reaction of helium and carbon (Dole, 1965).

Apart from traces on Venus and Mars, Earth is the only planet with abundant oxygen but, as has been suggested, evidence exists that this was not always the

case. Amongst this evidence is the fact that the Earth's crust is sub-oxidised, meaning the rocks can, and do, continue to take up oxygen; if free oxygen were available at the time of volcanic eruptions, rock would have already been fully oxidised. In addition, abundance of carbon in fossilised rock suggests that free oxygen was not available in Earth's initial atmosphere. If it were, photosynthetic reaction would have resulted in equal amounts of carbon and oxygen. Further support to the theory of an oxygen-free planet derives from the fact that amino acids (the building blocks of life) are very short lived in the presence of oxygen and light; thus for life to have started, oxygen needed to be absent (Abelson, 1957 in Dole, 1965).

Finally, it is thought that during the Earth's formation most inert gases would have escaped with no free gases existing in the atmosphere; the only gases retained, therefore, would be chemical combinations: H₂O (water); CO₂ (carbon dioxide); O₂ (oxygen) and N₂ (nitrogen). If this was the case, as the Earth stabilised, these gases would necessarily be liberated from chemical combination by processes such as photochemical reactions, where atomic oxygen (O) would be released from H₂O and in the presence of nitrogen and photons (light energy) would form molecular oxygen O₂ (Dole, 1965).

Dole (1965) suggests that because of less intense radiation from the Sun the Earth in earlier times was much colder than today and seas may have been unformed or frozen. In order for life to start the Earth needed to warm up: ozone (O₃ - a triatomic molecule consisting of three oxygen atoms which is far less stable than O₂) needed to accumulate in the upper atmosphere to form a layer necessary to provide protection through absorption of ultraviolet light. It is suggested that these processes would happen very slowly. Therefore it is possible that early oxygen which

diffused to earth was entirely consumed by oxidation of the Earth's crust, as described previously, and it is hypothesised that the content of oxygen on Earth was very small for many millions of years (Berner et al., 2007; Lane, 2010).

This early lack of protection from the Sun's ultraviolet light leads to the theory that life in its simplest forms developed in the depths of the oceans or stagnant bays, initially as anaerobic organisms. Later the emergence of cyanobacteria, about two to three billion years ago, developed primitive photosynthetic processes that harnessed the Sun's energy to extract hydrogen from water. The strategy for metabolism was hugely successful resulting in Earth quickly being covered with cyanobacteria. One problem however resulted: the production of oxygen as a waste product (Johnson, 2009), and as life on Earth evolved it had to adapt to the increasing level of oxygen.

All these deductions lead to the theory that oxygen in the atmosphere today was produced mainly by photosynthesis (plant respiration involving the reaction of carbon dioxide and water to produce oxygen and glucose in the presence of chlorophyll) (Berner, 1999). It is thought that the presence of cyanobacteria about 2.7 billion years ago released the first free oxygen through photosynthesis (Lane, 2010). Initially this oxygen would have been soaked up by iron dissolved in the oceans, as evidenced by iron oxide deposits throughout the Earth's outer crust. At the point of saturation of iron, oxygen was then released free into the atmosphere. This point of saturation was thought to be the fulcrum of a major change to the Earth's atmosphere, often referred to as 'The Great Oxidation Event', or oxygen catastrophe, about 2.4 billion years ago (Lane, 2002). It is believed that this phase of the Earth's evolution may have wiped out the majority of anaerobic inhabitants and that cyanobacteria were essentially responsible for what is believed to be the largest extinction in Earth's history (Berner et al., 2007). It is also thought that it was at this

point in natural history that the ozone layer was created, thus offering a vital protective shield from the Sun's ultraviolet radiation, trapping hydrogen and oxygen, and enabling further evolution of life.

The volume of oxygen in the air has thought to fluctuate over time, reaching a maximum of 35% about 300 million years ago (Berner et al., 2007). This high peak of oxygen concentration is thought to have been caused by a proliferation of large woody vascular plants (evidenced by the abundance of coal seams) which may have contributed to large sizes of insects and amphibians – giantism. This high peak in atmospheric oxygen led to increased metabolism and aided the invasion of land by invertebrates (Graham et al., 1995). Lane (2010) outlines what is thought to have been an 'oxygen pulse' in the evolution of the atmosphere. This suggests that following the peak of 35% the levels fell back to 15%, probably caused by a global freeze (precipitated by the oxidation of volcanically released methane) (Lane 2010) before reaching the equilibrium of 21%. It is hypothesised that this 'pulse' eliminated species that had developed to survive in a hyperoxic atmosphere of 35%. Thus life on Earth today has specifically evolved to tolerate oxygen at an atmospheric level of 21%: no more, no less.

The further evolution of life on earth concerned the adaptation of anaerobes, for which oxygen was a waste product and toxic, to tolerate and even utilise oxygen. It is believed then, through scientific deduction presented here, that only life itself can produce free oxygen in abundance. How life then evolved further to both utilise oxygen, and to protect itself against oxygen's potentially harmful effects and how this relates to use of therapeutic oxygen today will be explored further in the following sub-sections.

2.2 THE EVOLUTION OF CELLULAR RESPIRATION

The ability to harness oxygen as a fuel was developed through acquisition of mitochondria, which are thought to have appeared about 1.5 billion years ago (Semenza, 2007). Mitochondria are the powerhouses of the cell, located in the cytoplasm, and are a feature of *eukaryotic* cells found in most animals, plants and fungi. Eukaryotic cells are those which have a true nucleus housing DNA (deoxyribonucleic acid) within a membrane, as opposed to *prokaryotic* cells, such as bacteria, which do not have a true nucleus. Mitochondria are principally involved in cell division, cell death and cell respiration (Semenza, 2007).

The first metazoan organisms (multicellular animals whose cells differentiate to form tissues) are thought to have appeared about 0.5 billion years ago (Semenza, 2007). Their evolution was dependent upon highly efficient recovery of energy contained within glucose through oxidative phosphorylation (the utilisation of oxygen as an electron acceptor in mitochondria to accelerate energy production). This is referred to as aerobic respiration – with oxygen. During cell respiration, rod shaped mitochondria convert O_2 and nutrients into ATP (adenosine triphosphate - the cellular chemical currency of energy) via electron transport chains. Aerobic respiration is much more efficient than anaerobic respiration, producing about 15-18 times more energy. So it is considered that evolutionary development of mitochondria enabled oxygen to be harnessed as an economic fuel (Lane, 2002). Thereafter increasing availability of oxygen in the atmosphere supported evolution of complex organisms with high energy demands. It is believed that mitochondria are the inherited legacy from photosynthetic ancestors (Freeman, 2000). Without the presence of mitochondria in cells, complex animals with large energy needs could not have evolved.

Paradoxically, adaptation to aerobic respiration required additional adjustment to offer protection against toxic effects of oxygen. The structure of mitochondria themselves seems central to this protection: it includes two membranes which act as filters and divide the organelle into an intermembrane space and a larger internal matrix. It is within this matrix that the mitochondria DNA is contained (mitochondria has its own DNA and reproduces independently of the host cell). Many proteins involved in respiration are embedded within the matrix, including the enzyme that generates ATP. It is thought that this primary evolutionary function of compartmentalisation of mitochondria protects the cells' nuclei from the damaging toxic side-effects of oxygen metabolism (Abele, 2002).

Contrarily, the use of oxygen as a fuel gave rise to the problem of oxygen toxicity. This toxicity arises from oxygen's tendency to radicalise, forming incompletely-reduced free radicals also known as reactive oxygen species (ROS). ROS are atoms or compounds containing one or more unpaired electrons in their outer orbits. The most potent of these are superoxide ($O_2^{\cdot-}$), hydrogen peroxide (H_2O_2), hydroxyl radical (HO^{\cdot}) and nitric oxide ($\cdot NO$). ROS can be regarded as unstable molecules produced during normal metabolism that can, in excess, be damaging. An excess of ROS results in oxidative stress.

Not all free radicals are detrimental: as a natural by-product of normal cell metabolism some have important roles such as cell signalling and homeostasis, and some are involved in defence mechanisms such as phagocytosis (Lane, 2011). Indeed $\cdot NO$ is now recognised as an important signalling molecule central to the mediation of blood flow and tissue oxygen delivery (Freeman, 2000). It follows that the presence of free radicals is essential to normal metabolism, and their presence must be tolerated. To enable this, the body has evolved sophisticated enzymatic

anti-oxidant defence systems to prevent free radical damage (Monaghan et al., 2009). It is these complex metabolic processes that maintain a fine balance in health which is disrupted by pathological disease states. When this balance is upset, cumulative oxidative stress at cellular level can cause genetic degeneration and physiological dysfunction leading to progressive aging of a cell and cell death (Dowling and Simmons, 2009). The sensitive equilibrium that mitochondria aim to achieve therefore is to keep cellular oxygen concentration high enough to meet the tissue's demands, but low enough to minimise or control ROS formation.

The formation of excess ROS under local hypoxia which therefore produces oxidative stress is known for a range of human pathologies, e.g. ischemic brain injury (stroke). This mitochondrial ROS production often serves as an alarm signal to induce protective reactions that conserve cellular energy balance. In the case of stroke, brain cooling (though ischemia) enforces a slowdown of neuronal metabolism thus ameliorating hypoxia induced ROS by ischemic brain mitochondria, preventing further oxidative injury. All mammals have similar hypoxic genes that are transcribed in response to oxidative stress. These are factors that switch on anaerobic energy production and induce vasodilatation to get blood into the hypoxic areas, a process known as *hypoxic vasodilatation*.

In relation to oxygen therapy it is known that excess ROS are generated when tissue O₂ levels are high. It is these cytotoxic levels caused by hyperoxygenation that are thought to be detrimental to metabolism and cause damage at cellular level (Bryan and Jenkinson, 1988). Hypoxia can, in some instances, be seen to be protective, and hyperoxia can, in certain situations, prevent these natural protective mechanisms occurring, together with an increase in ROS; a double-edged sword.

It can be summarised then that when an excess of ROS or a depletion of antioxidants occurs, oxidative stress results, causing damage and cell injury. These free radicals in excess are known to cause mutations and cancers through damage to DNA and protein, and lipid damage causes loss of functionality and an excess of toxic by-products in cells. They are implicated in inflammation, carcinogenesis, ischaemia-reperfusion injury, atherosclerosis, aging and death (Van der Walt, 2006). Seemingly the evolutionary irony of oxygen is that in addition to sustaining life it is also what limits lifespan and ultimately kills.

2.3 THE DISCOVERY OF OXYGEN

Leonardo Da Vinci at the outset of modern science in the late 15th century was credited with noting that air incapable of supporting combustion was also incapable of supporting life, suggesting the existence of some form of 'vivifying spirit' (Freeman, 2000). The actual discovery of oxygen in history books is often attributed to the Swedish apothecary Carl Scheele and English clergyman and chemist Joseph Priestly. Yet 170 years prior to this, Michael Sendivogious, a Polish alchemist, was probably the first to have unwittingly isolated oxygen and, although not aware of the full significance, identified its importance. Sendivogious termed the discovery in 1604 as something that was in the air, "a secret food of life" (Lane, 2002:3). He was later thought to have shared his idea with a Dutch inventor and alchemist Cornelius Drebbel. Drebbel, amongst many other inventions, built the world's first submarine for King James I of England; launched on its maiden voyage into the Thames, the submarine reportedly stayed underwater for three hours with 12 men on board. Regarding how Drebbel had managed to refresh the air it was reported by some that he had used a bottle of liquor; others, reportedly the chemist Robert Boyle in 1660, suggested a gas was used to refresh parts of the air. It is presumed that Drebbel,

following instructions from his mentor Sendivogius, had successfully bottled oxygen gas through the heating of potassium nitrate (KNO_3) (Lane, 2002).

Other early founders recognised that air was made up of various components. Boyle regarded respiration and combustion as similar processes and John Mayow, Boyle's contemporary, went further in 1674 by showing that what he termed '*aerial nitre*' (oxygen) was a normal constituent of air. Mayow recognised a parallel between combustion and respiration (Sternbach and Varon, 2005) and described this '*aerial nitre*' as something that "*... becomes food for fires and also passes into the blood of animals by respiration ... It is not to be supposed that the air itself, but only it's more active and subtle part, is the igneo-aerial food*" (Lane, 2002:5). Yet despite this seemingly accurate concept it was not until a century later that Priestly and Scheele isolated oxygen.

In 1771 Scheele and in 1774 Priestly, both discovered oxygen independently (Severinghaus, 2002) but neither fully recognised the significance. Both nevertheless appreciated that burning (of candles) was more vigorous in the presence of the gas (Priestley, 1775: 10; Scheele, 1777: 23). Scheele used the term 'fire-air' to depict the gas; Priestly named the gas 'dephlogisticated air'. This term originated from the accepted 'phlogiston theory' of the time; this theory maintained that phlogiston, a contaminant, was released in the process of burning, therefore dephlogisticated air represented pure air. It seems this dogma blinded both Scheele and Priestly to the true meaning of their discoveries. Despite Scheele's initial discovery, a delay in publication until 1777 bestowed credit to Priestly as the first to isolate the newly discovered gas.

Priestly foresaw not only the potential medical applications of oxygen but also its potential dangers. The remarkable words of Priestly, demonstrate this insight pithily:

“From the greater strength and vivacity of the flame of a candle, in this pure air, it may be conjectured, that it might be peculiarly salutary to the lungs in certain morbid cases, when the common air would not be sufficient to carry off the putrid effluviu[m] fast enough. But, perhaps, we may also infer from these experiments, that though pure dephlogisticated air might be very useful as a medicine, it might not be so proper for us in the usual healthy state of the body; for, as a candle burns out much faster in dephlogisticated than in common air, so we might, as may be said, live out too fast [sic] and the animal powers be too soon exhausted in this pure kind of air. A moralist, at least, may say, that the air which nature has provided for us is as good as we deserve.” (Priestley, 1775:53)

“The feeling of it to my lungs was not sensibly different from that of common air; but I fancied my breast felt peculiarly light and easy for some time afterwards. Who can tell that, in time, this pure air may become a fashionable article in luxury.” (Priestley, 1775:54)

There is clearly in Priestley’s writing a recognition of therapeutic benefits of oxygen and the ‘ease’ with which breathing pure air can feel, but he also ponders on potential toxicity that may indeed accelerate aging and shorten life. Astonishingly Priestley’s insight into the use of oxygen as a *‘fashionable article in luxury’* is unprecedented in contemporaneous and subsequent literature. Priestley was an extraordinary free-thinking protagonist with influential friends such as Benjamin Franklin, James Watt, and Erasmus Darwin (grandfather to Charles), and he harnessed their power and influence to fund his experimental pursuits. Priestley eventually fled Britain to the USA following persecution because of his radical religious and political views.

Priestley therefore can be attributed to be the first to suggest that oxygen may accelerate aging and indeed be toxic in certain circumstances. But although oxygen

as a medical therapy was embraced by Priestley's contemporaries its toxicity was not further documented until a hundred years later when Lorrain Smith (1849) reported that oxygen at higher tensions than atmosphere can act as an irritant, causing inflammation of lung tissue. This early work however was based on animal studies and findings were slow to be adopted.

Despite Scheele and Priestley's initial discoveries, it was not until 1777 that Antoine Lavoisier, a French tax-collector, regarded as the father of modern chemistry, cast off the flawed theory of phlogiston, and identified and named oxygen (*from the Greek word oxys meaning sour taste of acid*) as the reactive constituent of air. Priestley acknowledged that a pre-existing myth had potentially prevented the advancement of science.

2.4 OXYGEN AS A THERAPEUTIC AGENT

The first reported use of oxygen as a medical therapy was in 1783 by a French physician named Caillens who treated a young woman suffering from tuberculosis with daily inhalations, reporting that she '*very much benefitted*' (Grainge, 2004).

In 1798 the Pneumatic Institute opened in Bristol with the aim of investigating the therapeutic value of oxygen through treatment of previously incurable diseases. Thomas Beddoes, the founder of the institute, was joined by Humphrey Davy (later to invent the Davy lamp) and James Watt the physicist (Leigh, 1974a). Watt was, together with Joseph Priestley, a member of the Lunar Society of Birmingham. The aim of the Lunar Society was to encourage transfer of new scientific knowledge; they – the 'Lunatics' – met every month on the night of the full moon, allegedly to allow members the advantage of moonlight when walking home through the city's

unpoliced streets (Grainge, 2004). Through one of these meetings, it is believed, Watt learned about the new dephlogisticated air from Priestly (Grainge, 2004). The Pneumatic Institute and administration of oxygen (free of charge), proved unsuccessful, probably because Beddoes was over ambitious with the choice of intractable diseases (including consumption, dropsy, palsy and venereal disease) and of impurities in the gas. It is reported that Beddoes, Watt and Davey made no claim for cure but rather were investigating the efficacy of oxygen in the treatment of disease: the short inhalations usually contained concentrations of oxygen higher than normal air (23-28%), but sometimes it was *lower* (Leigh, 1974a). It is alleged that Beddoes' generally incorrect assumptions about disease, together with the Bristol typhus outbreak in 1800, brought about conversion of the institution to a normal hospital, and subsequently its closure in 1802. Scientific investigation into oxygen therapy came to a temporary halt. A review of the work of the Pneumatic Institute postulates that Beddoes favoured the idea that in some cases oxygen was beneficial and in others it could do no harm; a philosophy that has followed practice (Leigh, 1974a).

Thereafter for much of the 19th century problems with oxygen therapy persisted, probably due to impurities in the gas, lack of specific scientific knowledge and diverse delivery methods: one such method involved bubbling gas through a water bottle at the bedside and wafting room air towards it and the patient (Lane, 2002; Grainge, 2004). The production of oxygen at the patient's bedside by the attending physician, usually from substances such as mercuric oxide, was common at this time.

In conjunction with these delays in scientific development and understanding of physiology there were hyperbolic claims of quacks and charlatans, further

impeding scientific advancement. Much literature was published in the 1800s proclaiming the virtues of oxygen therapy; for example two papers by Dr S B Birch. The principle ethos being that as oxygen is essential to life so it should be a treatment for all diseases (Leigh, 1974a). The first paper published in 1857 starts out promisingly by highlighting the neglect of the execution of fair trials because it “*involves some trouble and loss of time to the practitioner*” (Birch, 1857: 112). But far from condemning this dearth of empirical evidence Birch appears to perpetuate it by heralding a case study that apparently exemplifies the curative nature of oxygen. The case in question was a 33 year old with ulcerated legs caused by syphilis, which, by the time he consulted Birch, seemed to have developed into wider systemic symptoms of secondary syphilis. The patient was administered oxygen of the ‘*largest quantity that could be borne, and ordered a moderate inhalation in the evening*’ (Birch, 1857: 113). In less than three months of twice daily inhalations not only were his ulcerated legs cured but also his ‘*consumptive cough*’ and ‘*nocturnal perspirations*’. Birch attributed this recovery to oxygen as a ‘*purifier of the blood*’ which, in relation to skin, enabled it to ‘*throw off an immense amount of morbid and poisonous matter*’ (Birch, 1857: 113). In the paper, published in *The Lancet*, Birch openly condemned colleagues ‘*opinions*’ that suggested oxygen may precipitate pulmonary inflammation. In a further publication in *The Lancet* in 1869 he wrote about oxygen ‘*in connexion [sic] with a new, agreeable, and easy form of administration by the stomach*’ (Birch 1869: 492). What Birch was referring to was ‘*oxygenated bread*’. Heralding its merits in relation to already well received oxygenated water (promoted by the manufacturing chemist George Barth [Leigh, 1974a]), Birch advocated ‘*a surprisingly small bit of this oxygenated bread proves its special influences in suitable cases*’, including indigestion from nervous weakness

(Birch 1869: 492). Additionally oxygen was claimed, by Birch, to improve many other ailments including intractable ascarides (worms) in children (Birch 1869: 493). Preservation of the bread was reportedly problematic but Birch suggested the use of a piece of paper soaked in phenic acid within the lid will keep mould at bay: '*... and will prove a positive advantage to some patients who desire medical flavour*' (Birch, 1869: 493). Analogies with the placebo effect can be made here. The comparison of similar claims made today for oxygen water suggest that 'quacks' still persevere to pervade scientific knowledge and understanding.

Birch was not the only perpetrator of the folly of oxygen as a cure for all diseases. R. H. Goolden, a senior physician at St Thomas's Hospital in London likewise wrote in *The Lancet* in 1866 regarding two cases that he successfully treated with oxygen: the first with syphilitic ulceration of the head and neck responded '*beyond expectation*' to twice daily inhalations in three weeks (Goolden, 1866:270). Even more astounding was the second case when oxygen cured not only ulcerations on his head and torso and his double pneumonia, but it also acted as a deodoriser making tolerable the smell of the 28 year old man which was, prior to treatment, '*so offensive that he had to be removed to a separate room*' (Goolden, 1866:271). Goolden reported a full recovery and '*No smell whatsoever about him*' (Goolden, 1866:271). His closing remarks could not be further from today's contemporary approach to evidence-based medicine:

"I hope soon to have other cases to report. They may not be so successful, but as these two have been so very satisfactory I think my professional brethren may wish to have the opportunity of trying these remedies in similar cases, where hitherto we have experienced so much difficulty and disappointment in their management." (Goolden, 1866:271).

Critics of such approaches were forthcoming; Dr Wallian in 1890, an opponent of the purveyors of compound oxygen (usually diluted nitrous oxide) referred to these preparations as “bosh and pretentious nonsense” (Leigh, 1974a). Unfortunately his own recommendations of oxygen therapy twice daily, advocating cutaneous absorption, were also dubious. Of course there may well have been some therapeutic benefit to treating pneumonia with oxygen therapy but additional claims that often accompanied such ‘evidence’ exposed a basic unawareness regarding any real scientific foundation.

Other claims to success with specific diseases, for example pneumonia, appeared more trustworthy. Dr Albert Blodgett was one who reportedly used oxygen to treat a 46 year old woman with pneumonia quoting “...*the patient was irrevocably doomed, and the best result that I looked for was simply relief to the sensation of suffocation...*” (Blodgett, 1890: 483). But the woman recovered with what is estimated as continuous administration of about 6 litres of oxygen per minute (Grainge, 2004). A dose that does not seem excessive today but for which the supplier of the gas had warned that “...*no human being could possibly stand so great an amount of oxygen, on account of the dangerous degree of stimulation to the system and the increased combustion of tissue*” (Blodgett, 1890: 483). Blodgett correctly identified oxygen as ‘*tiding the system over*’ rather than curing disease, allowing for the body’s respite and recuperation (Blodgett, 1890: 484). More importantly he also recognised the potential toxicity of oxygen: “*Pure oxygen I believe to be too powerful an oxidizing agent when used alone, especially when there exists inflammation of the air passages*” (Blodgett, 1890: 485). Echoes of Priestley’s warning that breathing oxygen may cause individuals to ‘*live out too fast*’ (Priestley, 1775:53) are evident here. “*Judicious employment*” (Blodgett, 1890: 483),

and stopping oxygen as soon as possible were advocated by Blodgett; history now reveals that these cautionary warnings of the use of oxygen were seldom heeded, right up to and including the 21st century.

Initial claims of success were nevertheless limited and the situation of stifled progress throughout the 19th century was exacerbated by impostors peddling ‘*compound oxygen*’ to trusting recipients, seldom containing any molecular oxygen at all (Grainge, 2004). This compound oxygen was often coloured to convince patients of the benefits (Grainge, 2004), probably in much the same way as oxygen is today bubbled through coloured and flavoured water in oxygen bars. Critics were forthcoming with condemnation for these therapies but nevertheless the widely publicised, and expensive, therapies potentially contributed to further delays in scientific advancement.

The use of oxygen therapy for treatment of dyspnoea was also prolific in this era. It is probably obvious, given limited knowledge of physiology, that the sensation of breathlessness and lack of oxygen were often considered synonymous. Priestley himself probably started the craze when he noted “*an agreeable glow and lightness of the chest*” after inhalation. One further example of endorsement of such practice was published in 1891 by Dr Robert Reed, writing: “*In general terms one may say any disease which gives rise to dyspnoea will be benefitted by oxygen, and the greater the dyspnoea the greater the need of oxygen*” (Reed, 1891 in Anon, 1901). This philosophy appears to have traversed the decades with little modification and is parallel to the ‘*more is better*’ liberal use of oxygen in the pre-hospital setting.

Focus eventually shifted to use of higher pressures of oxygen, building on previous experiences of physicians such as Blodgett (1890) and based on reported

findings in Mexico, where patients with pneumonia living at high altitudes were found to have an enhanced recovery in the higher oxygen pressure of the lower plains (Grainge, 2004). Not all initial applications of oxygen were successful with reports such as a '*miraculous*' recovery of a 40 year old clergyman with bronchopneumonia (Brunton and Prickett, 1892: 172), and '*remarkable*' improvement in a 57 year old widowed lady (Gilchrist, 1892: 327). Both cases were eventually fatal but perhaps it was the combined treatment of oxygen and strychnine (used as a respiratory stimulant but later abandoned because of its lethal toxicity) and, on occasion leeches (Gilchrist, 1892; Myers, 1907) that deposed the therapeutic benefits of oxygen. Nonetheless it was becoming apparent, as reported in the literature, that availability of oxygen was improving, with condensed oxygen being obtained commercially in iron bottles (Brunton and Prickett, 1892).

Additional reports, one such by Myers in *The Lancet* in 1907, furthered knowledge regarding application of oxygen by supporting its continuous, rather than intermittent, use. Myers' case reported a patient with bronchopneumonia who was commenced on oxygen for two minutes every half hour, then ten minutes every three hours, but finally, continuous oxygen for 110 hours was necessary for the patient to recover. The utility of continuous rather than intermittent oxygen was confirmed further by the findings of Vernon in 1909 who demonstrated that through the inspiration of oxygen, breath holding could be prolonged. Vernon (1909) recognised that these oxygen stores are fairly modest, further supporting benefits of continuous administration.

Fick (1829-1901) and Bert (1833-1886), both physiologists, advanced understanding further by describing oxygen tension in terms of units of partial pressure and described central nervous system toxicity at high oxygen tensions

(Grainge, 2004). Bert had already established that the effects of oxygen on living animals were associated with oxygen tension, and that higher tensions could be toxic to the nervous system, eventually causing death (Smith, 1849). Building further on the work of Fick and Bert, John Scott Haldane published '*The therapeutic administration of oxygen*' in 1917. This landmark paper represents the origin of the rational use of oxygen. Haldane often conducted experiments on himself in decompression chambers, and famously led an expedition to Pike's Peak in the Rocky Mountains, Colorado in 1913 that helped to characterise the effects of hypoxia on normal volunteers in order to endorse some of Paul Bert's theories (Petty, 1989). Haldane, in his seminal paper, outlined the regulation of the respiratory drive by carbon dioxide and its effects on the blood hydrogen concentrations which subsequently affected pH; he considered oxygen as more than palliative and suggested that it allows the body respite and recuperation (Haldane, 1917). Haldane classified three causes of anoxaemia: lack of oxygen, lack of haemoglobin and lack of circulation. In a further paper in 1919 he added a fourth: "*alteration of the dissociation curve of oxyhaemoglobin so that it gives off oxygen less readily*", citing the work of Bohr of Copenhagen in 1904 (Haldane, 1919: 65).

Haldane's legacy to respiratory medicine was prolific. He was one of the first to explain the physiology of carbon monoxide poisoning. He outlined the need to know what percentage of oxygen is being breathed and the concept of ventilation perfusion matching. Amongst his other discoveries was that solubility of carbon dioxide is greater than oxygen, and therefore typically with poor ventilation it is oxygen that is impaired without alteration of blood CO₂ levels. His solution: raising the percentage of oxygen in alveolar air and so increasing the diffusion pressure (Haldane, 1917). In 1919 Haldane alluded to toxicity of oxygen when he made

reference to the work of Lorrain Smith who discovered that administration of 80% oxygen was found to produce fatal pneumonia within three to four days (Haldane, 1919). Haldane's cautious advice therefore was to give only as much oxygen as would "*suffice to relieve anoxaemia*" (Haldane, 1919: 69); a key message in today's guidelines. As Grainge (2004) outlines, Haldane was writing about ventilation perfusion matching whilst others were still recommending oxygen gas as a subcutaneous treatment; these discoveries can be considered an intellectual leap in oxygen therapeutics.

Twenty five years after Blodgett's first reported case of apparent success, oxygen therapy progressed at an advanced pace. In part this was due to progress in science and medicine as outlined here, but a more profound cause was undoubtedly the experiences of horrific gas poisoning in the First World War (WW1) (1914-18). During this period Haldane's expertise came to the fore. Phosgene was a colourless gas used commonly as a poison in the trenches which principally caused pulmonary oedema; oxygen therapy became the primary treatment.

Empirical knowledge regarding oxygen was clearly evident by the end of WW1. Single blind experiments had shown that oxygen improved survival in the acute phase of gas poisoning, and reduced morbidity in the chronic phase (Royal Society of Medicine, 1920). Advances in cylinders and delivery devices led to the use of oxygen in trauma care. Intermittent use of oxygen, for example five minutes in each hour, was still common practice, although often condemned as '*useless*' (Douglas in Royal Society of Medicine, 1920: 152). It seems ambiguity regarding oxygen therapy in clinical practice had been established.

Still, advances in physiological understanding progressed. In 1920 Meakins published experimental work in the *British Medical Journal* outlining methods for

calculating oxygen saturation of haemoglobin (Hb) as a percentage; the greater the degree of unsaturated haemoglobin the more critical the patient's condition. Through administration of inhaled oxygen Hb saturations were raised, in both pulmonary disease and health (Meakins, 1920: 326). But Meakins was a physiologist and neglected the clinical outcomes of oxygen treatment, and robust studies regarding efficacy of oxygen failed to materialise.

The sound scientific basis for oxygen therapy was definitively proposed in 1922 by Haldane through his publication, *Respiration*, further accelerating the understanding of therapeutic oxygen. Almost two centuries after Joseph Priestley's prediction that it might be "*peculiarly salutary to the lungs in certain morbid cases*" (Priestley, 1775:53) Haldane suggested that physicians "*make every effort to avert the effects of want of oxygen*" (Haldane, 1917: 182). Regarding existing oxygen administration systems as crude, Haldane devised a delivery method consisting of a face mask, rubber tubing, oxygen cylinder, pressure gauge and "*adjustable governor allowing oxygen to be delivered through a range of 0-10 litres per minute*" (Haldane, 1917: 183). This equipment was derived from recognition of the principles that the percentage of what is breathed should be known, and kept as low as possible, balancing the risks of hypoxaemia and hyperoxaemia (Haldane, 1917); the same key principles that guide oxygen administration today.

Reluctance to use oxygen continuously still pervaded practice and Haldane, in summarising the custom of intermittent use, is reported to have said "*intermittent oxygen therapy is like bringing a drowning man to the surface of the water – occasionally*" (in Campbell, 1965a: 864); Campbell offers a contrary perspective: "*it is like pushing him down between times*" (Campbell, 1965a: 864). Campbell went on to describe the use of intermittent oxygen as "*bad practice which I think and hope is*

disappearing" (Campbell, 1965a: 864). Almost fifty years on Campbell, amongst others, would surely be disappointed with progress in common clinical practice.

Following WW1 the development of modern oxygen therapy gained momentum with Binger in 1928 publishing his American case series of patients with pneumonia demonstrating that oxygen saturation, whilst the patient was receiving 40% oxygen, was prognostic; the survivors often maintaining a level of 90% saturation while fatal cases did not achieve this (Binger, 1928).

The use of oxygen as a generic treatment for hypoxaemia rather than targeting specific cases became common practice in the 1930s. Christie (1938: 876) wrote that "*in describing the indications for oxygen therapy the real issues are confused if individual diseases are discussed*". This approach, combined with the introduction of anti-bacterial chemotherapy, certainly changed the management and prognosis for pneumonia (Leigh, 1974b). The issue of carbon dioxide retention, although recognised, was still not resolved and probably contributed to the continuation of intermittent oxygenation during this period. In fact even in 1932 Haldane was still of the belief that death, in certain patients, was due to lack of oxygen accompanied by rapid shallow breathing, advocating treatment of carbon dioxide as a respiratory stimulant. The use of re-breathing masks at this time was considered an advantage (Leigh, 1974b). It wasn't until 1956 that the notion of re-breathing was questioned and the use of the Haldane non-rebreathe mask, introduced in 1917 to prevent wastage of oxygen with a non-return valve, was advocated in routine practice (Cotes & Merrick, 1956). The use of re-breathe masks is now redundant, but intermittent oxygen therapy continues. It seems that even though the use of intermittent oxygen therapy has long since been disputed, the practice still persists today. Leigh (1973) surveyed 73 (51.8% response rate)

hospital physicians involved in intensive therapy and found that 34% still prescribed intermittent oxygen on occasion. A similar survey today would possibly fare no better.

Attitudes to the use of oxygen therapy in chronic respiratory failure were evolving. Haldane had already established in 1917 that oxygen should be administered at a minimum required concentration. But consensus in the 1930s suggested that optimum concentration of oxygen should be between 35% and 60% for therapeutic benefit to be obtained (Leigh, 1974b). Barach (1938) outlined the dangers of carbon dioxide retention, reporting possible onset of mental changes produced by administration of oxygen therapy. And, although Barach advocated, controlled and titrated oxygen as means of avoiding potential toxicity in this manner, he also suggested the use of intermittent oxygen therapy as the patient improved. The use of intermittent oxygen was thought to restore the anoxic stimulus during the pause, and therefore to blow off the carbon dioxide. Once again the clinical practice of intermittent oxygen therapy was endorsed.

Simultaneously, as the issue of controlling oxygen doses was debated, the widespread use of 100% oxygen was endorsed for several indications. Boothby et al. (1939:477) reported "*The ability to administer practically 100 per cent oxygen in the inspired air, economically, efficiently and comfortably, has opened a new field for oxygen therapy.*" Based on physiological principles, they endorsed use of 100% oxygen to all patients as a preventive measure in traumatic surgery, extensive elective surgery, and as a means of nitrogen wash-out. Additionally it was recommended for the relief of headaches (with or without nausea), the alcoholic headache "*the morning after*", seasickness, atelectasis, acute pulmonary oedema and angina ("*Relief of the pain of angina pectoris sometimes is obtained with striking*

rapidity":479). All treated with 100% oxygen "... *without the slightest evidence of pulmonary irritation*" (479). Recommendations were based on personal experiences, though claims were cautioned: "*It is not a panacea*". Current practice often suggests that this caveat was not heeded and that oxygen as an effective treatment for numerous clinical presentations was instinctive, and controversies were established.

With regards to cautionary tales of potentially lethal toxicity of oxygen, carbon dioxide narcosis was further described by Donald in 1949 as a condition of confusion, tremors, convulsions, potentially leading to coma and death. This condition caused a therapeutic problem: relief of hypoxia without a dangerous rise in carbon dioxide tension. Donald (1949) advocated an oxygen tent of 35-40% oxygen, interspersed with periods of breathing air. But practice was being questioned and in 1953 a leading article in *The Lancet*, reporting the possibility of CO₂ retention exacerbated by oxygen therapy, conclusively warned that "*patients must not be allowed to die of anoxia because of an exaggerated fear of carbon dioxide poisoning*" (Anon, 1953: 381). So recognition was established of the fine balance between sufficient oxygen to correct hypoxia, but not enough to induce or worsen hypercapnia.

In order to address the risk of worsening hypercapnia, Campbell in 1960 advocated small increments of oxygen sufficient to correct hypoxaemia; in 1963 he furthered the case for controlled low dosage oxygen therapy in chronic respiratory failure by specifying a suggested range of 24-28%. A practice endorsed, certainly in the UK paramedic guidelines, until 2003 (Ambulance Service Association, 2003), but a ritual that probably still persists with many clinicians today and which could potentially be detrimental to patients whose hypoxia is not corrected with such low doses (Massero, 1962). Campbell's main argument was not about limiting the dose

but rather “*advocating care and precision in dosage*” rather than “*haphazard and imprecise dosage*”, claiming controlled evidence should not be required to prove this pragmatic approach (Campbell, 1963:503). Today many clinicians anecdotally cite this lack of evidence regarding low dose oxygen as potentially contributing to the perpetuation and continuation of “*haphazard*” practices.

In 1962 it was recognised that for patients with respiratory acidosis hypoxaemia is actually more profound following treatment with *intermittent* oxygen than for continuous administration, with accompanying hypercapnia and lowering of pH. This finding supported the agreement that “*continuous administration using low flow rates with graded increases will help avoid serious worsening of hypercapnia while maintaining acceptable oxygen tensions*” (Massaro et al., 1962: 627). A philosophy echoed today in emergency oxygen guidelines (BTS, 2008).

Further evidence supporting judicious use of oxygen therapy was advocated by Hutchinson et al. (1964), suggesting that an arterial oxygen tension of 50 mmHg (about 7kPa) would prevent death from hypoxia in patients with respiratory failure, calling for accurate dosage of oxygen and determination of blood gas tensions and pH. This followed a clinical trial involving nine patients (ten episodes) to test the efficacy and side effects of controlled oxygen in respiratory failure. Amongst the major findings researchers concluded that controlled oxygen failed to provide an arterial oxygen level > 50mmHg (7kPa) and a pH >7.35 in three of the ten occasions and uncontrolled oxygen at 60% can cause serious exacerbations of CO₂ retention. The final recommendation was to administer controlled oxygen to maintain a PaO₂ >50 mmHg (7kPa) and a pH >7.35. Tracheotomy and mechanical ventilation were proposed if these parameters were not achieved: strategies which called for a more widespread use of blood gas analysis. These minimum levels were raised by

Campbell in 1965(b) in consideration of a secondary aim (the primary being prevention of cell death) to keep arterial oxygen at a level “*to guard against further deterioration ... and to relieve the strain of adaptive responses to hypoxia*” (Campbell, 1965a: 862); Campbell further defined respiratory failure as $\text{PaO}_2 < 60$ mmHg (8kPa) and $\text{PaCO}_2 > 49$ mm Hg (6.5kPa) and introduced the first controlled oxygen ‘Ventimasks’ with Gebbie in 1966 (Campbell and Gebbie, 1966). Campbell advocated analysis of blood gases to distinguish between respiratory failure and breathlessness *per se*, indicating that the two are not synonymous. Campbell categorised two types of respiratory failure: those that are commonly referred to today as Type I ($\text{PaO}_2 < 60$ mmHg/8kPa) and Type II ($\text{PO}_2 < 60$ mmHg/8kPa and $\text{PaCO}_2 > 49$ mmHg/6.5kPa). He also highlighted the clinical significance of the oxyhaemoglobin dissociation curve: “*in hypoxaemia the brink of disaster is very sheer – quite different from hypercapnia*” (Campbell, 1965b: 1456).

Further to this, Campbell (1965b) talks about the paradox of hypercapnia being less dangerous than hypoxaemia, but diagnosis of hypercapnia being more valuable because it indicates adequacy of ventilation in relation to metabolic needs. When outlining treatment he further points out that the aim is to stop CO_2 rising higher, rather than to lower it (Campbell, 1965b). His advice was never to withdraw oxygen completely, even if it was thought that uncontrolled and excessive oxygen may exacerbate respiratory failure in a patient, “*other measures must be used to try to rectify the situation while the O_2 is continued*” (Campbell, 1965b: 1459). Withdrawing oxygen suddenly from hypercapnic patients, recognised today as rebound hypoxaemia (Kane et al., 2011), can provoke hypoxaemia that is more severe than that before oxygen was started. Until recently, abrupt removal of oxygen

when hypercapnia is suspected was still recommended and, despite revised guidance (BTS, 2008), a common practice that still persists.

Leigh (1974b:342) outlines the then contemporary issues regarding confusion of 'controlled' and 'uncontrolled' devices, citing many occurrences in mainstream medical literature perpetuating this confusion, and suggesting that oxygen has been taken for granted. Leigh (1973: 250) refers to "*clinical opinion not yet ready to shake off the shackles of several generations*". Forty years of anecdotal evidence suggests confusion persists regarding device selection, and what constitutes controlled or uncontrolled devices.

So, the place of blood gas measurement to guide oxygen therapy was established. Principles of the value of knowing O₂ levels being limited and CO₂ levels being essential, were established (Campbell, 1965a). It was argued that establishing oxygen levels had its limits because it was safer and quicker to administer oxygen to a patient who may be hypoxic than to wait for an arterial oxygen reading; this rationale is somewhat redundant in today's clinical environment with instant access to oxygen saturations and bedside blood gas analysis. Nonetheless the sentiment stands: oxygen therapy should not be delayed if hypoxia is suspected. CO₂ levels are deemed essential because it gives an insight into the patient's ventilation status, differentiating the cause of the respiratory failure and therefore directing management. That CO₂ levels dictate oxygen therapy in respiratory failure is still relevant, however Campbell's cautious method of oxygen administration – commence at 25% and increase if no progressive under ventilation is noted – would be considered poor practice today (Campbell, 1965a). The sometimes overreliance on pulse oximetry and lack of CO₂ monitoring in today's clinical environment is a worrying perspective given these principles.

Boxes 1 and 2 outline key assertions evident throughout the evolution of therapeutic oxygen demonstrating contrast and conflict that existed and permeated into today's clinical practice. Figure 4 represents the timeline of key events in the history of therapeutic oxygen therapy.

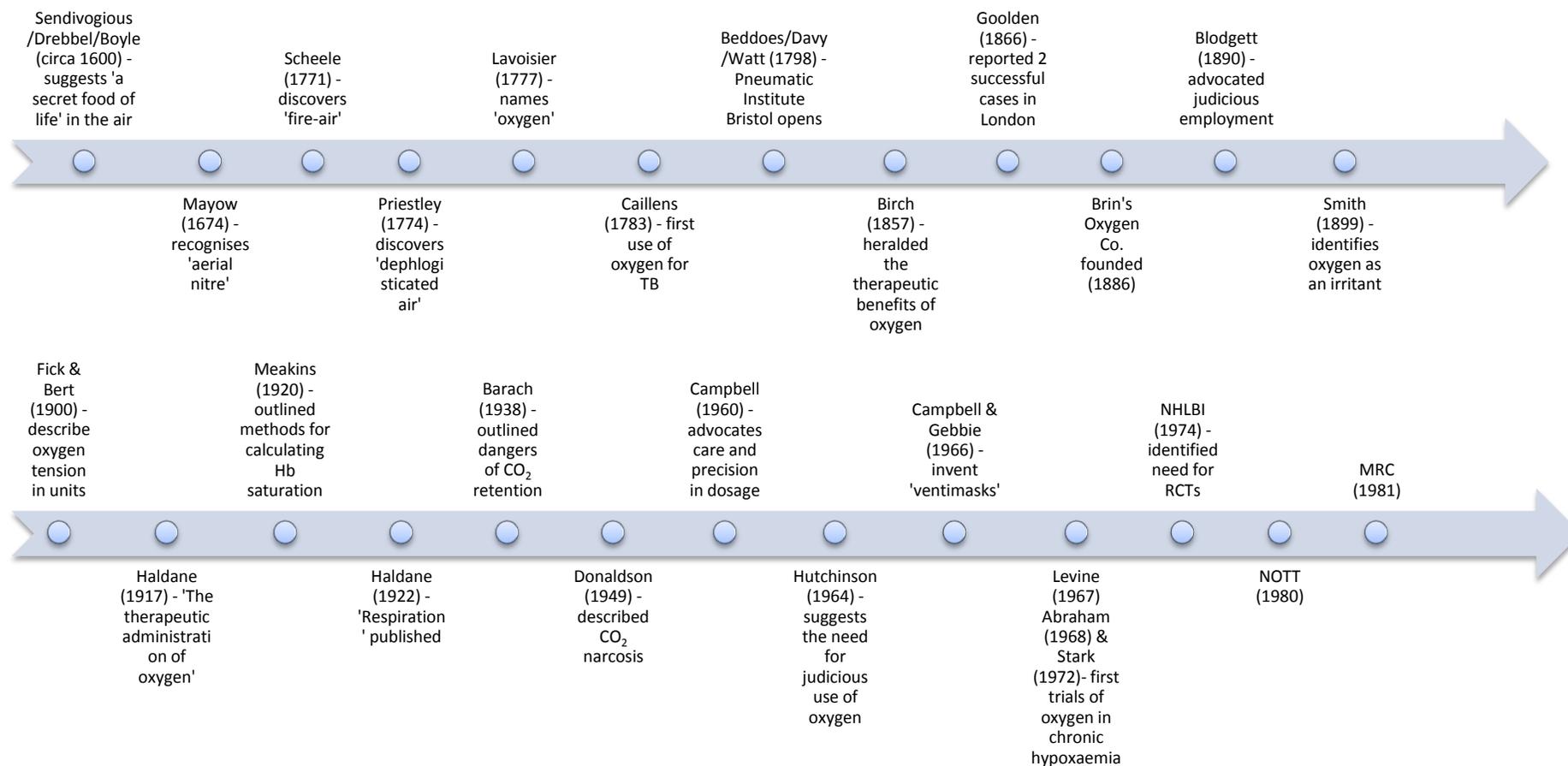
Box 1: Dates of Key Assertions: The Dogma

1774 – oxygen virtuous as a placebo
1793 – oxygen is harmless
1857 – oxygen as a panacea
1890 – PRN use of oxygen advocated
1891 – oxygen for dyspnoea
1939 – 100% oxygen for all

Box 2: Dates of Key Assertions: The Science

1849 – toxicity of oxygen recognised
1890 – judicious employment advocated
1920 – just enough to relieve hypoxia
1920 – PRN use of oxygen deemed 'useless'
1960 – caution not to worsen hypercapnia
1962 – abrupt withdrawal worsens hypercapnia

Figure 4: Historical Review of Oxygen Therapy Timeline



2.5 LONG-TERM OXYGEN THERAPY (LTOT) IN RESPIRATORY DISEASE

Probably precipitated by the introduction of lightweight liquid oxygen apparatus (Sackner, 1974), the first noted trial of oxygen therapy in chronic hypoxaemia involved recruitment of six patients with *cor pulmonale* (Levine et al., 1967). In the confines of a clinical research unit patients were first stabilised, rehabilitated and medication optimised for a month. The second month ambulatory oxygen therapy was introduced via nasal cannula to bring the saturation >90% for 24 hours per day. Improvements in pulmonary artery pressure and a reduction in red cell mass was evident but most dramatic was the increase in exercise tolerance. In 1968 Petty and Finigan, in the USA, reported on 20 patients with advanced COPD receiving continuous oxygen from a liquid oxygen supply system. Results endorsed improvements in pathological markers of disease severity, such as improvement in *cor pulmonale*, reduction in haematocrit, increase in body mass and an additional benefit of reduction in hospitalisation in one patient. The risk of carbon dioxide retention was eliminated through use of controlled low-flow oxygen and observations of blood gases. A similar study of six patients conducted in the UK also endorsed reversibility of pulmonary hypertension with continued administration of oxygen (Abraham et al., 1968).

Further trials in the UK focused on daily requirements needed for oxygen to be effective in *cor pulmonale* and found that as little as 15 hours per day resulted in a reduction in pulmonary hypertension with a focus on practicability for individuals still working (Stark et al., 1972). Five of these original 11 patients were followed up longitudinally to assess whether benefits were sustainable, whether oxygen in the home was practicable and whether physiological benefits impacted on the patient's clinical condition (Stark et al., 1973). All these preliminary studies lacked rigour, with

inclusion of small samples and no comparison groups. One study did use a historical control of United States veterans and showed a reduction in mortality associated with *cor pulmonale* by 30%, and with hypoxia by 40% (Neff and Petty, 1970). Despite the methodological limitations, establishment of this, albeit limited, evidence paved the way for larger randomised controlled trials. The theorem generated was that continuous oxygen therapy in patients with chronic hypoxia reverses pulmonary hypertension (through regression and alleviation of pulmonary vascular resistance), reduces secondary polycythaemia, improves renal plasma flow and enhances activity levels.

In 1974 a landmark conference was organised by the NHLBI (National Heart, Lung and Blood Institute) in Pennsylvania, USA, to evaluate the scientific basis for outpatient respiratory care practices. One of the outcomes of this conference was the proposal for the Nocturnal Oxygen Therapy Trial (NOTT), a major multicentre randomised controlled trial (RCT) of 203 patients comparing nocturnal oxygen (12 hours) to continuous oxygen (24 hours) given for one year (NOTT, 1980). At the same time in the UK a multicentre RCT was launched to compare 15 hours per day of oxygen therapy with no oxygen (MRC, 1981). This British trial included 87 patients (66 male) with stable hypoxic COPD ($\text{PaO}_2 < 8 \text{ kPa}$) and hypercapnia with five year survival as the principle outcome measure.

Because these two monumental studies recruited patients who were well matched, regarding demographics and disease severity, the findings from both studies are often superimposed; in brief these combined findings demonstrated that survival is increased with oxygen, when compared to no oxygen; survival is better at 15 hours than at 12, but maximum survival benefit was achieved at 24 hours per

day. The mechanisms for improvements in physiological parameters however were never clearly established.

Limitations were inherent in both studies, casting doubt regarding reliability of findings, yet repetition was prevented owing to ethical dilemmas of denying a proven therapeutic intervention to a control group. In comparison to more contemporary RCTs testing therapeutic efficacy, these sample sizes were modest. Exclusion of patients with co-morbid disease in both trials limited generalisability (although not acknowledged at the time) to a COPD population who have a significant prevalence of co-existing disease, in particular cardiovascular disease (Sin et al., 2006). In the MRC study curious findings such as late emergence of survival benefit in men (>500 days) and surprisingly poor survival in the female control group have never been explained, although with current knowledge it is possible that phenotypes of chronic bronchitis and emphysema (evident by recorded lower body mass index (BMI)), which were never matched, probably influenced the results. Nonetheless results of these two pioneering studies profoundly influenced the widespread use of domiciliary oxygen therapy throughout the western world.

Whether these early trials in fact hindered clinical progress with oxygen as a therapeutic intervention remains debateable: the last reported results were in 1981. Many questions remain unanswered and it is likely that controversies regarding use of LTOT permeated clinical practice. Ambiguities include mechanisms for survival benefit: was 90% saturation necessary to achieve results; which method of delivery is best (these varied both within and between the NOTT and MRC trials) (Petty, 1989). Additionally findings are often extrapolated to other disease areas such as heart failure where LTOT is often prescribed to correct chronic hypoxia. Nonetheless LTOT remains one of only two proven interventions that prolong survival in COPD

(smoking cessation being the other). An on-going multicentre longitudinal trial: Long-Term Oxygen Treatment Trial (LOTT, is due to complete in December 2015 (NHLBI, 2013) which should answer some outstanding questions such as effect on exacerbation frequency, impact on exercise tolerance, enhancing quality of life and impact on mortality.

Numerous research studies have followed since these landmark trials, exploring issues such as compliance, quality of life, and ambulatory oxygen therapy. Organisation and provision of domiciliary oxygen have undergone radical change in the UK in the last decade alone and improvements in assessment and review, although financially driven, must be beneficial to patients.

2.6 EXPERIENCES IN OTHER SPECIALIST AREAS

Whilst the use of oxygen was pioneered through anaesthesiology and respiratory care, other specialist areas encountered their own dilemmas and controversies, as dogmas of practice were established and then challenged.

2.6.1 Hyperoxia in Neonatal Care

The issue of oxygen toxicity is not confined to lung parenchyma. The development of retinopathy of prematurity (ROP) (a disease of the eye affecting prematurely-born babies that may lead to blindness) is possibly one of the most well-known examples of the consequences of hyperoxygenation. Oxygen was first reportedly given to neonates in 1780 (Silverman, 2004a) and thereafter routinely recommended for premature babies with cyanosis since 1900 (Robertson, 2003). ROP was first recognised in 1940 but it wasn't until 1956 that results of the first controlled trial implicating oxygen as the cause were published (Kinsey, 1956). This

was a period when the clinical focus was on breathing patterns and apnoeic episodes, and advances in incubator design led to liberal use of even higher concentrations of oxygen with little criticism or worry (Robertson, 2003). The result: oxygen as a potential cause of the increased incidence of ROP was completely overlooked and an estimated 10,000 infants worldwide had been blinded before oxygen was ever suspected (Silverman, 2004a).

The emergence of this evidence led to recommendations that oxygen in neonates should be restricted to 40% maximum. The result: an increase in mortality rate and incidence of cerebral palsy; the knee-jerk reaction of restricting oxygen undoubtedly the cause. Silverman (2004a) accused anti-trialists of ultimately prolonging delay in optimising practice regarding oxygen in premature infants. To quote one highly respected paediatrician at the time: “*Nor have we ever treated alternate patients with and without oxygen, and I rather hope we never shall*” (Silverman, 2004a: 109). Further, Silverman suggests that confusion appears to have persisted with a failure to use rigorous clinical research methods (Silverman, 2004b). Systematic reviews conclude evidence is still sparse regarding what are the most appropriate target levels of oxygenation in neonates (Askie and Henderson-Smart, 2001; Askie et al., 2009). Five on-going RCTs are expected to report in 2015 (Askie, 2013), however one trial has already been suspended owing to the significantly higher mortality rate in infants with a lower saturation target range (Stenson et al., 2013). Consensus therefore is still to be reached.

2.6.2 Cardiac Care

Recent debate in cardiology literature has discredited the long established practice of administering 100% oxygen to patients with acute angina and myocardial

infarction. The practice, dating back to 1900 when Steele first described it (Beasley et al., 2007), was further endorsed by Boothby et al. in 1939. The first caution that administering 100% oxygen may be detrimental to ischemic myocardium in the normoxic patient was issued in 1950 (Russek et al.). In 1969 Bourassa et al. reported from experimental studies that high flow oxygen can reduce coronary blood flow sufficiently to worsen outcomes. Yet the practice persisted, endorsed for a further forty years, and despite subsequent changes in guidelines (BTS, 2008; JRCALC, 2013), there is evidence that it still continues (Burls et al., 2010). Possibly the spotlight on advances in pharmacological treatments and surgical interventions was sufficient distraction such that the growing evidence of concerns regarding hyperoxygenation was overlooked. In 2005 McNulty et al. provided contemporary evidence that high flow oxygen reduces coronary artery blood flow and confirmed the previously disregarded evidence base. Uncertainty persists: a Cochrane Review summarised that there is no conclusive evidence and further clinical trials are urgently needed (Cabello et al., 2013). A more recent literature review concluded that although the level of evidence is insufficient there is confirmation that oxygen therapy is ineffective and hazardous (Shuvy et al., 2013). A Large RCT is currently underway and due to be reported in 2015 (Frew, 2013).

2.6.3 Stroke

Confusion regarding whether to administer oxygen routinely following ischemic brain injury (stroke) is also apparent. Hypoxia is common immediately following stroke, yet fear of exacerbating oxygen free radical injury and an absence of positive benefit, in terms of survival or disability in experimental studies (Singhal, 2006), has led to controversy. A *BMJ* editorial outlines the fact that clinical guidelines differ across countries and are indeed contradictory, having changed over time with

apparently no justification (Godlee, 2012). Evidence also is conflicting, with some studies suggesting that hyperoxia is harmful to the ischemic brain, whilst other studies report a neuroprotective effect, and it has been suggested that hyperoxia could indeed narrow the therapeutic window time for thrombolysis (Singal, 2006). Hence, debate continues with regards to administering oxygen in stroke; current UK guidelines endorse its use only in hypoxic patients (BTS, 2008). Major on-going clinical trials are anticipated to yield results but the consensus is only treat when hypoxia is present until further evidence is available (Pountain and Roffe, 2012).

2.6.4 Other Areas of Use

Although stroke and ischemic heart disease present as the main areas of current contention and confusion with regards to oxygen therapy, other areas of clinical practice are worth a mention. Oxygen is commonly used in the absence of any robust evidence in routine surgery post-operative care, and indeed has been found to mask hypoventilation caused by respiratory depression in sedated patients (Kopka et al., 2007). On-going clinical trials continue to seek to establish the efficacy of oxygen on mortality, surgical site infections, nausea and atelectasis with varying results (Togioka et al., 2011; Meyhoff et al., 2012; Hovaguimain et al., 2013). Likewise on-going research is attempting to position the use of hyperoxygenation in cluster headache (Jürgens et al., 2013) and the use of hyperbaric oxygen for various chronic wounds (Kranke et al., 2012; Howard et al., 2013).

So it appears the enigma of oxygen permeates many areas of clinical practice and it can be speculated that therapy which is often regarded as readily available, and easy to use, is in fact more complex than previously anticipated. The messages are mixed and confusing.

2.7 SUMMARY

Leigh (1973) describes oxygen as a powerful therapeutic tool which is also one of the most misused and abused remedies in medicine. The historical review presented here outlines potential ambiguities, myths and misunderstandings that have permeated both clinical environments and social contexts.

This review has attempted to position oxygen in relation to its very origins on Earth and the way that life evolved, not only to withstand oxygen's toxicity, but also to harness its potential as a mediator in the production of energy. The adaptation of life to the presence of oxygen seems to support the notion that Priestley first proposed: *the air which nature has provided for us is as good as we deserve.*" (Priestley, 1775:53).

The contribution that the early scientists of the 18th, 19th & 20th centuries made to establishing oxygen as a medical therapy is undisputed. Whether they unwittingly established widely held beliefs regarding oxygen therapy as something that can treat disease and improve health far beyond scientific evidence, remains an enigma. Established myths prevail today.

Oxygen as a therapy evolved from work of scientists and physiologists and empirical evidence was often based on case series rather than large well conducted clinical trials. This often led to *a priori* knowledge being adopted widely and the need to conduct experimental trials diminished, and was even hampered by ethical considerations. Protagonists of oxygen, it seems, inadvertently advocated this approach. Campbell in 1963 stated "...it is not usual to require controlled evidence that this [controlled oxygen] is better than haphazard and imprecise dosage" (p503). So based on the presumptions that hypoxia is harmful: that clinical judgement on

presence of hypoxia is unreliable; that access to laboratory tests is more difficult than putting on oxygen; that the oxygen dissociation curve means transition from safe to dangerous states may be rapid and unpredictable; and that prevention is better than cure (Campbell, 1963), the widespread use of oxygen was encouraged and the legacy for today's practice established.

The story of oxygen clearly contributed to the evolution of evidence-based medicine. Yet empirical evidence for oxygen is still profoundly lacking. Perhaps it was the insidious nature of the emergence of oxygen as a therapy, from Priestley's original suggestions to Blodgett's case reports and later the application to physiological principles, that all led to an eagerness to embrace what was a comparatively unsound evidence base when the first RCTs were published in the 1980s. This eagerness to embrace may subsequently have stifled progress and led to practice that was often open to interpretation. It seems that perhaps oxygen therapy has evolved on a trial and error basis, founded on historical perspective and further observed in other specialist areas, where the sluggish application of gathering evidence has undoubtedly inflicted further harm and cost lives.

This review does not claim to be definitive or all encompassing. The intention is to provide an overview of the historic nature of the origins of oxygen and of its therapeutic uses through to contemporary practice.

CHAPTER 3 – CRITICAL INTERPRETIVE SYNTHESIS OF THE LITERATURE

3.1 INTRODUCTION

This chapter will aim to substantiate the research problem and provide a platform upon which to locate the phenomenon of perceptions of oxygen therapy. The literature, in a style true to qualitative research, is utilised to provide a backdrop to inform, influence and debate the main study and the inductive nature of the enquiry.

3.2 REVIEW OBJECTIVE AND QUESTION

3.2.1 Review objective

To identify research studies that have investigated, detailed or recorded in some manner respiratory patients' and/or healthcare professionals' perceptions of oxygen therapy.

3.2.2 Review question

How do respiratory patients and healthcare professionals perceive oxygen therapy?

Utilising the question components advocated by Khan et al. (2003) a PICO framework was devised (Figure 5).

Figure 5: PICO Framework

Population	people with chronic respiratory disease or healthcare professionals
Intervention	oxygen therapy
Outcome	perception; belief
Study design	any empirical study design

3.2.3 Working definitions

Respiratory patients – any person with a diagnosed chronic lung disease

Healthcare professionals – any registered healthcare professional who has prescribed or administered oxygen therapy

Oxygen therapy – oxygen administered for any medical therapeutic purpose, including acute oxygen therapy, long term oxygen therapy, ambulatory oxygen therapy, short burst oxygen therapy or oxygen therapy for palliative care.

Perception – Whilst the array of terms varies, all definitions encompass similar qualities with regards to what is meant by perception; for the purpose of this review *perception* was considered as *an individual's understanding, belief or opinion* (Cambridge Dictionary, 2010) regarding oxygen therapy.

3.3 REVIEW METHODOLOGY

Contemplation of reviewing the literature prior to undertaking the study formed a key event regarding the approach to be taken. The option for a systematic review, as opposed to a more traditional narrative review, seemed quite intuitive given the current topical focus on systematic reviews in today's evidence-based context of healthcare. Systematic reviews are considered the gold standard and feature highly in hierarchies of evidence (NICE, 2012). Dixon-Woods et al. (2006) state the advantages of adopting a systematic review methodology lie in the rigour and transparency of the process. Traditional systematic reviews have however been criticised. It is recognised that the inclusion of only experimental studies is flawed in that it excludes intuitive, embodied and tacit knowledge that allows exploration of complex health related research questions (Pope et al., 2007). This leads to a key denigration that evidence-based medicine is a reductionist and standardised approach that fails to acknowledge variability and influence of context (Forbes & Griffiths, 2002).

Traditional narrative reviews can on the other hand be biased by the author's perspective. To counter this bias the systematic approach requires explicit criteria, methods that identify, critically appraise, and synthesise, relevant literature. The systematic review itself is undertaken to reduce the possibility of bias and it is considered that to be regarded as research in its own right, the same degree of rigour that is applied to primary research must be adopted (Hawker et al., 2002). Traditionally based in the positivist domain the focus on systematic review has more recently recognised the importance, and encouraged the incorporation, of qualitative studies (CRD, 2009).

The review question identified is orientated towards patients' and healthcare professionals' perceptions of oxygen rather than effectiveness of the intervention. The literature base therefore appears dominated by qualitative research as these voices are brought to the fore. Relevant quantitative data was also identified and therefore directed the review toward an integrative approach. Integration and synthesis of both qualitative and quantitative research, although complex and challenging, has the potential to enhance holistic understanding of the topic being investigated, and therefore to increase relevance (Whittmore and Knafli, 2005). The nature of the phenomenon itself, because it was predominantly situated in the qualitative domain, ultimately guided the decision to utilise an interpretative, rather than an aggregative, approach.

Barnett-Page and Thomas (2009) offer a critical review of approaches to synthesis of qualitative studies depicting a range of methods. One such, meta-ethnography (Noblit and Hare, 1988), aims to make sense of what a collection of studies are saying through synthesis, rather than just narrating the various findings. Pope et al. (2007) further discuss meta-ethnography as being concerned with

conceptual translation and transformation of concepts from individual studies. Meta-ethnography therefore is interpretative and aims at novel synthesis to develop new theory from qualitative studies.

A variant of meta-ethnography, Critical Interpretative Synthesis (CIS) was later developed by Dixon-Woods et al. (2006) in a response to their identified criticisms of the former method, and the need to include a diversity of methodologies (meta-ethnography includes only qualitative studies). CIS, through building on previous work, allows explicit integration of qualitative and quantitative evidence through an interpretative process. A distinguishing feature of CIS is that whilst it draws upon conventional systematic review methodology, it differs by allowing discretion in study selection to include papers which may contribute to findings whilst not necessarily answering the review question directly. The use of the authorial voice in both the selection and interpretation of the literature is a further defining feature of CIS (Dixon-Woods et al., 2006).

Flemming (2010) refers to this interpretation as synthetic constructs. Dixon-Woods et al. (2006) suggest that although alternative accounts of the same evidence might be possible, it is imperative that all accounts are grounded in the data, verifiable and plausible. Booth et al. (2012) describe CIS as a pragmatic attempt to handle comparatively large bodies of literature, which permits holistic judgement of quality and coherence rather than deconstructing data into units of individualised studies that have been quality assessed; examining a body of literature, rather than individual studies (Booth et al., 2012). For the purpose of the current review, and in consideration of the dearth of literature directly addressing the research question, CIS was deemed the most suitable review methodology.

The systematic approach therefore aimed to locate existing knowledge on the topic of perception of oxygen therapy. The meta-synthesis of existing data utilised thematic analysis enabling a synthesising argument to be constructed (Flemming, 2010). This argument then informed the inductive nature of the main study and provided a platform upon which to build new knowledge through collective synthesis. The CIS approach therefore draws on a traditional systematic review methodology whilst incorporating a disparate evidence base.

3.4 REVIEW METHOD

Based on tenets of a conventional systematic review the methods included: formulating the review question; conducting an exhaustive search; utilising a structured approach to quality appraisal; and synthesis of the evidence. The latter process is made transparent through reporting frequency of emergent themes and verifying the data through verbatim extracts.

3.4.1 Search Strategy

A systematic approach to searching, locating and retrieving relevant literature was adopted (Centre for Reviews and Dissemination (CRD), 2009). The initial search was conducted after seeking advice from a Clinical Information Specialist on selection of databases, search terms and variants. Studies were located through searching electronic databases, hand searching key journals and conference proceedings, together with 'citation snowballing' (Booth, 2001) from reference lists of located studies. In an attempt to further minimise bias, such as publication bias, a wider internet search, including search of grey literature, was conducted in order to identify any reports or papers not published in peer reviewed journals. Discussion with experts in the field, together with searching key respiratory conference

proceedings ensured inclusion of contemporary literature not yet indexed in databases. To overcome the potential problem of poor indexing (an issue particularly evident with qualitative studies) subject specific terms were searched but no methodological approach was specified; in other words all empirical studies were included.

Databases

The following databases were searched for relevant literature via NHS Evidence Health Information Resources (www.library.nhs.uk); Medline (1950-2014), Embase (1980-2014), CINAHL (1981-2014), British Nursing Index (1985-2014) and PsycINFO (1806-2014) using the keywords; *oxygen therapy, chronic respiratory disease, COPD, interstitial lung disease* (see Appendix A – for the full search history). These databases were chosen as they contain references of interest to this systematic review. The search was undertaken 21st December 2011 and re-run on 12th March 2014 to capture further relevant studies published since the initial search.

Search Terms

Synonyms and term variants were also searched and combined using the Boolean 'OR' (e.g. oxygen therapy OR O₂ therapy). Different facets were combined by use of the Boolean 'AND'. Relevant thesaurus terms unique to each database were located to increase the sensitivity of the search and reduce chances of missing any potentially relevant studies. Truncation (*) was utilised to capture plurals and spelling variants (eg. Oxygen therap* would capture the singular oxygen therapy and also the plural oxygen therapies). Advanced search operators for phrase searching ("") were also used to improve the focus of the search. A broad approach to the search terms was adopted in order to minimise the chance of missing relevant

publications. The search was limited to English language, human and adult studies as per inclusion criteria (Table 1). Studies were considered from any country of origin in order to identify any culturally specific issues within the narrative of findings.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Any recorded perceptions of receiving, administering or prescribing oxygen therapy by respiratory patients (any disease category – acute or chronic, adults > 18 years, in any setting) or healthcare professionals (any profession, any setting, acute or chronic, and any country).	Non-respiratory patients. Carers, lay healthcare workers. Studies concerned only with the efficacy of oxygen rather than perceptions.
Intervention – oxygen therapy delivered as part of medical management including acute oxygen therapy, domiciliary oxygen therapy and palliative oxygen therapy.	Any papers detailing oxygen as a complementary therapy.
Empirical studies with a clear, methodological stance, although actual method is unimportant.	Any papers without an explicit stated methodology.
English language.	Papers unavailable in English language

Hand searching key journals

The following journals were searched prompted by electronic alerts for the period 2010 to 2014 to capture recent studies not yet indexed in the databases: Thorax; Primary Care Respiratory Journal; Chronic Respiratory Disease; British Medical Journal; American Journal of Respiratory and Critical Care Medicine. These particular journals were selected on the basis of their respiratory focus.

Experts Contacted

Discussion with experts in the field elicited research studies regarding oxygen therapy that were being proposed. Reciprocal sharing of proposals provided an opportunity to cross check reference lists, though this strategy did not reveal any further sources.

Other Resources

The following conference proceedings were searched to locate studies that may not have reached publication: British Thoracic Society Summer and Winter meetings, 2011-2014; European Respiratory Society Annual Conference, 2011-2013; American Thoracic Society Annual Conference, 2011-2014. This was an attempt to avoid publication bias (Khan et al., 2003) and enable more contemporary literature to be included.

Grey literature was searched via GreySource (www.greynet.org); Royal Collage of Nursing Library: Steinberg Collection of Thesis (www.rcn-library.rcn.org.uk) and GoogleScholar®. No additional thesis or reports were identified from this strategy.

3.4.2 Screening and Appraisal Procedure

Khan et al. (2003) refer to the 'strengths of a review's inferences' (p15). As the outcome in question is not an intervention *per se* then there will not be inferences as such, but rather informants (for the current study). This approach required an inclusive strategy for selection so that doubt erred on the side of inclusion rather than exclusion. Initial selection was made via reading titles and abstracts which reduced the number from 1504 to 180. Papers were then considered for eligibility against the inclusion and exclusion criteria (Table 1).

In order to facilitate study selection a proforma was devised (Appendix B) and piloted on a subset of primary studies. The proforma was then applied to all 180 papers resulting in 60 included studies and 120 excluded studies. Two reviewers independently screened the title and abstracts for eligibility against inclusion and

exclusion criteria (Table 1) and relevance to the research question. In the event of disagreement the full text was requested. Value judgements regarding credibility and potential contribution were then deferred to the quality appraisal phase.

Soundness of study design formed the foundation for inferences and recommendations, and therefore only studies with explicitly stated methodology were included. The process of identification and selection of papers with such a diverse methodological stance proved time-consuming since a large selection of papers needed to be retrieved for full reading; a finding similarly reported by others (Lloyd Jones, 2004).

3.4.3 Quality Assessment

A leading contention in relation to quality assessment and integrative reviews is whether studies should be excluded on the grounds of poor quality (Mays and Pope, 2000; Petticrew, 2001; Dixon-Woods et al., 2004; Flemming 2010). Kuper et al. (2008) argue that thorough assessment of qualitative research is an interpretative act that requires informed reflective thought rather than a simple scoring system. Content and relevance of findings therefore was a key consideration and papers were quality appraised both on their own merit and within the context of the review question. As the focus of most studies was not specific to the review question this was an important aspect.

The diversity of studies identified as relevant warranted development of a hybrid quality appraisal/data extraction sheet (Appendix C) based on criteria for disparate data (Hawker et al., 2002). Using this protocol for assessment a score of 1 to 4 was assigned to each of ten criteria resulting in an accumulative score that indicated the overall assessed methodological rigour of each empirical study

(ranging from 10 [very poor] to 40 [good]) (Appendix D) (Hawker et al., 2002). This protocol and descriptors were chosen for the present review because of their application to disparate data. Based on these considerations a quality checklist to appraise individual studies and extract data was devised in order to identify methodological strengths and weakness, together with utility (Appendix C).

This approach enabled the quality appraisal to be undertaken in context of data that was relevant to the review question. The iterative approach to the review enabled the final selection to be determined as papers were read and re-read for relevance and emerging themes. An overzealous approach to quality appraisal with qualitative research appraisal tools has been regarded as reductionist (Barbour, 2001). This further informed the quality appraisal tool design, attempting to highlight importance of utility in addition to methodological rigour. Nonetheless the checklist considered key quality appraisal issues for qualitative studies, such as triangulation, respondent validation, clear exposition of data collection methods and analysis, reflexivity, attention to negative cases and fair dealing (Mays and Pope, 2000). Likewise characteristics of validity, reliability, generalisability and design were applied to quantitative studies.

Using the method advocated by Hawker et al. (2002), quality appraisal was initially considered for the overall study and latterly applied specifically to the relevant extracted information. This identified various methodological strengths and weaknesses for consideration without excluding studies of poorer quality (Dixon-Woods et al., 2006).

A cross-section of papers was second-checked by an independent reviewer and differences resolved by discussion and consensus. This process of quality

appraisal reduced the number of studies from 60 to 52. The reasons for exclusion together with references of papers are outlined in Appendix E.

At this stage papers were separated into two categories: patients (42 studies) and Healthcare Professionals (HCP) (13 studies); a total of 52 papers (three papers being eligible for inclusion in both).

3.4.4 Data Extraction Strategy

A data extraction proforma was constructed that detailed characteristics and quality appraisal of included studies, including relevance to the research question (Appendix B). A cross-sample of these was independently reviewed.

The logic adopted was that of theoretical extraction of applicable data rather than an inclusive approach of all data (Dixon-Woods et al., 2006). Greenhalgh et al. (2005) discusses that utilising such a process allows the researcher to identify data for inclusion intuitively. But this can mitigate against the review's reproducibility. Dixon-Woods et al. (2006) acknowledges this but supports CIS in that it recognises that alternative accounts of the same evidence might be possible using different authorial voices, suggesting that transparency is achieved through grounding assumptions in the evidence. In order to provide transparency on this account examples of verbatim extracts from qualitative studies representing the 'voice' within the literature are provided Tables 4 and 7 (pages 94 and 123).

3.4.5 Synthesis of the Extracted Data

Synthesis is broadly categorised as aggregative or interpretative (Dixon-Woods et al., 2006). Interpretative synthesis can be characterised by its concern with the development of concepts. It is an iterative approach that yields concepts and

develops theory rather than aggregates data (Dixon-Woods et al., 2006). The interpretative approach therefore reaches beyond original data to form a fresh interpretation. These principles underpin the review and thematic analysis undertaken. This approach however can be criticised as being not strictly reproducible and researcher bias may be inherent (Booth et al., 2012). Quality checks were adopted to guard against and offset these potential threats.

Mirroring criteria set out by Flemming (2010), the current review adopted the following stages of synthesis: the paper was read and understood in relation to itself; relevant data were extracted and concepts, themes and metaphors were identified; translations were synthesised into emergent synthetic constructs; finally, relationships were explored between constructs, thereby allowing explanatory accounts to be suggested in the form of synthesising arguments. This integration of evidence from across studies allowed, in the absence of evidence directly addressing the research question, new interpretations of data which is demonstrably grounded in existing evidence (Dixon-Woods et al., 2006).

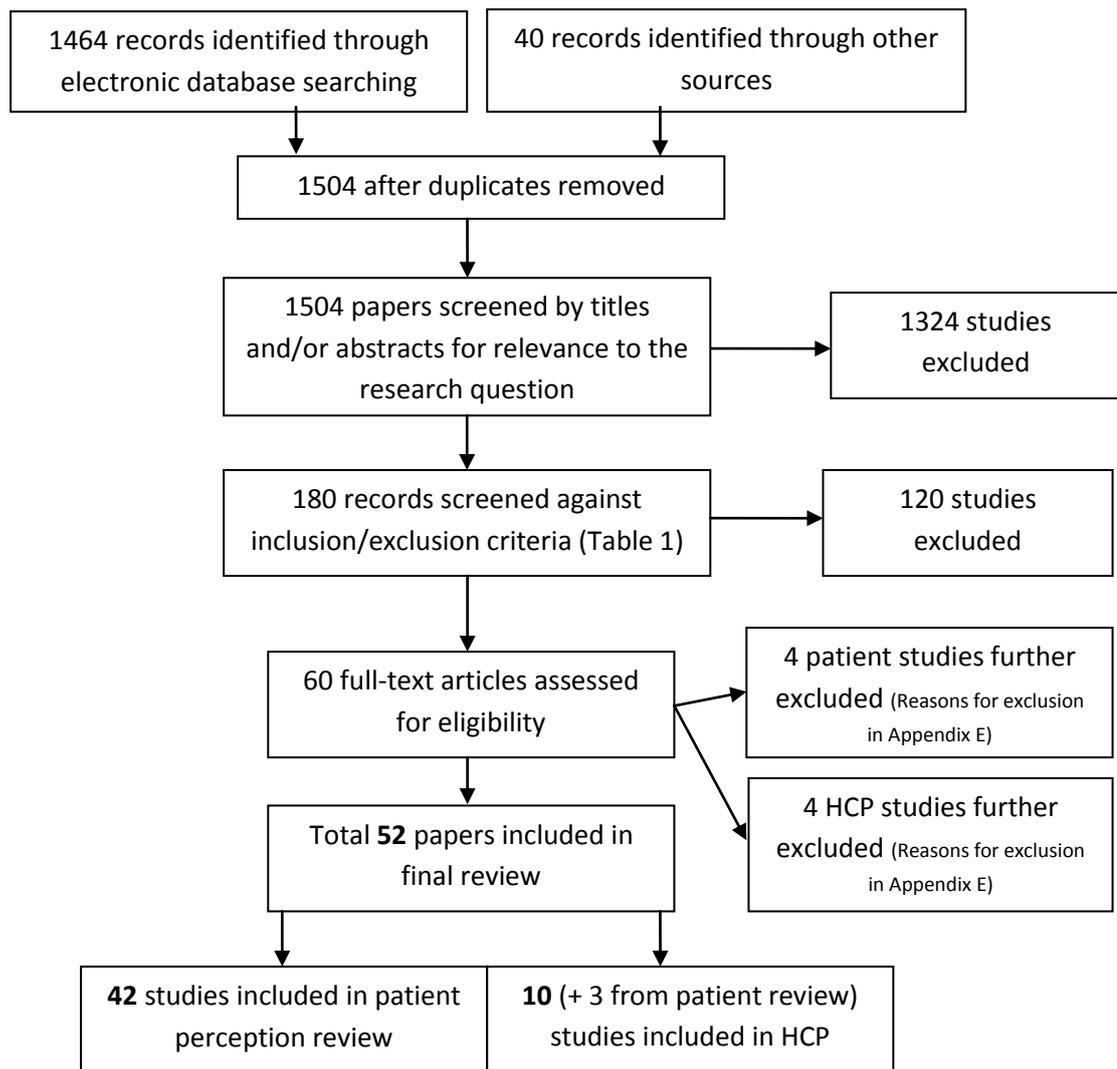
3.5 FINDINGS

The flow chart (Figure 6, page 86), adapted from PRISMA (Moher et al., 2009), provides a summary.

Few studies directly addressing the research question were identified, therefore studies were selected on the basis that some aspect of, or reference to, the study's findings included patients' or HCPs' perceptions of oxygen therapy.

The final results of the review are presented in themed narratives of data that emerged from the literature referring to both patients' and healthcare professionals' perspectives of oxygen therapy. These will be reported separately.

Figure 6: Flowchart of Selection



3.5.1 Patients' Perceptions of Oxygen Therapy

Table 2 summarises all the selected studies pertaining to patients' perceptions of oxygen therapy including summaries of critical appraisal. The final selection of 42 papers consisted of varying methodological approaches, quality, countries of origin, and patient groups, reflecting the heterogeneity of studies. The number of patients in each study ranged from 5 to 1504. Quality appraisal scores ranged from 21 (poor) to 38 (good) out of a maximum score of 40; as discussed previously, no papers were excluded on the basis of quality alone.

Table 2: Study Characteristics: Patients' Perceptions

Author/Year	Methodology	Context	Participants	Focus of Study	QA	Relevance & Supporting Evidence
Adams 2008	Phenomenology	Australia	5 patients on domiciliary O ₂	Impact on patients in rural settings	35	Mainly relates to experiences of living with chronic respiratory disease /LTOT, rich data that can be extrapolated to review question; feel safe with O ₂ ; positive; gives energy; helps sleep; helps breathing; keeps alive; mobility; expectations > experience; self-care enabled; enables to live.
Arnold et al. 2011	Qualitative	UK	27 COPD patients	To appraise compliance with ambulatory oxygen therapy	39	Although specific to ambulatory oxygen therapy and compliance, several themes identified regarding patient perception. Patients overwhelmingly believed oxygen for dyspnoea, were disappointed, felt restricted and embarrassed. Also reported that oxygen made them feel safe.
Berg* 1996	Qualitative	USA	7 patients transtracheal oxygen/ hypoxic	Perceptions of QOL of patients with transtracheal O ₂	30	Failure/unable to name oxygen & related devices. Dangers of O ₂ expressed. Positive (control of events & activities of daily living) benefits of O ₂ recognised.
Booth et al. 1996	RCT	UK	38 terminal cancer patients dyspnoea Hypoxic & normoxic	O ₂ vs air for relief of dyspnoea	25	Both air & O ₂ beneficial. ?self-fulfilling prophecy ?placebo effect. No correlation with hypoxia. Advocates trial of O ₂ (n=1) in both hypoxia and normoxia.
Borak et al. 1991	Prospective Quantitative Study	Poland	48 hypoxic & severe COPD patients on LTOT	Evaluation of psychological status of patients on LTOT	23	Majority of patients reported to not believe in efficacy of the therapy but insufficient detail in the write up to explore this aspect. Only 2 patients positive (22 indifferent; 24 negative). Increased levels of anxiety and depression reported.
Bruera et al. 1993	Double-blind RCT cross-over	Canada	14 patients dyspnoea & hypoxia > 90%	Effects suppl. O ₂ with resting hypoxic dyspnoea	28	Beneficial in patients with terminal cancer and hypoxic dyspnoea in reducing dyspnoea. Historical value but some offerings to current review question.
Bruera et al. 2003	RCT	USA	33 Cancer normoxic	To determine efficacy of O ₂ over air for dyspnoea	36	No difference O ₂ and air. Both benefit dyspnoea - ? placebo/?positive attitude related. Advocates no evidence to support use of oxygen in normoxia.

Cicutto and Brooks 2006	Mail Survey	Canada	353 (78% response)	Perceptions of self-management from patients	28	Some discussion of O ₂ use motivators: value of HCP instruction highlighted – ‘faith in’. No details of O ₂ status or prescription. Very limited application to review question.
Clancy et al. 2009	Phenomenology	UK	10 hypoxic patients prescribed LTOT and their carers	Experiences of patients & carers start, 3&9 months	34	O ₂ perceived as inevitable decline. Memories of experiences of others (negative). 7 had very negative views/2 positive.
Cornford* 2000	Qualitative	UK	24 patients on O ₂ – no oxygen status. ? mixed hypoxic/normoxic	Lay beliefs about from patients on domiciliary O ₂	33	Ambivalent findings: O ₂ as restricting vs. benefiting. Only 7 out of 24 patients took O ₂ > 15 hours. Some useful verbatim quotes. Quite applicable to review question.
Crockett et al. 2006	Qualitative	Australia	17 Domiciliary O ₂ – no diagnosis stated	To identify common concerns & problems with domiciliary O ₂	26	Limited relativity. Poster only, so limited detail. Key themes of embarrassment, grief & loss and social isolation. <i>Contacted authors for more detail – response initially but then no further follow-up regarding request for further results.</i>
Cullen & Stiffler 2009	Meta-synthesis	USA	4 studies Qualitative	LTOT, hypoxic patients <i>experiences</i> of LTOT	38	Limited because of different research question but four common themes encapsulate this limited literature (adaptation/ restriction/self-management & submission/dependency). Data that I extrapolated from these studies individually differed subtly. <i>*Studies included</i>
Currow et al. 2009	Prospective Quantitative	Australia	1239 community hospice patients	Relief of dyspnoea in palliative care	29	Limited applicability. Conflicting benefit/no benefit. No oxygen status recorded.
Demirel et al. 2003	Retrospective Case note study & patient review	Turkey	127 patients with continuous O ₂ therapy	To evaluate use, indications for continuous O ₂ , satisfaction	23	Limited, focus on prescribing. 16% reported fear of addiction. Subjective benefit – 77% felt improvement. Other 23% no different or worse – majority O ₂ <15 h.p.d. No correlation between hypoxia level & usage though.
Doi 2003	Survey	Japan	144 LTOT patients compared with 100 CRD no O ₂ and 51 healthy	Measure psychological impact of progress of CRD & LTOT	21	PSM – tool used in LTOT to measure negative attitudes – Four factors revealed: hopelessness; burden & misery; denial against O ₂ and dependency & anxiety. Bias may be inherent because of pre-determined phrases (p997).

Earnest* 2002	Qualitative	USA	27 hypoxic COPD patients on LTOT	Patterns of adherence to supplementary O ₂ in hypoxic COPD	35	3 patterns of adherence: PRN, part and full time. Also included compromise/adjusting/adapting. Good verbatim quotes. No oxygen status reported only 'hypoxic' although other data. recorded quantitatively (FEV ₁ , SGRQ, BSI).
Eaton et al. 2001	Audit	New Zealand	405 SBOT patients	To examine if patients prescribed SBOT meeting LTOT criteria at 2 months	25	Commentary regarding patient misinformation and unrealistic level of expectations. Patients not prepared for oxygen withdrawal if needed. Psychological dependency observed – reported distressing for pts & staff if O ₂ to be withdrawn. But no data reported that would support this.
Fraser et al. 2006	Phenomenology	USA	10 COPD patients – no oxygen status	How COPD has affected lives	35	Limited discussion of use of oxygen for dyspnoea.
Gardiner 2009	Qualitative	UK	21 COPD patients no oxygen status reported	Explore fears of death & dying in COPD	32	Some limited reflections on past experiences of other with O ₂ . One 'snippet' of a patient reporting taking oxygen into the blood – perhaps only physiological reference in the literature.
Goldbart et al. 2013	Qualitative	UK	27 patients with COPD plus carers and HCPS	LTOT: Views & expectations of patients and carers	30	Two global themes identified: positive (including enabler and mastery) and negative (dependency, deterioration of health status and embarrassment.
Gruffyd-Jones et al. 2007	Prospective observational study	UK	25 COPD patients post AECOPD 12 on LTOT only 9 had sats < 92%	To identify patients' needs post discharge	31	O ₂ useful for breathlessness & anxiety during an exacerbation. Patients perceived a need for O ₂ but uncertain why not provided or, if provided, when they should use it.
Habraken et al. 2008	Prospective qualitative	Netherlands	11 COPD patients Purposeful sample with & without O ₂	To gain insight to why COPD patients do not express a wish for help	33	O ₂ PRN used as a coping strategy. No saturations recorded.
Hasson et al. 2008	Descriptive qualitative	N. Ireland	13 COPD patients on LTOT / LTOT+NIV	Explore the potential for palliative care in advanced COPD	31	Use of O ₂ for relief of symptoms & "attacks". Reliance on O ₂ – psychological dependency discussed but no real data. All on LTOT but no blood oxygen status.

Ingadóttir and Jonsdottir 2006	IPA & narrative analysis	Iceland	6 patients with LTOT + NIV – range of diagnosis.	Patients & families experiences of LTOT + NIV	25	Limited because of NIV. Some embarrassment noted. Mixed blessings (Blessing & Life lost meaning).
Jaturapatporn et al. 2010	Qualitative	Canada	8 palliative cancer patients with O ₂	Experiences of patients using palliative O ₂	34	Mixed findings: more positives than negatives. Positive: increase functional capacity; life-saving; symptom management. Negative: decrease mobility; discomfort; noise.
Jones et al. 1978	Mixed: observational & qualitative	UK	45 pts with domiciliary O ₂ for dyspnoea – no blood O ₂ status	How patients use & cope with O ₂	33	Overall benefit of O ₂ slight though most claimed helpful. Authors summarised benefit probably placebo.
Kampelmacher 1998	Quantitative Survey	Netherlands	528 patients various respiratory diseases. On LTOT > 6 months	Compliance and related issues	32	Mostly negative experiences but questionnaire negative - 34% reduction in dyspnoea; 40% frequent complaints, oxygen prescription and usage unknown to 234 patients; 46% prescribed O ₂ for dyspnoea. Categories of complaints detailed p72: restricted autonomy; delivery device; oxygen source; feeling ashamed.
Lai et al. 2007	Qualitative	China	11 patients advanced lung cancer. On O ₂ – ‘as required’	Perceptions of dyspnoea and how patients manage	35	Most found O ₂ essential; half said burdensome/restrictive. Good verbatim quotes on personal image. Regard HCP as unhelpful – this could be culture specific though.
Lewis et al. 2003	RCT (single blind – air v O ₂)	New Zealand	22 stable COPD patients normoxic at rest but desaturate on exercise	SBOT efficacy in relation to dyspnoea and exercise	36	Negative findings. Patients asked regarding expectations pre-study: all expected O ₂ would help post exercise, most pre. Authors comment that patients have strong belief that SBOT reduces dyspnoea (supported anecdotally by authors and to include carers and HCPs as well).
Neri et al* 2006	Survey	Italy	1504 patients & physicians. Patients on LTOT (liquid) > 6 months	Behaviour & knowledge re O ₂	31	Mostly relates to compliance. Two questions relevant: perception of improvement – 88% yes; why prescription: – 51% low blood oxygen, 38.5% believed it was prescribed for dyspnoea. Unsure of exact rationale for prescription but 94% prescribers were respiratory physicians so presume met criteria.

O'Neill et al. 2005	Survey	UK	100 COPD patients on SBOT	Use & cost of SBOT in COPD	32	Oxygen used for dyspnoea in 90% patients. 4 patterns of use (pre, intra, post exercise and rest). 87% used after exercise, 46% at rest. No blood O ₂ status. Authors comment relief of dyspnoea with O ₂ post exercise may correspond with cessation of exercise.
Peckham et al. 1998	Quasi-experimental	UK	45 patients on LTOT PaO ₂ <7.3kPa vs. 41 controls LTOT (ABGs avail on 51%)	Efficacy of assessment for LTOT & 1 hour education	29	Limited. Beneficial effect of education on compliance possibly relate to knowledge (93% vs 41% knew why taking O ₂).
Quantrill et al. 2007	Experimental	UK	22 patients on SBOT Reported benefit of O ₂ & used O ₂ post activity	Efficacy of SBOT on daily activities	30	Limited. SBOT shortens recovery time both objectively & subjectively. Highly selected group who had already reported benefits. Small sample size.
Reinke et al.* 2008	Grounded theory	USA	55 pts (advanced cancer or COPD) O ₂ dependant	Comparison of patients & HCPs perceptions regarding transition of illness	31	Very limited, regarding transition of illness mainly. O ₂ seen as a restriction, O ₂ a sign of deterioration (surprised I didn't see more of this – possibly denial??) HCPs perception mainly regarding illness transition so little relevant to the HCP part – but one quote on p 606 – “ something else to try”.
Ring & Danielson* 1997	Phenomenology	Sweden	10 hypoxic patients on LTOT No specific diagnosis	Describe patients LTOT experiences	32	Four key findings: restricted to time & room; an advantage for the body; living in one's life rhythm; put up with in order to live. Advantage to the body suggests an awareness of physiological rationale but no verbatim quotes to support. Author refers to 'diminished oxygen reserve' – does this show their lack of in-sight into physiological tenets?
Ringbaek 2001	Q Survey	Denmark	142 patients prescribed O ₂ <12 h.p.d. or PRN	Effect of SBOT	26	Very Limited. Some subjective improvement reported in dyspnoea and quality of life. ? placebo. No correlation between subjective effect & usage.
Roberts et al.* 1993	Mixed methods	Canada	10 late cancer patients/12 nurses	Experience of dyspnoea last year of life – patients & nurses perspective	33	Limited to 2 short but relevant points. Patients' frustration. From nurses the psychological benefit is acknowledged: for patients, carers & HCPs. 66% used O ₂ as a measure for alleviating dyspnoea.

Robinson 2005	Phenomenology	UK	10 severe COPD on LTOT	Experiences of living with severe COPD	28	Most reported O ₂ positively but powerful negative verbatim quotes. This paper is often referenced in respect of negative experiences.
Uronis et al. 2008	SR & Meta-analysis	Australia	4 studies all quantitative Cochrane methodology	Determine efficacy of O ₂ for relief of dyspnoea in cancer	31	O ₂ did not improve dyspnoea. Normoxic patients with concentrators. Identifies a population who O ₂ does appear to help.
Williams 1993	Mixed Methods	UK	92 patients PhD Study/Book 3 pub outputs not relevant to O ₂	Experience of chronic respiratory disease - focus on social consequences	34	Multiple references to living with oxygen in the context of living with chronic respiratory disease; book from qualitative arm of study (24 patients) no reference of oxygen in other published outputs. Good methods.
Williams et al. 2007	Qualitative	UK	6 COPD students 5 had O ₂	What is important to COPD patients?	36	Oxygen was an important aspect of their disease for patients who used it. Although was restrictive, caused embarrassment and was seen as a visible sign of disease.
Wrench 2012	Phenomenology	UK	7 patients, 4 carers	Adaptation to LTOT	26	Themes of fear, denial and frustration, loss of independence and acceptance. Outlines the patients' journey and likens it to the grieving process. Study write-up limited to the format of a letter.

* Studies included in Cullen & Stiffler's meta-synthesis.

* Studies also included in the review of Health Care Professionals' Perception

The synthetic constructs and their subsequent synthetic arguments can be classed into three distinct domains: *negative perceptions*; *positive perceptions* and *impartiality*. These constructs, together with the number of papers which contributed to each, are outlined in Table 3 and Table 4. A more detailed record of the grid of themes, sub-themes and occurrences can be found in Appendix F and G.

Table 3: Synthetic Constructs and Synthesising Argument

Synthetic Construct	No. of Studies	Synthesising Argument	Domain
Keep alive	7	Feeling Safe	Positive perceptions
Faith in	8		
Symptom relief	23	Enabler	
Mastery	11		
Benefit	15	Comfort	
Placebo	11		
Declining disease status	9	Fear	Negative perceptions
Memories (of others)	5		
Fear of dependency	9		
Disappointment	10	Oxygen versus self	
Hopelessness & Existing	7		
Social isolation	14	Restriction	
Frustration	11		
Complaints	12		
Attitude of others	9	Embarrassment	
Changing body image	9		
Shame	8		
Guilt	3		
Adaptation	5	Mixed Blessings	Impartiality
Compromise/trade-off	4		
Knowledge & understanding	8		

Table 4 shows illustrative verbatim extracts from the qualitative studies representing the ‘voice’ within the literature.

Table 4: Grid of Themes and Representation from the Literature – Patients

Domain	Synthesising Argument	Synthetic Construct	Representation from the literature - Voice
Positive perceptions	Feeling Safe	'Faith in'	<i>"I had an extension of life; 'it can also save my life' and ...I don't know if I'd be around if I didn't have it"</i> (Jaturapatporn et al., 2010:767).
		Keep alive	: <i>"...without the oxygen I wouldn't have a life"; "The benefit is it is keeping me alive..."</i> (Adams, 2008:18).
	Enabler	Symptom relief	<i>"After I'm finished, I come back to the bedroom and take oxygen for about 10 minutes"</i> (Habraken et al., 2008:846)
		Mastery	<i>"When you wake up and you get out of bed on a morning, I feel as if I have to use it straight away."</i> (Cornford, 2000:792)
	Comfort	Placebo	Four RCTs (Booth et al., 1996; Lewis et al., 2003; Bruera et al., 1993; Bruera et al., 2003) suggest that symptomatic benefit not entirely dependent on the literature and a 'placebo effect' may play a role.
		Benefit	Jones et al., (1978) mixed methods observational study reported that 83% of 45 patients claimed benefit. <i>"When she goes to bed she hasn't got that fear"</i> (Goldbart et al., 2013).
Negative perceptions	Fear	Declining disease status	<i>"I didn't realise things had got this bad"</i> Wrench, 2012
		Memories (of others)	<i>"I knew that I would be on oxygen because I'd seen my mother deteriorate..."</i> (Clancy et al., 2009:82)
		Fear of dependency	<i>"How can I face others... They think that I am an addict"</i> (Lai et al., 2007:E5)
	Oxygen versus self	Disappointment	<i>"I've been on oxygen three years and I still get progressively worse. I don't know if that is my fault or the illness"</i> (Robinson, 2005:41)
		Hopelessness	Doi (2003) questionnaire survey found four factors related to the psychological impact of LTOT: 'hopelessness'; 'burden and misery', 'denial against oxygen' and 'dependency and anxiety'.
		Existing	<i>"...I'm not the same person as I used to be and I'm not going to be able to do the things I used to do and I haven't been able to do the things I used to do"</i> (Adams, 2008:22)
	Restriction	Social isolation	<i>"I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops – it's like you are on a leash, tied to a regimen"</i> (Reinke et al., 2008:606)
		Frustration	<i>"...tied to that machine"</i> Williams, 1993:103

	Embarrassment	Complaints	<i>"This thing [the oxygen tubing] was cutting into my ear – this stupid thing here...it twists, twists, twists. I untwist it and it gets twisted again!...I don't know if it does much good or not. I seem to get along without it just as good as with it"</i> (Kampelmacher et al., 1998:315)
		Attitude of others	<i>"...I dislike when people stare at me. They definitely think that I have been smoking myself to death..."</i> (Ingadóttir and Jösdóttir, 2006:22).
		Changing body image	<i>'Well what are they gonna think with me walkin' in with a blimmin' great oxygen cylinder and what have you',</i> (Williams, 1993:112)
		Shame	Neri et al. (2006) survey found people were ashamed of being seen by passers-by (p800)
		Guilt	<i>"I feel like I have to do it because I smoked"</i> (Earnest, 2002:753)
Impartiality	Mixed Blessings	Adaptation	Earnest (2002) refers to physical <i>adaption</i> such as rigging vehicles with oxygen to enable fishing trips; running oxygen lines upstairs and ways of mobilising equipment.
		Compromise/trade-off	<i>"I am willing to put up with the nuisance for the benefit of oxygen; the burden does not mean much"</i> (Robinson, 2005:767-768)
		Knowledge & understanding	Neri et al.'s (2006) survey reported that 51% of the 1504 patients included, understood that oxygen was given for low blood oxygen levels, whilst 38.5% believed it was for dyspnoea. Cicutto and Brooks (2006) considering the value of healthcare professional instruction regarding oxygen therapy – 57% 353 COPD patients identified the most common motivator as <i>'their healthcare provider told them to do it'</i> (p1543).

Positive Perceptions

Three main themes were constructed from patients' positive perceptions in respect of oxygen therapy: *feeling safe*, *oxygen as an enabler* and *oxygen as comfort*.

Feeling safe: keeping alive and faith in healthcare professionals

It is apparent within several reviewed studies that patients often regard oxygen as tantamount to keeping them alive (Ring and Danielson, 1997; Lai et al., 2007; Jaturapatporn et al., 2010, Hasson et al., 2008). A key finding of Ring and Danielson's (1997) phenomenological study of ten COPD patients' experiences of living with LTOT, was oxygen being '*an advantage to the body*' (p341). This apparent awareness can only be partially translated into knowledge of what oxygen is doing to the body. Verbatim quotes include reference to terms such as '*cyanosis*' and '*the organs lack of oxygen*' but these are outnumbered by more obscure statements such as '*it's my life*' (p340). Methods in this study were clearly outlined with intersubjective agreement between researchers, and use of verbatim quotes upholds credibility and strengthens the paper.

Lai et al. (2007) interviewed 11 patients with advanced lung cancer and reported similar perceptions of oxygen being '*essential*'; again no specific reference was made regarding what manifested this belief. The positive connotation in this study ends there, with the rest of the patients' perceptions relating to the burdensome nature of oxygen therapy. The transferability of the study itself is limited to the fact that all patients had terminal lung cancer, which would undoubtedly affect patients' symptom load and psychological state. Set in China this study offers additional insight into patients' cultural perspective through strategies adopted to

improve dyspnoea, including seeking spiritual relief and the use of traditional Chinese medicine. This contrasts with western patients seeming reliance on medicine (in particular oxygen) to relieve dyspnoea and is perhaps worthy of further exploration with regards to psychological dependence.

A further qualitative study from Canada specifically asked patients about the advantages of oxygen (Jaturapatporn et al., 2010). This was a small study of eight palliative care cancer patients in which five patients reported perceiving oxygen as a life-saving intervention: '*I had an extension of life*'; '*it can also save my life*' and '*...I don't know if I'd be around if I didn't have it*' (Jaturapatporn et al., 2010:767). It is not clear from the published paper whether the notion of oxygen as life-saving and life-giving therapy (even in the terminal phase of cancer) could be endorsed by patients' expected benefits, or related to their faith in their prescribing health care professionals. Again the terminal phase of the patients will undoubtedly influence the findings and credibility of the study is affected by inclusion of few verbatim quotes.

Adams (2008) carried out a phenomenological study of five patients on LTOT in rural Australia. Although limited in generalisability owing to the geographical setting (the main aim of the research was to explore how LTOT had impacted on the lives of rural patients in comparison to urban settings) the findings do allow some accounts of perception to be extrapolated. Adams (2008) discusses oxygen as '*enabling patients to live*' and therefore patients relate to removal or denial of oxygen as a sign of impending death. This finding may be relevant with regards to why patients are often considered to 'demand' oxygen. Other studies similarly reported oxygen enabling patients to feel safe, whether through increased confidence (Arnold et al., 2011) or relief of dyspnoea (Goldbart et al., 2013).

Earnest et al. (2002), examining patterns of adherence to oxygen regimes in hypoxic COPD patients, highlights patients' stated trust in the prescribing physician as important. This notion of faith and trust in HCPs is further legitimised by Cicutto and Brooks (2006) in a mail survey of 353 COPD patients exploring self-management strategies. One of the factors identified as a motivator for self-care was that oxygen was recommended by a healthcare professional. This study had a high response rate of 78% but did rely on patient recall. The questionnaire itself was not validated, though it was based on previous work of the same authors.

The key theme of patients *feeling safe* is grounded in the notion of oxygen as something that keeps patients alive and was found in 12 of the 38 papers. Patients appear to have *faith in oxygen*, yet the literature does not appear to offer any tangible insight regarding why this may be the case. Whether this is a consequence of their faith in the prescribing healthcare professional is not clear, but the fact that the therapy was recommended by a healthcare professional was often associated with compliance, and identified as a motivator for self-care.

Enabler: Symptom relief and mastery

Oxygen therapy is perceived by patients as an enabler through both the *relief of symptoms* and as a means of achieving *mastery* (over their symptoms and disease). The theme of enabler was the most frequently recurring with a total of 20 papers making reference to the use of oxygen for relief of symptoms, in particular, breathlessness, and a further nine papers citing the impression of oxygen enabling mastery.

Patients clearly utilise oxygen as a tool for symptom management (Jaturapatporn et al., 2010; O'Neill et al., 2005; Adams, 2008; Cicutto and Brooks,

2006; Fraser et al., 2006; Neri et al., 2006; Goldbart 2013; Arnold 2011). Accounts of oxygen helping breathlessness and enabling patients to perform activities suggest that patients actively use oxygen to also manage their disease (Cornford, 2000; Berg, 1996). A meta-synthesis looking at the patient's perspective of oxygen therapy (Cullen and Stiffler, 2009) identified four key themes, one of which was the fostering of self-management. Jaturapatporn et al. (2010) further reported that palliative patients were started on oxygen for shortness of breath, despite the fact that only three actually had documented hypoxaemia. This rationale for prescribing oxygen for dyspnoea rather than hypoxaemia was common (Booth et al., 1996; Fraser et al., 2006; Gruffydd-Jones et al., 2007; O'Neill et al., 2005) and may have a bearing on patients' expectations.

Enablement through improvement of both subjective dyspnoea and objective recovery with oxygen post activity was recorded by Quantrill et al. (2007). Using air as a control, this experimental study aimed to determine whether oxygen improved breathlessness during exercise; recovery time was shortened with oxygen (vs. air) but the effect was small. It may be that this highly selected group of 22 patients represent a sub-group of responders who, at entry to the study, were already reporting benefit from oxygen. Those patients who distinguished oxygen from air, however, perceived that it was '*better than nothing*' (p 703), suggesting a possible effect from the sensation of air flow as a means of reducing dyspnoea (Schwartzstein et al., 1987; Liss and Grant, 1988) and thus enabling increased activity.

It has been reported that the relief of breathlessness post exercise may correspond with cessation of exercise itself rather than oxygen (O'Neill et al., 2005; Habraken et al., 2008). The practice of taking oxygen for relief of breathlessness

following exercise is recurring, but the respite may be parallel to cessation of exercise and recovery. Other accounts of enablement refer to oxygen increasing stamina and giving strength (Ring and Danielson, 1997), giving energy (Adams, 2008), managing anxiety (Gruffydd-Jones et al., 2007) and improving quality of life (Ringbaek et al., 2001).

The use of oxygen to relieve breathlessness is the most commonly recurring theme and clearly relates to enabling patients. Whatever contributes to this symptom relief, it is apparent that oxygen used in such a context enables patients to achieve some degree of mastery over both their symptoms and, consequently, their disease.

Comfort: Benefits and the placebo effect

Reference to oxygen's beneficial effects of *comfort* totalled 25 citations. Quantitative studies aiming to assess the benefits of air versus oxygen in relation to dyspnoea were included in this review if they contained some data or insight into patient perceptions. Subjective benefits of oxygen were found to be comparable with air in experimental studies (Booth et al., 1996; Lewis et al., 2003; Bruera et al., 2003) which were unrelated to the extent of hypoxaemia (Booth et al., 1996; Lewis et al. 2003) and a possible placebo effect is acknowledged (Booth et al., 1996; Lewis et al. 2003; Jones et al., 1978). The physical and psychological consequences of terminal illness however need to be considered when interpreting these results, which could possibly be a self-fulfilling prophecy in respect of either gas helping, or the effect of nasal/ facial cooling (Schwartzstein et al., 1987; Liss and Grant, 1988), or as a result of a psychological phenomenon.

Although physiological benefit in terms of reduced breathlessness for hypoxaemic patients cannot be disputed, for patients who do not demonstrate

hypoxaemia there appears additionally to be a placebo effect. It is apparent that symptomatic benefit is not dependent on the correction of hypoxaemia, and that relief of dyspnoea from placebo in the form of cylinder air is equally effective (Booth et al., 1996; Lewis et al., 2003; Bruera et al., 2003).

The cessation of breathlessness due to the use of oxygen, as perceived by patients, does not necessarily manifest in expected outcomes. A systematic review and meta-analysis (Uronis et al., 2008) determining the efficacy of palliative oxygen for relief of dyspnoea showed that oxygen did not always provide symptomatic benefit to patients with refractory dyspnoea. This may reflect the subjective nature of dyspnoea and the difficulty of measuring this complex phenomenon.

Oxygen appears as a positive addition to therapeutic treatment for respiratory disease commonly within the literature, it fosters a feeling of safety and is synonymous with life. The finding of *faith in oxygen to keep patients alive and relieve symptoms* certainly appears to contribute to the notion of mastery and self-management with indubitable benefits to patients.

Negative Perceptions

Within the considered literature four major themes were identified as negative perceptions regarding oxygen therapy for patients: *fear, oxygen versus self, restriction and embarrassment*.

Fear: declining disease status; memories (of others); and fear of dependency

Contributing to the over-arching theme of *Fear* are the sub-themes of *declining disease status*, observed in six papers; *memories (of others)*, seen in five studies; and *fear of dependency* in six studies.

Papers reported oxygen being symbolic of *declining disease status* or patients '*getting worse*' (Reinke et al., 2008; Crocket et al., 2006; Clancy et al., 2009; Wrench, 2012; Williams, 1993). Reinke et al. (2008) utilised a grounded theory approach to compare 55 oxygen dependent (advanced cancer and COPD) patients' perceptions of illness transition with that of healthcare professionals' perceptions. Although most reported data dealt with generic issues of illness perception, oxygen was considered under the theme of '*initiation of oxygen therapy*' (p606). The initiation of oxygen therapy was seen as a key milestone in the disease trajectory, and symbolised *declining disease status* with one patient reporting that initially they thought they would '*get off*' it but then accepting that "*this is the way it's going to be*" (p606). Initiation of oxygen was referred to as a '*transition phase*' (p607) and as such could be utilised as a means of introducing the notion of palliative care. What is not evident from this study is whether this revelation also occurs to patients.

Crocket et al. (2006), in an Australian qualitative study of domiciliary oxygen therapy patients, suggested '*grief and loss for one's former self*' (p200) as a common occurring theme. This could be related to acceptance of disease decline. Unfortunately only a poster publication of this otherwise seemingly relevant study could be traced. Despite acknowledged receipt of initial contact with the authors, subsequent requests for unpublished data were not forthcoming, limiting quality appraisal of the reported findings (Boland et al., 2014).

One of the most significant seminal works that gives insight to the experience of chronic respiratory illness comes from Simon Williams (Williams, 1993; Williams and Bury, 1989). Using a mixed methods approach researchers focused on the social consequences of chronic respiratory illness, in particular: meaning, experience, impact and management of the condition. Ninety two patients were

included in the quantitative phase which utilised multiple robust validated outcome measures to show that although lung function does not correlate well with disability ($r=0.38$; $p=0.001$), dyspnoea does ($r=0.90$; $p=0.001$) (Williams and Bury, 1989), suggesting the impact that dyspnoea may have. The qualitative phase involved semi-structured interviews with 24 of these patients. The results are detailed and extensive, and contained within the published output are some in-sights into patients' perceptions of oxygen therapy and the connotations this brings. In one particular instance a patient recalled starting oxygen therapy: "*It was quite a shock...I felt as if my world was crumbling about my ears*" (Williams, 1993:90). The implication that commencing oxygen brings could highlight a lack of communication earlier in the disease trajectory when disease progression, and therefore patient expectations, could ideally have been discussed. The study's strengths are in the rigour and attention to detail of this Ph.D. project. Nonetheless, limitations are inherent by the nature of single researcher work.

Clancy et al. (2009) similarly to Crocket et al. (2006), explored experiences with LTOT in ten hypoxic patients in England. Although some limitations were evident, for example omission of detail regarding the sampling strategy and data analysis, some aspects of the findings relate quite specifically to patients' perceptions of oxygen as a therapy. The authors refer to recognition of inevitable decline of disease as '*fatalism*' (p82). An issue quite clearly linked with *memories (of others)*, with one patient reporting: "*I knew that I would be on oxygen because I'd seen my mother deteriorate...and we moved her bed downstairs and then eventually took her to a home. You get to see what is coming for you!*" (p82). Another patient reported: "*When they said I needed oxygen it reminded me of my brother and the*

way that he became bedbound" (p83). A further comment related to oxygen as a "death sentence" (p83).

Reflection on previous experiences is further seen in Gardiner et al.'s (2009) qualitative study. Exploration of oxygen in respect of living with COPD revealed recalled memories of others using oxygen: "...the fact that it could get to the stage where my father was...connected to an oxygen pipe" (p694). Earnest (2002) reported similar reflections but on patients' own experiences rather than others', stating that fear of past events such as an exacerbation, panic and fear of running out of oxygen all led to increased usage.

Fear of dependency was another recurring theme. Earnest et al. (2002) discussed some patients were being fearful of oxygen through concepts such as addiction; two patients likened this to "*weakening their lungs*" and therefore needing to reduce usage in order to "*make my lungs work*" (p752). Other authors make reference to similar concerns such as patients not using oxygen due to fear of addiction (16% of 127 patients) (Demirel et al., 2003); and the perception that others have of them whilst wearing oxygen in public: "*Wearing an oxygen cannula just looks like someone addicted to drugs...How can I face others...They think that I am an addict*" (Lai et al., 2007:E5). Cullen and Stiffler's meta-synthesis (2009) refers to this fear of dependency competing against self-care and mastery.

This fear of addiction can be related to non-compliance, supported by reports of 20% of patients using oxygen for fewer hours per day than prescribed as a result (Kampelmacher et al., 1998).

Fear seems to be a multifaceted concept with regards to oxygen and 17 citations contributed to this premise. Oxygen, for some, is a sign of deterioration

often synonymous with palliative care and death. Previous experiences of others clearly support these fears, which are probably, on occasion, well founded. The symbolism of oxygen in respect of disease progression and potential for addiction can be a powerful negative emotion, and can ultimately impact on compliance. These negative findings provide a stark, if less frequently reported, contrast to the positive aspects of oxygen. This in turn potentially competes against mastery of disease, making patients more submissive to symptoms, with consequences to lifestyle and mental wellbeing.

Oxygen versus self: disappointment, hopelessness and existing

This theme captures some form of internal struggle that patients experience with oxygen. Contrary to expectations, patients often report feeling disappointed with oxygen; for some this was in relation to their breathing, reporting progressive worsening of their condition despite oxygen (Robinson 2005; Adams 2008). Futility was identified: “*I’ve been on oxygen three years and I still get progressively worse*” (Robinson 2005:41); “*I’m still out of breath*” (Arnold 2011:4). This reported synopsis of lack of benefit is perhaps suggestive of the belief that oxygen is curative. Borak et al. (1991) commented on some patients being convinced that they would return to an active life as soon as their symptoms disappeared. This can be related to disappointment which results from a lack of alleviation of symptoms and may be linked to patients’ belief that oxygen has curative qualities. Unrealistic expectation with regards to prognosis perhaps highlights a fundamental lack of knowledge and understanding. Additionally, disillusionment with lack of efficacy may lead to poor compliance.

The sub-theme *Hopelessness and Existing* is found in six papers and further amplifies the struggle patients have accepting oxygen therapy as a beneficial adjunct (Doi, 2003; Borak et al., 1991; Adams, 2008; Kampelmacher et al., 1998; Robinson, 2005; Wrench, 2012). Doi, (2003), reporting a questionnaire survey in Japan assessing psychological impact of chronic respiratory disease (n=144), found four factors: '*hopelessness*'; '*burden and misery*', '*denial against oxygen*' and '*dependency and anxiety*'. The aim of the analysis was to identify negative emotions which subjects had about oxygen therapy and, as such, patients were asked to score against pre-determined phrases such as '*feel miserable and rather die*'. Clearly these negative undertones in responses could bias the patient's attitude whilst completing the questionnaire. Nonetheless the findings demonstrate that these negative emotions exist and care should aim to counter these.

Adams (2008) evidenced patients' *loss of self* and *existing* together with feelings of grief: "*I just thought I'm not the same person as I used to be and I'm not going to be able to do the things I used to do*" (p22). Likewise Kampelmacher et al. (1998) reported 505 of the 528 patients in their survey complained of restricted autonomy. This loss of ability to govern one's own life and actions seems to be an internal struggle with patients striving to accept oxygen, which potentially leads to restriction, loss of independence and reduced activity.

In an attempt to adjust and accept oxygen patients appear to have an innate struggle, suffering disappointment and hopelessness if oxygen does not meet expectations: a situation that often leads to a state of existence rather than living. False hopes regarding the curative nature of oxygen manifest in disillusionment, compounded by grief for loss of previous health, all of which have implications for compliance when expectations are not met.

Restriction: social isolation, frustration and complaints

Restriction seems to stem from issues of *social isolation, frustration* and *complaints* regarding the physical inconvenience of oxygen. In contrast to the theme of enabler, but with a similar occurrence (26 citations), many studies reported patients regarding oxygen as restrictive (Jaturapatporn et al., 2010; Lai et al., 2007; Reinke et al., 2008; Doi, 2003; Ring and Danielson, 1997; Cornford, 2000; Goldbart et al., 2013; Arnold et al., 2011; Williams et al., 2007).

Lai et al. (2007) reported half of advanced lung cancer patients felt oxygen was burdensome or restrictive, but as discussed previously this may be reflective of more options available in the Chinese culture, and would certainly influence its use in the terminal phase of illness. Reinke et al. (2008) add to this dimension reporting activity limitation and functional decline as one of their main themes. Mostly related to disease in general, one verbatim quote captured the added insult that oxygen can have with regards to mobility: *“I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops – it’s like you are on a leash, tied to a regimen”* (p606). Williams (1993:103) quotes *“tied to that machine”* when referring to alterations in patients’ social life, recreation and pastimes. The physical burden of oxygen therapy as a portable device, and especially in relation to weight, is referred to by Doi (2003) as a contributor to decreased mobility, especially for an emaciated body, leading to rejection of oxygen therapy. Williams (1993) further discusses the *‘loss of spontaneity’* experienced by patients with chronic disability, compounded by the addition of oxygen therapy.

Cullen and Stiffler (2009) in their review identify the theme of *‘living in a restricted world’* in which they cite Ring and Danielson’s (1997) theme of *‘restricted*

to time and space'. They discuss reduction in activity and isolation that can interfere with lifestyle. Trying to include 15 hours of oxygen per day involves developing a pattern of use that sometimes can lead to non-compliance as patients rationalise its use while negotiating lifestyle. Reference to stigma and guilt further extend restriction which could inevitably lead to, or compound, social isolation; a dominant theme also referred to by Crocket et al. (2006).

Adams (2008) discussed the restrictive nature of oxygen '*as an enabling paradox*' reporting that although oxygen enabled participants to do more, it was often considered inconvenient (p17). Apart from physical restrictions patients make reference to restricted autonomy (Kampelmacher 1998) and feelings of frustration: "*This thing [the oxygen tubing] was cutting into my ear – this stupid thing here...it twists, twists, twists. I untwist it and it gets twisted again!*" (Roberts et al., 1993:315). The patient's frustration is clearly evident as he weighs up benefits versus inconvenience.

Earnest (2002) considered the patients' perspective of adhering to supplemental oxygen therapy. The findings focused on patient reported barriers, including physical difficulty, self-consciousness, lack of perceived benefit, fear of side effects and a sense of social stigma. Interestingly, although lung function and quality of life (utilising a validated respiratory specific tool) were measured, no comment on blood gas levels was reported, therefore findings cannot be related to physiological requirements. Cicutto and Brooks (2006) further reported specific barriers to use of oxygen, namely aesthetics (13%) and apparatus too cumbersome (20%). Cornford (2000) similarly reported noise and inconvenience of the cylinder as a restriction of activities. Issues such as these must contribute to compliance and adherence.

Oxygen therefore can be seen as an irony to enablement with the main issues of physical side effects, restriction in terms of reduced mobility, and changes to daily activities, all leading to inevitable consequences of isolation. Reporting of the notion of oxygen as 'restrictive' in considered studies is prevalent, and therefore represents a significant finding.

Embarrassment: attitude of others; changing body image; shame and guilt.

Subthemes of *attitude of others*, occurring in six papers; *changing body image*, seen in five papers; *and shame and guilt*, six and three papers respectively, contribute to the overarching theme of *embarrassment*.

Attitude of others appears important. Ingadóttir and Jósðóttir (2006) in an Icelandic study interviewed six patients utilising LTOT and non-invasive ventilation and their carers. An IPA study, identified themes related to dependence on oxygen and the ventilator. One theme recognised patients as '*wanting to be seen as healthy*'. The use of therapy in public, or even the notion of somebody knowing that they use it, threatened their image of themselves as healthy persons. One patient quoted: "...*I dislike when people stare at me. They definitely think that I have been smoking myself to death...*" (p22). In the published poster by Crockett et al. (2006) '*embarrassment*' was recorded as one of the most common themes when patients were asked to describe the impact of oxygen on their life.

This relationship between embarrassment, shame and guilt can be further typified when patients refer to changing body image: "*Well I do get a bit embarrassed to be quite honest with you, particularly with strangers*" (Williams 1993:112). Further reference to patients' feelings of fraud and oxygen legitimising their sick role raises a possibility that using oxygen helps patients to dispel shame and guilt (Williams,

1993). Patients with chronic respiratory disease are often severely disabled by their breathlessness yet can appear, at rest, in good health.

Doi's (2003) findings refer to '*the negative body image*' (p996) in association with lower activity scores in LTOT patients. Borak et al. (1991) report that loneliness, old age, and poverty, compound problems, and reported low self-esteem in all 48 hypoxic patients on LTOT, relating this to influencing factors such as decreased activity and lack of social interaction.

Earnest (2002) discusses the '*conspicuous nature*' of oxygen; one that '*advertises*' illness: a '*public*' therapy. A finding endorsed by Williams et al. (2007) who noted that oxygen made patients' illnesses '*visible*'. Interestingly Adams (2008) noted that most patients, when interviewed, did not wear oxygen and the concentrator was out of sight.

The myriad of negative emotions captured under the themes of *fear*, *oxygen versus self*, *restriction* and *embarrassment* seem to culminate in a profound sense of grief and loss for some patients, including a loss of identity and loss of power to change (Earnest, 2002). These feelings ultimately lead to acceptance and a sense of patients having to *put up with* oxygen. Fear of dependency appears to subside as patients strive to come to terms with oxygen and, in some cases, accept it as a penance.

Impartiality: Mixed blessings

In total this middle ground is reported less than either positive or negative perceptions (a total of 16 occurrences) but nonetheless contributes significantly to the narrative.

Whether perception of oxygen as a *mixed blessing* develops from a need to adapt, or conflicting views and beliefs, or a lack of knowledge, is unclear within the literature. Either way it appears that facets such as *adaptation; compromise and trade-off*, and *knowledge and understanding* contribute to patients' acceptance of the need for oxygen and seeming impartiality.

Mixed Blessings: Adaptation, Compromise and Knowledge and understanding

Earnest (2002) refers to physical *adaption* such as rigging vehicles with oxygen to enable fishing trips; running oxygen lines upstairs and ways of mobilising equipment. When Ring and Danielson (1997) refer to '*living in one's own life rhythm*' (p341) they discuss patients knowing their own bodies and how to handle special situations, and working at their own pace. Cullen and Stifler's (2009) meta-synthesis identified the theme '*adapting oxygen to life's circumstances*' (p144); this finding was based on the identification of patients rationalising oxygen while negotiating the interference with lifestyle. They refer to the influence of individual health beliefs on driving the rationale for use and preferences for administration.

Robinson (2005) considers adaptation as a need for *compromise*, claiming that patients in their study adopted a '*put-up-and-shut-up*' (p42) attitude. Jaturapatporn et al. (2010) also refer to patients' willingness to compromise; one patient quoted: "*I am willing to put up with the nuisance for the benefit of oxygen*" (p767-768). A recognised bias in these studies is the exclusion of patients not currently using oxygen; a population who may not have been willing to *put up with* or adapt.

Ingadóttir and Josdóttir (2006) use the term '*mixed blessings*' as a major theme. Patients make reference to purposefully developing an optimistic view of

therapy, probably as a *trade-off* for inconvenience. A similar compromise is seen in Cornford's (2000) qualitative study of lay beliefs of 24 patients receiving oxygen; one patient quoted their '*respect*' for oxygen, reporting limiting usage to preserve effect. This may be another subliminal attempt to *trade-off*, legitimising the limitation of oxygen through belief that efficacy will be conserved.

The literature depicts how patients find tactics to adapt to oxygen therapy in countless ways including physical, social and, sometimes, psychological compromise. The reasons why some patients adapt better than others remains obscure. Health beliefs appear to influence compromise and adaption, but this facet clearly needs further exploration.

The final sub-theme regarding *mixed blessings* is *knowledge and understanding*, included in the domain of middle ground because it appears as neither a positive nor a negative aspect. Although this review has already alluded to education as potentially improving compliance, it is not necessarily evident that this is a positive issue for patients. Likewise it has been discussed that a lack of knowledge and understanding about oxygen – related to both not having it and, if patients had it, when they should use it – adds to fear and anxiety connected to breathlessness. It is also apparent that health beliefs of individuals may play an important part in the ways they use and adapt to oxygen. Although Cornford (2000) sets out to explore health beliefs the themes found [*restrictions and their mastery; oxygen: a means to maintain mastery; oxygen: concerns about being mastered*] referred more to practicalities than beliefs regarding how or what the oxygen does.

Neri et al.'s (2006) Italian survey tried to uncover beliefs regarding patients' understanding and knowledge of LTOT. The results reported that 51% understood

that oxygen was given for low blood oxygen levels, whilst 38.5% believed it was for dyspnoea. The authors discuss PaO₂ of patients, stating that 25% had a PaO₂ > 8kPa at the last follow-up visit (a level higher than the minimum level to meet criteria); it is not clear however how this related to understanding of rationale for use. A patient's understanding of why they are prescribed a therapy must surely influence their compliance and concordance.

Berg (1996), interviewing seven patients with transtracheal oxygen therapy identified '*failure to name*' as an unexpected theme. Despite the fact that patients were finding therapy helpful they referred to oxygen as "*it*", "*the thing*" or "*you know*" (p38). Berg identifies this serendipitous finding as unique within the literature; a statement that still holds true as patients' understanding of oxygen remains elusive.

Cicutto and Brooks (2006) add a further dimension to this debate when considering the value of healthcare professional instruction regarding oxygen therapy. Fifty-seven percent of the 353 Canadian COPD patients identified the most common motivator to use as '*their healthcare provider told them to do it*' (p1543). This was a survey of COPD and self-management strategies more generally, and the demographics did not reveal how many patients were receiving oxygen or what their blood gas status was. Nonetheless the faith that patients have in professionals caring for them is interesting and probably impacts upon patients' acceptance of therapy.

The significance, or the blind faith, that patients have for professionals caring for them has already been recognised as making patients *feel safe*. Additionally, this probably impacts on patients' acceptance of the therapy and need for education and understanding. A further aspect to this is patients' anxieties and fears, as identified

following discharge from hospital, associated with uncertainties regarding provision of oxygen therapy (Gruffydd-Jones et al., 2007). Patients' perceived that oxygen was needed following hospitalisation, but were uncertain why it hadn't been provided or, if it had, when they should use it. Further commentary regarding patient misinformation and unrealistic levels of expectation is apparent, with patients not always prepared for withdrawal of oxygen if necessary (Eaton et al., 2001). This lack of knowledge and understanding can be related to the need for, or lack of, improved education.

Peckham et al. (1998) demonstrate a beneficial effect of education on compliance which could, in effect, increase potential efficacy for those meeting criteria for LTOT. In this quasi-experimental UK-based study researchers identified that patients (n=86) who received education following LTOT prescription had a better understanding (93% intervention group and 41% in control) of why they needed oxygen and showed better adherence to prescription regimes. Education clearly impacts on patients' understanding, and, ultimately, perceptions of oxygen.

The over-arching theme of mixed blessings seems to portray the necessity for patients to accept therapy in order to adapt and reap benefits. Oxygen becomes part of patients' lives and in order to accept it there appears to be compromise between the positives and negatives. Health beliefs probably play an important role in this acceptance, however what these beliefs are, and how they influence an individual's ability to adapt, remains elusive in the literature.

Discussion (Patients' Perceptions of Oxygen Therapy)

Although few studies specifically addressed the review question, data extracted from existing literature allowed illumination of patterns and construction of synthetic arguments concerning patients' perceptions of oxygen.

For many patients oxygen is regarded as a positive therapy, a life-giving intervention, although it is not clear whether this arises from patients' expected benefits, or faith in HCPs. *Obeying* the doctor has been found in other studies exploring attitudes towards oxygen (Langton et al., 2012) and may be a reflection of the culture that regards doctors as superior and eliciting a power over patients. Juxtaposed to giving life, patients relate to removal or denial of oxygen as a sign of impending death. This finding may be relevant regarding why patients are often considered to *demand* oxygen or resist removal of established therapy.

As far as patients understand, oxygen is commonly given for relief of dyspnoea. Lack of rationale for oxygen prescription is apparent throughout the literature and makes it impossible to judge whether individuals physiologically require oxygen, or not. For some, oxygen helps to control dyspnoea but whether this is as a result of the sensation of air flow (Schwartzstein et al., 1987; Liss and Grant, 1988), cessation of exercise, or a placebo effect, is unclear. Studies have shown that compared to room air there are no additional benefits of oxygen for the palliation of dyspnoea (Abernethy et al., 2010). A Cochrane review (Uronis 2011) of the efficacy of oxygen for symptomatic relief likewise gives no firm conclusions.

Although physiological benefit for hypoxaemic patients cannot be disputed, for normoxic patients there appears to be an additional placebo effect (Abernethy et al., 2010). Interestingly Roberts et al. (1993) noted that although several patients in their

last year of life were taking morphine or an anxiolytic, none believed that these had been prescribed for relief of dyspnoea, highlighting patients' pre-conceived ideas regarding the rationale for treatments and resultant expectation.

The rationale, as perceived by the patient, for commencing oxygen therapy could have a bearing on their expectation. How patients build their expectations remains unclear, but it has been suggested that unrealistic expectations need to be reduced in order to encourage adherence (Arnold et al., 2011). It would seem logical that oxygen given to a breathless patient could lead to relief of breathlessness; a self-fulfilling prophecy perhaps. Conceivably this is further evidence of patients' faith in HCPs or it could be that mastery itself reduces anxiety by allowing control over symptoms. Expectations do seem to contribute to the culture that exists regarding the use of oxygen for dyspnoea.

Oxygen for some is a marker of disease severity, often synonymous with palliative care and death. Oxygen is a visible therapy and for some it legitimises the sick role (Williams, 1993) making visible an otherwise imperceptible illness. Harrison et al. (2014) identify a similar concept in a meta-synthesis exploring patients' responses to acute exacerbations of COPD. They identified that by making breathlessness visible to others, patients could communicate the seriousness of their condition. Contrary to this finding embarrassment also appears significant, closely related to shame and guilt through aesthetics, and often related to issues such as smoking. In this respect oxygen use in public is perceived as a stigma, a display of their sick bodies, and may, for some, be regarded as a penance.

This current review has identified perceptions that may contribute to poor compliance; this has been discussed elsewhere (Eaton et al., 2004; Cullen et al.,

2006). Disillusionment with the lack of efficacy is one such aspect, seeming to relate to the belief that oxygen has curative qualities and that disappointment results from a lack of alleviation of symptoms. This could demonstrate an unrealistic expectation with regards to prognosis and perhaps highlights a fundamental lack of knowledge and understanding. Fear of addiction and dependency may also feed into these perceived negative associations.

Fear as an over-arching theme is a multifaceted concept with regards to oxygen. Previous experiences of others are clearly significant, and probably on occasion well founded. Fear of what oxygen symbolises in respect of disease progression and potential for addiction seems a powerful negative emotion which may ultimately impact on acceptance and compliance.

Oxygen is shown as an irony to enablement. In this context it reveals itself as a therapy that is not totally benign and often requires compromise, potentially propagating reduced physical activity and increased social isolation; a situation that so often self-perpetuates in the familiar downward spiral for patients with chronic respiratory disease.

Education is undoubtedly important and has potential to influence not only patients' knowledge and understanding, but also their perceptions (Godoy et al., 2012). Knowledge and understanding appears central but remains obscure; there seems an inability for patients to articulate the rationale or therapeutic benefit of oxygen. Whether use of medical terms and jargon, the patient's inability to understand physiology, or whether information is regarded as unimportant, merits further investigation. Many patients may have stopped using oxygen through choice,

rejection or removal; the views and opinions of this group are not evident in the published literature.

Patient perceptions of oxygen therapy demonstrate a paradoxical narrative with oxygen as an analogy with life and death, an enabler and restrictor, and something to flaunt or hide. The ambivalence that manifests, then further develops to a stage of acceptance for some, but not all, patients. There appears uncertainty from patients regarding the purpose of oxygen: whether it is to relieve symptoms or enable them to live. Faith in the healthcare professional endorsing oxygen nevertheless seems incontestable.

Overwhelmingly patients perceive oxygen as a positive therapy but the findings from this review demonstrate that negative perspectives also exist and suggest that care should aim to counter these. The impact of oxygen on individuals and their carers is not insignificant, and the common belief that it is a benign therapy needs to be dispelled.

3.5.2 Healthcare Professionals' Perceptions of Oxygen Therapy

In contrast to the reasonably well-documented patients' perception of oxygen therapy, literature pertaining to perceptions from healthcare professionals' perspective is very limited. The final sift identified 17 papers, 4 of which were excluded at quality appraisal (Figure 6, page 86). The reasons for exclusion, together with references of papers, are outlined in Appendix E. Three of these papers (Neri et al., 2006; Reinke et al., 2008; Roberts et al., 1993) were also included in the review of patients' perceptions bringing the total of included studies to 13. The number of participants in each study ranged from 12 to 1504, reflecting heterogeneity of design and methods. Quality appraisal scores ranged from 21

(poor) to 35 (good) out of a maximum score of 40. Four papers in total scored < 30 however only one scored < 25. The remaining nine papers scored > 30, equating to 'good' with regards to methodological quality. The final selection of 13 papers related to HCP perception, together with summaries of critical appraisal is presented in Table 5.

Table 5: Study Characteristics: Health Care Professionals' Perceptions

Author/Year	Methodology	Context	Participants	Focus of Study	QA	Relevance & Supporting Evidence
Abernethy 2005	Survey	Australia & N. Zealand	214 physicians	Pilot to define clinical efficacy of palliative O ₂	21	Outlines most frequent reason for prescribing oxygen as retractable dyspnoea. Majority believed oxygen was beneficial.
Atiş et al. 2001	Q survey	Turkey	379 physicians	Characteristic/compliance of LTOT patients	26	Relates education (from a physician) to increased compliance 33.2% patients told to use oxygen only when breathless.
Austin et al. 2010	RCT	Australia	HCPs, number not stated 405 patients	High flow versus titrated oxygen	30	Finding post-trial deviation from protocol: Alludes to attitudes and culture but no empirical data to support.
Barr et al. 2005	Survey	USA	1051 primary care physicians	Patient and physician perception of COPD	32	Symptoms as criteria for prescribing.
Breaden et al. 2013	Qualitative – focus groups	Australia	7 focus groups across 3 Australian capitals 51 palliative care nurses	Clinical and social dimensions of prescribing palliative home oxygen	35	Relevant to current study exploring factors that influence Australian specialist palliative care nurses. Consideration of burden, managing expectations of family, carers and other HCPs
Considine & Botti 2006	Quasi-experimental	Australia	20 Registered nurses	Effect of education on clinical decisions	33	Effect education on clinical decision making in emergency O ₂ Some changes in management post intervention/ other aspects of assessment no change.
Considine et al 2005	Quasi-experimental controlled	Australia	88 emergency department nurses	Effect of education on knowledge	32	Education increased knowledge; increased knowledge was a predictor of independent decision making.
Glaab et al. 2006	MCQ mail survey	Germany	845 physicians	Compliance to guidelines	25	Limited discussion of knowledge of effect on survival towards respiratory specialists.
Neri et al. 2006*	Survey	Italy	1504 pts & physicians. Pts LTOT >6 months	Behaviour & knowledge regarding O ₂	31	Mostly relates to compliance. Two questions relevant: perception of improvement; why prescribed, 38.5% believed it was for dyspnoea. Exact rationale for prescription unclear.
Pepin et al. 1996	Q Survey	France	310 physicians	Daily use of oxygen in COPD LTOT patients	35	Evidence of poor compliance to prescription criteria and inconsistent education – related to patient compliance.

Reinke et al. 2008*	Grounded theory	USA	84 physicians / 55 pts O ₂ dependant	Comparison perceptions re. transition of illness	31	Very limited, regarding transition of illness mainly. O ₂ seen as a restriction, O ₂ a sign of deterioration.
Roberts et al. 1993*	Mixed methods	Canada	10 late cancer patients/12 nurses	Dyspnoea last year of life – patients & nurses perspective	33	Limited to 2 relevant points. Patients' frustration. From nurses the psychological benefit is acknowledged: for patients, carers & HCPs. 66% used O ₂ as a measure for alleviating dyspnoea.
Stringer et al. 2004	Telephone survey	Canada	21 physicians	Prescribing practices of palliative oxygen	28	Variable practice attributed to lack of evidence and guidelines in palliative care. Ambivalence/uncertainty.

* *Studies also included in the review of Patients' Perception*

The same hybrid quality appraisal/data extraction sheet (Appendix C) was utilised and papers were selected primarily on relevance rather than strength of methodological quality. Papers were read and re-read for emerging themes. Findings were more limited for healthcare professionals due to the paucity of evidence; overarching themes reflected this with only three major themes identified. These themes were: *oxygen for symptom control*; *levels of knowledge and understanding*; and *oxygen as a therapy for healthcare professionals*. The occurrence of these themes in the literature is summarised in Table 6. Additional information relating to occurrences of themes can be found in Appendix G.

Table 6: Synthetic Constructs and Number of Occurrences

Synthetic Construct	No. Of Studies
Oxygen for symptom relief	7
Knowledge and understanding	7
Oxygen as a therapy for HCPs	4

In addition, Table 7 shows illustrative verbatim extracts from the qualitative studies representing the ‘voice’ within the literature.

Table 7: Grid of Themes and Representation from the Literature – Healthcare Professionals

Major theme	Representation from the literature
Oxygen for symptom relief	Abernethy (2005) e-mail survey of 214 physicians showed that palliative care physicians were more likely to prescribe palliative oxygen (29% vs. 9%, $p=0.009$) and that the most frequently (65%) cited reason for prescribing was ' <i>intractable dyspnoea</i> '.
	Roberts et al. (1993) mixed methods study of 10 palliative care nurses showed 66.7% reported using oxygen as an intervention manage their breathlessness.
	Barr et al. (2005) large survey of 1051 physicians found 51% of GPs and 10% of respiratory specialists thought that presentation of symptoms was additional criteria for prescribing oxygen therapy.
Knowledge & understanding	Atiş et al. (2001) survey reported that only 58.3% of patients were educated by a physician about oxygen therapy at the beginning of treatment.
	Considine et al. (2005) demonstrated oxygen administration was improved as a result of education and that increased knowledge was identified as a predictor of independent decision making.
Oxygen as a therapy for HCPs	" <i>The initiation of oxygen therapy was just one more therapy that might help</i> ". (Reinke et al., 2008:606)
	" <i>I often feel that nurses do it for themselves...because we're doing something...It's a major thing to do</i> " (Roberts et al.'s, 1993:317)
	Austin et al. (2010) RCT demonstrated 37% non-compliance to study protocols by paramedics, feedback suggested concern regarding insufficient delivery of oxygen in distressed patients as the reason for non-adherence to protocol, and referred to the common conception that ' <i>more is better</i> '.

Oxygen for symptom relief

The notion of HCPs perceiving oxygen to relieve breathlessness was common in the literature and appeared in half the considered papers. Abernethy (2005) published results of an e-mail survey of 214 physicians (93 palliative care physicians, 121 respiratory physicians). Primarily intended to define the necessary duration of a clinical efficacy study regarding palliative oxygen therapy, the survey captured habits of prescribing oxygen therapy for palliative care including frequency and indications. Findings showed that palliative care physicians were more likely than respiratory

physicians to prescribe palliative oxygen (29% vs. 9%, $p=0.009$), and that the most frequently (65%) cited reason for prescribing was '*intractable dyspnoea*'. Despite a low response rate (33%), the survey demonstrates that the majority of responding clinicians believe oxygen relieves dyspnoea.

A telephone survey of physicians' (n=21) prescribing practices of palliative oxygen reported variability in those practices, attributed to both a lack of evidence and clear guidelines (Stringer et al., 2006). Based on hypothetical scenarios, physicians were assessed in response to specified cues. Cluster analysis revealed three patterns of response: those who prescribed in the presence of hypoxaemia regardless of symptoms; those who prescribed only when both hypoxaemia and symptoms were present and those prescribing for breathlessness alone. Adding a 'dummy factor' of the effect of spousal concern revealed an increased tendency to prescribe, probably related to expectation from carers and perhaps patients. Ultimately the study, although a small sample, demonstrated that uncertainty and inconsistency exists when physicians are faced with the decision whether to prescribe oxygen to palliative care patients. The paper's authors suggest that this may be a reflection of inadequate understanding of pathophysiology and treatment, and that decisions to use oxygen are often based upon individual past experiences and biases.

Roberts et al. (1993) studied the experience of dyspnoea in the last year of life. The mixed methods study of ten patients with late stage lung cancer, and twelve nurses providing their care, investigated the phenomenon of dyspnoea, as experienced during the last weeks of life. A triangulated approach included patient self-report survey, chart audits (to record incidence and management of dyspnoea) and patient and HCP interviews. Of ten patients interviewed seven recalled no

suggestions made by the nurse regarding how to manage their breathlessness, although eight nurses reported using oxygen as an intervention. The study revealed an inconsistent understanding: with reference to oxygen therapy some nurses reported that it was helpful and that it should be ordered as soon as dyspnoea was apparent, whilst others claimed that although it wasn't '*clinically therapeutic*' they believed it had a '*symbolic benefit*' (p317). Several nurses' opinions were that oxygen provided psychological comfort to both patients and their families; whether this notion can be extended to HCPs themselves will be explored later.

Barr et al. (2005) recorded patient and physician perceptions of COPD in a large survey (1050 physicians, 1023 patients) in the USA. The main focus was COPD, but in relation to oxygen therapy physicians reported confusion regarding treatment options: 51% (n=523) of GPs and 10% (n=527) of respiratory specialists thought prescribing oxygen for dyspnoea with normal blood oxygen levels was permitted.

Adding to the synthetic construct of *oxygen for symptom relief*, a Turkish questionnaire survey aimed at exploring issues of compliance of LTOT by patients (n=379), provides some insight into the messages that HCPs provide (Atiş et al., 2001). Thirty-three percent of patients were told only to use oxygen when they were short of breath. Although limited by the response rate (34.5%) and its geographical specificity (in Turkey patients purchase their own oxygen), this study adds to the elusive, but anecdotally common, HCP belief that oxygen therapy relieves breathlessness.

A more recent qualitative study highlighted awareness that oxygen is no longer the first response to breathlessness is growing, and the importance of trying

other approaches such as fan therapy was recorded (Brearden et al., 2013). This study aimed to understand factors that guide Australian specialist palliative care nurses when initiating or recommending oxygen. Much of the data related to geography and therefore was not applicable to the current review question, but other aspects were very relevant. One major theme related to managing expectations of families, carers and other health professionals. This was linked to the prolific use of oxygen in ambulances and initiation in order to “*treat the caregivers’ anxiety*” (p270). It was also on occasion given as a form of security to facilitate home death and prevent last minute transfer to hospital.

Levels of knowledge and understanding of HCPs

Half the papers considered made reference to HCPs’ knowledge and understanding of oxygen therapy. Glaab et al. (2006) undertook a national mail survey of 845 physicians (486 generalist and 359 specialists) in Germany to investigate compliance to guidelines when prescribing. Although primarily concerned with generic COPD guidelines there is some limited reference to oxygen therapy. LTOT was generally regarded as an effective measure for improving quality of life and symptoms, rather than prolonging life expectancy. The knowledge of effect on survival rate however was higher in respiratory specialists than generalists ($p < 0.0001$). Response rate though is a consideration with only 26.5% of primary care physicians returning completed surveys.

Atiş et al.’s (2001) survey further reported that 58.3% of patients were educated by a physician about oxygen therapy at the beginning of treatment; who from or by what means the rest, if any, received education is not clear. Logistical regression identified that the likelihood of achieving compliance increased 4.5 fold

(CI 2.27 – 9.13, $p < 0.001$) when education was provided. This relationship between patient compliance and level of education supported an earlier French study by Pépin et al. (1996), which surveyed 219 physicians and 564 LTOT patients, assessing compliance and prescribing practices. Although 87% of patients were prescribed over 15 hours per day of oxygen therapy (as reported by the physicians) only 45% received over 15 hours therapy. Again, logistical regression showed that patients receiving a follow-up education session found an increased likelihood of receiving effective treatment 4.5 fold (CI 2.3 -9.1). The study concluded that supplementary education regarding LTOT, given by a nurse or physiotherapist, was an important factor for increasing the patients' compliance to therapy.

Considine et al. (2005) demonstrated that use of supplemental oxygen was improved as a result of education of HCPs in acute settings, and that increased knowledge was identified as a predictor of independent decision making. The quasi-experimental design set out to test assumptions that an increase in nurses' knowledge ($n=88$), through a self-learning package, improved clinical decisions, though a lack of randomisation and control limits the findings. Pre-test scores were comparable ($p = 0.091$) whilst post-test scores between the pre and post-test groups showed a statistically significant improvement (19.31 ± 3.56 vs 13.05 ± 3.76 ; $p = < 0.001$). Eighty-seven percent of nurses in the study reported making clinical decisions about oxygen therapy on a daily basis (91% of those decisions were autonomous). The calibre of these decisions clearly has potential to influence patient outcomes, and therefore it is important to consider factors that influence acquisition of knowledge.

A further study by the same Australian group (Considine and Botti, 2006) studied specifically the effect of education on clinical decisions regarding emergency

oxygen therapy. Utilising a similar design this smaller study of 20 emergency department nurses tested nurses' decision-making skills, rather than knowledge, following completion of the educational intervention. The results from this study were variable with some changes in management of hypothetical patients seen, in particular device selection, but in other aspects (for example the parameters used for assessment) no change was demonstrated. The authors suggest that factors other than knowledge may influence clinical decisions. What these factors are remains obscure and warrants further research.

Brearden et al. (2013) highlighted an increasing knowledge in palliative care nurses regarding the limitations of oxygen, but this was linked to an apparent tension when considering other factors such as family attitudes and requests for oxygen. The authors relate to recent empirical findings, suggesting that there is now a '*permission not to give oxygen*' (p272).

Oxygen as a therapy for healthcare professionals

The synthetic argument of *oxygen as a therapy for healthcare professionals* is probably the most ambiguous construct. Nonetheless it is evident in four of the reviewed studies that such a notion exists, and seems a familiar explanation for common prescription of oxygen for non-hypoxic patients. Relating to patients' fears and restrictions with palliative oxygen, Reinke et al. (2008) (though very limited in its reference to HCPs) refers to physicians' recognition of oxygen therapy as a milestone in a patient's condition; one physician stating: "*The initiation of oxygen therapy was just one more therapy that might help*" (p606). This quote seems to epitomise the often felt frustration of healthcare professionals regarding management of intractable dyspnoea.

Roberts et al.'s (1993) mixed methods study of lung cancer patients' experience of the last year of life draws on this idea further. With reference to oxygen providing palliative comfort to keep patients at home and 'happy', one nurse wondered whether the psychological benefit of oxygen was as relevant to patients and families as it was to nurses. *"I often feel that nurses do it for themselves...because we're doing something..."* (p317).

This rare recording of an anecdotally common perspective gives potential insight into HCPs' rationale for prescribing or recommending oxygen therapy. This revelation seems to be elusive with regards to variability and inconsistencies of oxygen prescription, and would support Considine and Botti's (2006) idea that factors other than knowledge and education influence clinical decision making.

A further tentative reference to oxygen being given to relieve HCPs' need to help patients manage dyspnoea, and the possibility of an entrenched culture, is alluded to by Austin et al. (2010). This well-designed and conducted RCT set in Tasmania, Australia, tested outcomes in relation to high-flow versus titrated oxygen in pre-hospital care of COPD patients. The main findings from this landmark study demonstrated that titrated oxygen significantly reduces hypercapnia, respiratory acidosis and mortality. The researchers however discovered a lower than expected adherence to study protocols. Of the 214 patient records, 37% showed that received treatment did not comply with study protocols (56% in the titrated arm and 21% in the high flow arm). In the titrated arm all violations involved administration of high flow oxygen at some point in pre-hospital care. The authors muse that this is probably a result of entrenched culture and training in emergency medicine. Chart reviews found no evidence of equipment malfunction, requests from patients, or lack of protocol understanding, but the authors report that feedback from some

paramedics indicated concern regarding insufficient delivery of oxygen in distressed patients, and referred to the common misconception that “*more is better*”. This study is potentially important in that it exposes, intangibly, a culture and the need to explore and substantiate the reasons why this exists is manifest. Although fundamentally relating to efficacy and detrimental effects of oxygen in acute settings, existence of persistent beliefs and entrenched practices is apparent.

The literature pertaining to perceptions from healthcare professionals is very limited but from what little evidence is available there appears to be a persistent belief that oxygen is useful for management of dyspnoea. There is also some degree of evidence that using oxygen for patients in such a way assists HCPs, and has the potential to offset guilt and frustration at not being able to help patients.

DISCUSSION (HCPs’ Perceptions of Oxygen Therapy)

Inconsistency of reported beliefs, understanding and variations in clinical practice, even among respiratory specialists, dominate this limited sample of empirical evidence. The reasons for inconsistency regarding indications and use of oxygen have been cited as a lack of clear guidelines, endorsed through the obscure nature of lucid information and directives.

It is apparent from the literature that education of healthcare professionals is important and that education given to patients has potential to improve compliance, and therefore, hypothetically, clinical effectiveness. The relationship between knowledge and clinical practice is clear. Transfer of this knowledge to patients is part of the therapeutic relationship, but it can be contested as being beneficial if that knowledge is not grounded in evidence, but rather in misplaced beliefs and misconceptions. Clearly education of patients is central to understanding the therapy

(and consequently compliance) but fundamental to that must be the knowledge and understanding of HCPs themselves. It is suggestive that the *faith in* HCPs that patients have, on occasion, may be poorly placed.

Overuse and misunderstanding of oxygen therapy by healthcare professionals has been alluded to in other literature (Downs, 2003; Troosters, 2004; Calverley, 2000; New, 2006; Tin, 2002), however there is very little proof to verify this and a dearth of empirical evidence to substantiate why these misunderstandings appear to be so prevalent amongst healthcare professionals. It is often cited that a culture exists whereby oxygen is given automatically to patients who present critically ill or breathless (New, 2006; BTS, 2008; Austin et al., 2010). It appears that this culture may be deep-seated and may in fact be so ingrained that it actually provides relief for HCPs themselves, as they feel they are doing 'something'.

The literature review overall offers some, albeit limited, insight into inconsistencies of oxygen prescription and administration, the importance of education and its potential relationship to clinical efficacy, and a glimpse of a culture and an innate response that may be obstructive to HCPs practicing evidence-based care.

3.6 SUMMARY

The literature renders a tentative insight into patients' and HCPs' perceptions of oxygen therapy. The narrative is at times divergent, uncovering contradictory views. There appears to be an uncertainty amongst both patients and HCPs with regards to the purpose and proposed benefits of oxygen therapy, though an underlying faith in healthcare professionals is apparent. This faith seems to foster

acceptance of a life-changing therapy, despite impact, burden and incomplete understanding.

It is interesting to note that overall the methodological qualities of studies pertaining to healthcare professionals are poor, with an over-reliance on survey. The rudimentary survey approach to gathering information can overlook the more deep-seated roots of beliefs, culture and practice which may inform seemingly resistant adoption of evidence-based practice in relation to oxygen.

The renderings presented here may uncover the extent and potential causes of misconceptions regarding oxygen therapy, so that recommendations to address these can be made. Healthcare professionals can be considered to have immense power over patients' lives in what they prescribe and advocate. With the possibility that perception is shaped by several influences including media, knowledge, cultural, historical, professional, and societal, these factors appear vague in the literature but should not however be disregarded as potential sources of antecedents.

From the literature it can be deciphered that knowledge affects clinical practice with regards to oxygen therapy, yet practice is not always influenced by education. It appears that it is difficult, even in a controlled experimental situation, to rise above deep-seated beliefs, especially when a patient is struggling to breathe. Yet, in order to improve practice, with regards to safety and efficacy of oxygen, these beliefs and cultures need to be challenged.

Although some enlightenment has emerged from this review there is a lack of tangibility and verification, and the need for further research regarding these elusive perceptions is supported.

3.7 STRENGTHS AND LIMITATIONS OF THE REVIEW

The high sensitivity of the initial search could be considered a strength of the review. Incorporation of participants' voices is a further strength, allowing an idiographic approach and verification of the interpretative account. The authorial voice is key to interpretations, and whilst drawing upon personal experience and pre-conceived ideas, can be considered a threat to impartiality; alternatively it can be argued that the level of insight brought to the review through expertise was the fulcrum to synthesising constructs and true to CIS.

Quality of the write-ups themselves was an inherent weakness, with many studies not being well described and methods of analysis not always explained. This issue of poor quality in write-up, as opposed to poor quality of methods, has been identified by other authors (Hawker et al., 2002), and lack of methodological detail can potentially jeopardise the whole review as a result of poor quality data being incorporated into the final synthesis. In addition data was, on occasion, extracted from the discussion rather than primary data; this could be considered speculative as the researcher is trying to make sense of data that has already been analysed and interpreted, thus further distancing the reader from the raw data.

Material selected displayed heterogeneity, being based on differing philosophical and scientific assumptions. This lack of similarity could be considered a weakness of the review, but alternatively it may be a strength, resulting in an eclectic selection, necessary with scarcity of directly relevant studies.

Single author data extraction could be regarded as a weakness, although independent member quality checks of a sample of papers did go some way to address this. Additionally, despite considerable rigour with the search strategy,

several additional relevant papers were identified via snowballing that had not been located through conventional means. This suggests that not all pertinent literature has been sourced and therefore relevant omissions from this review may exist.

Quality assessment was good overall but this was influenced by inclusion of utility which would bias results, since only papers that had something to add were included. With regards to hierarchy of evidence however, the vast majority of papers would be classed as low quality which would impact the grade of recommendation, had this been the sole purpose of the review. The review question itself favoured studies from the naturalistic paradigm and therefore it was unlikely that a large database of RCTs would contribute. Those experimental studies that were included were highly selected on the merit of containing some aspect of perception. As stated at the outset, the review's intent was to substantiate the research problem and provide a platform upon which to position the phenomenon of perceptions of oxygen, not to be definitive in its findings.

A further limitation was the exclusion of lay carers' perspectives. Additionally, General Practitioners (GPs), who are central to domiciliary oxygen prescribing in the UK, were absent in regards to recording their beliefs and perceptions. This is a gap in the literature that needs to be addressed.

Other identified gaps are lack of a clear correlation between hypoxia and perceptions. Most studies included patients on LTOT: few addressed normoxic patients' beliefs specifically, and when included they were grouped with hypoxic patients, making it impossible to extrapolate findings. This could be an important oversight.

Systematic review of the literature can be ultimately judged through achievement of its aim to answer a specific question; to reduce bias in selection and inclusion of studies, to appraise quality of studies deemed relevant and to summarise them objectively (Petticrew, 2001). Ultimately the purpose of this review was not to inform policy, nor even to inform practice (the paucity of data excluded this possibility), but to inform and give a foundation to this particular study through identification of what is already known/evidenced. This review has to some extent achieved this aim and has exposed gaps regarding what is known of the phenomena of perceptions of oxygen.

Dixon-Woods et al. (2006) suggests that reflexivity in CIS is important. Conscientious reflection on the utilisation of CIS included careful and repetitive consideration of the search strategy, study selection, data extraction and the process of synthesising both original data and the researchers' interpretations of this data, to produce synthetic constructs and subsequently synthesising arguments. The use of CIS itself opens the review up to criticisms of bias; however when considering the dearth of evidence available, any alternative approach may have resulted merely in a thematic summary of accounts as offered in the original literature, rather than in the context of the review question considered here.

The next chapter will outline the methodology and methods employed in the current study.

CHAPTER 4 – RESEARCH DESIGN AND METHODS

4.1 INTRODUCTION

The previous chapters have outlined the background of contemporary oxygen therapy, its physiological and historical roots and the scant empirical evidence that is available. These prologues have also highlighted problems and issues with oxygen therapy that exist and persist, despite the introduction of guidance and endorsement of a prudent approach. The reasons for these persistent beliefs, cultures and practices (for both patients and healthcare professionals) however remain elusive. Through the construct of synthetic arguments from available literature, some insight into the phenomenon has been uncovered, but this remains tentative. The need for research to explore existing beliefs and potential antecedents to ideas, was therefore established.

This chapter provides an outline of the theoretical approach taken to conduct the research and a justification of the chosen methodology. The specific methods employed in the study will then be detailed in advance of reporting findings in subsequent chapters.

4.2 METHODOLOGY

4.2.1 Theoretical approach

The nature of the research question itself, and paucity of evidence base available, directed the investigation towards a qualitative exploratory approach. Creswell (2014) suggests that qualitative research is a means to explore and understand the meaning that individuals or groups ascribed to a social or human problem. The philosophical worldview adopted for the proposed study is that of a

social constructivist perspective. According to Willig (2008) social constructivism draws attention to the fact that human experience, including perception, is influenced by history, culture and language. The approach acknowledges that individuals develop subjective meanings of their experiences and that these in turn influence how they interpret the world.

Research from a social constructivist perspective is concerned with how social reality is conceptualised and implicated to human experience and social context; attempting to show how reality is constructed rather than simply reflecting it (Willig, 2008). A recurring concept in psychological research is that individuals and their thoughts and rationalisations exist in a social context, and that meanings which individuals ascribe to things need to be understood within the culture in which the person is immersed (Smith, 2004; Willig, 2008; Langdridge, 2007).

Social constructivists therefore hold assumptions that individuals seek understanding of the world in which they live and work (Creswell, 2014). The approach acknowledges that individuals develop subjective meanings of their experiences and that these in turn can influence how they interpret the world. Meanings are varied and multiple (Creswell, 2014) and this in turn leads the researcher to look for complexity in these views rather than a reductionist approach of fewer categories or ideas. The participant is encouraged, through broad and general questioning, to construct the meaning of the topic being investigated. This epistemological approach aims to enable participants' voices to be heard.

The ontological position in this study is of the world basically being a function of human thought, analysis and perception; a view that could not be addressed through positivism. This stance – of subjectivity, multiplicity and complexity – towards

the nature of reality, informed how the data were collected and new knowledge revealed.

Through these philosophical assumptions the study adopted an interpretative, constructivist approach to address participants' understanding of oxygen as a medical therapeutic intervention. By studying both patients and HCPs, exploration of the similarities and divergences between participant groups attempted to identify social and historical perspectives, and uncover established perceptions in order to construct theory. Within the interpretive perspective it can be presumed that the social world acts in a state of fluid interaction (Oliver, 2008) and that it has to be interpreted to be at least partially understood; this relates well to the subject of oxygen as a contemporarily evolving topic within today's healthcare settings.

Through open questioning, the aim was to interpret perceptions of oxygen therapy in both a social and historical context; for instance, where and from whom information was sourced, when was knowledge of oxygen first encountered? Collection of data in such a way enabled the inductive inquiry to facilitate generation of meaning (Creswell, 2007).

Account was also taken of how subjective meanings of oxygen therapy are formed through interaction with others, hence social constructivism (Creswell, 2014). This could be an educational source for both health care professionals (general pre-registration training or post-registration courses) and patients (influence of family and peers, neighbours and friends, as well as health care professionals). This interaction amongst individuals is an important perspective in constructivist research (Creswell, 2014) and enables exploration of both historical and social perspectives of therapeutic oxygen in an attempt to make sense of perceptions of oxygen therapy.

4.2.2 Phenomenology

A naturalistic, qualitative research approach was chosen owing to the relative immaturity of the concept (Creswell, 2014) of 'perceptions of oxygen' and the lack of previous inquiry into this aspect. A need was identified to develop theory regarding perceptions of both healthcare professionals and patients. In order to progress to this goal, exploration and description of the phenomenon was required. Whilst grounded theory as an approach was considered as suitable for understanding social processes and developing, or grounding, theory (Creswell, 2007), it was decided that the first step needed to be exploration at an individual level in order for the social process to be fully understood. To this end a phenomenological approach was adopted.

Phenomenology offers a means of enquiry that attempts to understand individuals and their interactions with others and the environment (Lopez and Willis, 2004); the primary goal being to describe a lived experience. In philosophical terms it is believed that only those who have experienced phenomena can communicate them to the outside world.

Originally based on the tenets of transcendence of personal and contextual properties of experience, Husserl's (1970) philosophical ideas underpin most approaches to phenomenology. But whilst the notion of human actions being influenced by what people perceive to be real is an assumption grounded in this study, the idea that it is essential for the researcher to shed all prior personal knowledge – to achieve transcendental subjectivity (Koch, 1995) – was not considered appropriate. Therefore the notion of descriptive versus interpretative phenomenology was deliberated. A key differentiation between these two methods is

that description allows themes to 'emerge' or be discovered, allowing researchers to merely 'bear witness' to experiences, denying the active role of the researcher in the analysis (Pringle, 2011).

Underpinning Husserl's philosophy is a belief that any lived experiences are common to all persons who have that experience, referred to as 'universal essences' (Langdrige, 2007). Identifying these 'universal essences' is what underpins descriptive phenomenology. Using this descriptive tradition, and for the lived experience to be scientifically measured, commonalities in the experience are identified so that generalisations can be made. The belief that essences can be extracted from their context is believed to be an attempt of Husserl's to make phenomenology a rigorous science (Lopez and Willis, 2004).

As a further development of Husserl's approach and a response to criticisms of it being too theoretical and abstract, the interpretative tradition emerged. Attributed to the work of Heidegger (Cohen et al., 2005), assumptions of the descriptive approach, that the world around us and our experiences can be separated, were challenged. *Hermeneutics* as a process and method for bringing out and making manifest what is normally hidden in human experience through interpretation was thus developed (Allen, 1995).

Solomon (1987) considers the focus of an hermeneutic inquiry to be what humans experience, rather than what they consciously know. This is related to the concept of existentialism: a philosophy that emphasizes the uniqueness and isolation of the individual experience (Langdrige, 2007). LeVasseur (2003) reports that according to existentialists we are already thrown into our world and cannot extricate ourselves from it. Thus understanding is always made from perspective, and both

objects and subjects, through interpretation, must be perceived as something in order to represent reality. Thus an individual's perception of phenomena is characterised by experience specific to the individual. Because the aim of this study was to explore how participants perceive oxygen, the social, emotional, health, cultural and political contexts were considered vital aspects in analysis of the data; therefore an interpretative hermeneutic approach to phenomenology was a strong influence.

The focus of hermeneutic enquiry is to consider what the individual's narratives imply about what he or she experiences. These meanings may not always be apparent to participants but can be gleaned from narratives produced by them (Lopez and Willis, 2004). Participants were encouraged to describe how they felt about oxygen and the social or professional context for them, allowing interpretation of responses in relation to these various contexts. It is this perspective that led to the selection of *interpretative phenomenological analysis* (IPA) as a research method for the question posed.

4.2.3 Interpretative Phenomenological Analysis

The study aimed to explore how patients and healthcare professionals *perceive* oxygen therapy rather than simply how they experience it. Further to a phenomenological approach being deemed a suitable methodology, specific issues regarding the chosen topic and my role as researcher influenced and informed the specific approach of IPA. Discussed within the literature, IPA is deemed suitable for understanding personal experiences (Lopez and Willis, 2004; Brocki and Wearden, 2006, Smith and Osborn, 2007). It is a relatively, newly developed and emergent approach that allows creativity and freedom (Willig, 2008). The approach was

specifically developed within psychology but is now becoming more popular within health psychology (Brocki and Wearden, 2006). IPA is reported to be particularly useful when the topic under study is dynamic, contextual and subjective, relatively under-studied, and the self and sense-making are important (Smith, 2004).

IPA is implicated with trying to understand the lived experience and how participants themselves make sense of that experience (Smith, 2004). It is through this phenomenological approach that an individual's personal perception was explored rather than trying to produce an objective record in itself. The IPA approach, though rooted in Husserl's attempt to construct a philosophical science of consciousness, importantly considered that this cannot be done directly or completely, and that access is dependent on the researcher's own conceptions (Smith and Osborn, 2003). These conceptions therefore are required to make sense of that other personal world through interpretation rather than description. It is this approach of interpreting narratives in the context of experiences that was anticipated might have the greatest relevance to practice.

The interpretive stance of IPA acknowledges the philosophical roots of hermeneutics (Smith et al., 2009). Whilst hermeneutics is concerned with giving a voice to the participant and interpretation, it does however recognise that the interpretation should be influenced by the researcher as little as possible. This is where IPA offers an additional interpretative lens by acknowledging previous experience of the researcher in interpretation; this is considered to be a valuable guide to inquiry and can in fact make the inquiry more meaningful (Lopez and Willis, 2004). Heidegger recognised that it is impossible to rid the mind of the background of understandings that led the researcher to select the topic in the first place (Koch, 1995); this further supports the IPA approach in these circumstances.

Personal knowledge can be both useful and necessary to phenomenological research (Geanellos, 2000) and according to Smith and Osborne (2003) the researcher's own conceptions are indeed required in order to make sense of another's personal world through interpretative inquiry and in this context, previous knowledge can be seen as critical for analysis. IPA combines two styles of interpreting: empathetic hermeneutics and questioning hermeneutics; that is trying to understand what it (the experience) is like from the viewpoint of the participant, and asking critical questions of the texts (Smith and Osborne, 2003). Thus, drawing upon previous experience I was able to interrogate the narratives from an informed perspective. That said, it is still necessary within IPA to try to suspend preconceptions in an attempt to keep a degree of open-mindedness (Smith et al., 2009), a process facilitated by reflexivity.

IPA professes to be strongly *idiographic* (Smith, 2004), which is the study of the individual, rather than *nomothetic*, which is concerned with the study of a cohort of individuals. Although this requires initial detailed analysis of the case, IPA does acknowledge that this can progress to similarly detailed analyses of other cases. This approach enabled purposive selection of individual cases to explore various situational circumstances of therapeutic oxygen therapy, for both healthcare professionals and patients. Though this data will lack generalisability, nonetheless it will enable comparison of perceptions across cases to identify commonalities and divergences. Annells (1996) recognises that there is no one true meaning produced by an interpretative study, but suggests that results will reflect – provided that the meanings that are stated in the findings are logical and plausible – the study participants' realities.

IPA is often associated with homogenous groups (Smith et al., 2009). It could be criticised that through the study of both patients and healthcare professionals that heterogeneity is introduced. For this reason the central homogenous feature was that of oxygen therapy, and analysis of groups (that is patients and HCPs) was kept separate in order to further preserve homogeneity whilst allowing for comparisons (again, commonalities and divergence).

Although it has been identified within previous chapters that little literature and no theory exists regarding perceptions of oxygen, my personal experiences as a respiratory specialist and anecdotal evidence served as a prior conceptual framework to inform the strategy. This supports the notion according to Schwandt (1993) that no qualitative study begins from pure observation and that prior conceptual structure provides a starting point for all observations. By recognising personal previous experiences I, as the researcher, am positioned as an active participant within this qualitative study.

Critics of IPA suggest that the interpretative approach draws on a false scientific discourse (Langdrige, 2007), whereas descriptive phenomenology, as Husserl stressed, aims to establish fundamentals of a discipline, in other words understanding, through description. The false scientific discourse referred to here is the assumption that interpretation and explanation are privileged over description and understanding. Moving from description to interpretation has been accused of finding quick answers to the complexities of human nature and that staying close to the experience (through description) is both philosophically justified and methodologically sound (Langdrige, 2007). Smith and Osborne (2003) defend the role of utilising the researcher actively in interpretation, stating that these conceptions are necessary in order to make sense of that other personal world. This

two stage approach to interpretation: the participants trying to make sense of their world, and the researcher attempting to make sense of the participants trying to make sense, has been referred to as a 'double hermeneutic' (Smith and Osbourne, 2003). Thus the role of the researcher actively involved in the interpretation is theoretically endorsed.

This double hermeneutic approach allowed me to actively interpret data, drawing on personal experiences as a specialist healthcare professional in the clinical field, and to legitimise the influence of anecdotal scenarios and common practices. It enabled me to attempt to make sense of the experiences of participants orientated towards empathy and critique (Smith and Osbourne, 2003). This approach additionally provided a framework and a process for data analysis consistent with the theoretical underpinnings of IPA. Without this dimension the situational and contextual circumstances within which the participant is 'experiencing' oxygen may not have been fully integrated within the interpretation.

4.2 METHODS

4.2.1 The Research Question

"What are the perceptions of oxygen therapy within identified healthcare professional groups and a selected patient population?"

4.2.2 Research Aim

The aim of this study was to explore perceptions of oxygen therapy from both respiratory patients' and healthcare professionals' perspectives in order to identify and analyse the features and idiosyncrasies of oxygen therapy in modern day

healthcare, helping to direct future clinical practice and research in this fundamental area of health.

4.2.3 Research Objectives

1. To explore perceptions of oxygen therapy within a selected group of respiratory patients.
2. To explore perceptions of oxygen therapy from selected healthcare professionals.
3. To identify key themes which govern and influence both patients and HCPs perception of oxygen therapy and therefore clinical reality.
4. To inform future clinical, educational and research agendas for therapeutic oxygen.

4.2.4 Research Design

The phenomenological research design was directed by the nature of the research question and paucity of existing literature. IPA, as previously outlined, was selected because of consideration and inclusion of the researcher as an active participant in the data analysis. My background and knowledge of the focus and context of the study was deemed an essential element in the attempt to make sense of this complex, ambiguous and contentious area of healthcare.

Participant Selection and Recruitment

Consistent with qualitative approaches and IPA in particular, sampling was purposive; that is it sought experiences and opinions of the most appropriate persons for this particular research (Wilde and Murray, 2009). In this context participants were selected to represent a perspective rather than the total population

(Smith et al., 2009). Identification and recruitment of participants was different for patients and HCPs.

For the majority of patients recruited, a respiratory nurse specialist from a local general hospital acted as the primary contact and gatekeeper (Smith et al., 2009). With the brief to invite respiratory patients who had received oxygen at some point in their disease trajectory, patients were approached with an initial information invitation letter and reply slip containing my contact details and a stamped addressed envelope (SAE) (Appendix H). In addition the national charity The British Lung Foundation was asked to recruit via the organisation's patient support arm: Breathe Easy. This resulted in an advertisement being circulated via a local Breathe Easy group.

Sampling was intentional, based on factors such as diagnosis (COPD, pulmonary fibrosis) and oxygen prescription (LTOT, SBOT or no domiciliary oxygen at present) in order to be representative of the perspective: oxygen. Aspects of both emergency and domiciliary oxygen were explored, as often patients have experience of both, and based on social constructivism each experience may influence the other. The study of multiple groups aimed to give a more holistic picture whilst preserving homogeneity through oxygen. Following self-referral via the reply slip and SAE distributed by the hospital respiratory nurse, no patients dropped out or refused to be interviewed. The target sample size for patients was 30 but it was decided that data saturation was reached after 28 patients were interviewed. In IPA this data saturation can be considered in terms of the iterative process: reviewing earlier transcripts as analysis continues in order to identify the degree of re-occurrence and convergences (Smith, 2008).

Healthcare professionals were recruited opportunistically via the host university and a snowballing method. Again, an intentional sampling approach was utilised with consideration of participants' professional background, place of work (pre-hospital, primary or secondary care settings) and experience with chronic respiratory patients receiving oxygen. The target sample size for HCPs was 30 but it was decided, despite apparent data saturation, to continue recruitment past this target because of difficulty recruiting GPs; a perspective that I was keen to seek. This resulted in the final sample of 34 HCPs.

Individuals were approached with an initial invitation letter containing my contact details (Appendix I). This was done primarily through academic colleagues approaching students undertaking continuing professional development programmes and modules, and posting on professional networking sites (this enabled a sample of pharmacists to be recruited), and via snowballing. All participation was voluntary and no subject withdrew following initial response.

The total sample size was 62. Broki and Wearden (2006) report sample sizes in the published health psychology literature as varying from one to thirty, and it is recognised that a consensus towards the use of smaller sample sizes seems to be emerging. Smith et al. (2009) however recognize the application of IPA to a larger corpus and detail approaches to analysis that maintain individual cases whilst assessing key emergent themes for the whole group, identifying measurement of recurrence as important. They further suggest that group level themes should still be illustrated with particular examples taken from individuals (Smith et al., 2009). Performing IPA in this manner involves negotiating the relationship between 'convergence and divergence, commonality and individuality' (Smith et al., 2009:107).

All participation was voluntary with fully informed consent as detailed below. Demographic information is detailed in Chapter 5 (Tables 8 and 9, pages 169 and 174).

Data collection

IPA has a commitment to the person as a cognitive, linguistic, affective and physical being, assuming a chain of connection between people's talk and their thinking and emotional state (Smith and Osborn, 2003). Through employment of semi-structured interviews a dialogue ensued whereby initial questions were modified in the light of responses and I was able to probe important areas as they arose (Gray, 2009). Interview questions were open-ended and non-directive. In order to achieve this, an interview schedule was utilised with the aim of guiding, rather than dictating, the interview format (Appendices J and K).

The interview schedules aimed to explore how people *think* about the experience of oxygen through perceptions; facilitating them to tell their own story (Brocki and Wearden, 2006). Preparing the interview schedule in advance enabled me to direct participants explicitly to think about what it was hoped the interview might cover (Smith and Osborn, 2003). The schedule aimed to establish rapport with the participant, cover some general topics, and suggested prompts, both planned and floating (Fox, 2009). Smith and Osborn (2003) warn however that if the interview is dominated by these prompt questions the researcher may need to question how engaged the respondent is. "Are you really entering the personal/social life world of the participants, or are you forcing them, perhaps reluctantly and unsuccessfully, to enter yours?" (Smith and Osborn, 2003:62). This consideration was kept to the fore throughout the interviews.

The order of questioning was not deemed to be important and I was at liberty to follow respondents' concerns or interests, allowing them maximum opportunity to tell their own story. It allowed structure and direction without being prescriptive and my role in data generation, in addition to data collection, became apparent within the process. The disadvantages of this approach need consideration: I experienced a reduction in control over the situation and the data was more difficult to analyse (Cohen et al., 2005). Interviews were audio-recorded, transcribed verbatim and subjected to detailed qualitative analysis as per IPA teachings (see below).

The interviews varied in length from 13 to 42 minutes for patients and from 12 to 45 minutes for HCPs. The semi-structured schedule itself was informed by findings from the literature and my own experiential and anecdotal experience. The schedule was reviewed and endorsed by the supervisory team. The intention was to guide, rather than dictate the interview script; there was scope to probe answers or ask new questions in response to emerging responses throughout. New topics that emerged during interviews were added to the schedule for subsequent interviews.

All patient interviews were conducted in their own homes as people usually feel most comfortable in a familiar setting (Smith and Osborn, 2003). For the majority, only the patient and I were present. Seven participants however did have another person in attendance; full details can be found in Chapter 5, page 169.

For HCPs, interviews were offered in the university, their clinical area or via telephone. The latter option was introduced part way through the data collection phase, following approval of the amendment by the NHS Regional Ethics Committee, as a result of initial poor recruitment,. This strategy of utilising telephone interviews proved successful as it took into consideration the busy work environment

and lifestyles of HCPs, and was in response to several individual's polite decline to participate in the study. All HCP interviews were conducted with only the participant and I present. Full details of setting and method of interview (face to face or telephone) are detailed in Chapter 5 (tables 8 and 9, pages 169 and 174).

Congruent with IPA, the commitment to a detailed interpretative account remained, despite a large sample. This was justified by the study's relatively narrow focus: oxygen therapy – merely a part of the participants' life/clinical practice.

The project was always initially regarded as two individual IPA studies: one of healthcare professionals' perceptions, and the other exploring patients' perceptions, of oxygen therapy, with convergence of the two only after initial analysis. This approach was intended to stay faithful to IPA philosophy of homogeneity and idiography whilst exploring broader concepts through two distinct groups.

4.2.5 Ethical Considerations

Ethical approval was received from Edge Hill University and NRES (National Research Ethics Service) Committee North West – Cheshire (Appendices L and M). In addition, approval from the participating NHS Trust Research and Development Department where recruitment was undertaken involved issue of a 'research passport' and sanction from senior managers and clinicians (Appendix N).

Ethical considerations within this study primarily include issues of consent, protection of anonymity and confidentiality. Informed consent was obtained from each individual at recruitment and interview stage following provision of a participant information sheet and introductory letter (Appendices O and P). These detailed the purpose, aim, potential risks and benefits, procedures for data collection, and plans

for dissemination to the participant, with the right to withdraw at any stage of the study, without prejudice, together with an invitation to view the results before public dissemination. Questions were invited from participants at the recruitment stage and immediately prior to the interview. Following this point participants were asked to sign a consent form (Appendices Q and R).

Anonymity and confidentiality were assured through the use of pseudonyms for both individuals and places, and assurances were made to remove any disclosure from data collected that may threaten anonymity.

Data in the form of transcripts will be kept for a period of five years from the end of the study in a locked, secure cupboard. After the period of five years data will be discarded by shredding or incineration to ensure it is not misappropriated.

The potential consequences of the study were considered from participants' viewpoints, specifically to identify any potential repercussions (Creswell, 2014). It was deemed necessary to consider this separately for patients and healthcare professionals. From a patient perspective data generated was unlikely to compromise them, although reassurance was given, via the invitation letter and the participant information sheet, that participation would not affect any medical care or treatment. From a safe practice point of view, if during interviews I identified an educational need by a patient, concerning oxygen, this was discussed. Interventions were offered in the form of a referral to an appropriate health care professional for educational intervention, or details of patient support groups and literature were offered. This possibility was made explicit in the information sheet and discussed with patients prior to commencement of the study. Any additional disclosed needs

were agreed to be referred to the patient's general practitioner following agreement, although this occurrence did not arise during the study.

Potential consequences of data generated from healthcare professionals were deemed more sensitive. Theoretically, opinions were being invited from participants that may compromise their professional credibility; indeed it may even have exposed unsafe practice. In this situation I was obliged, as a registered practitioner, to act upon such disclosure of any poor practice. It was agreed with both ethics committees that in the first instance this would be facilitated through discussion with the participant (signposting guidelines, literature, sources of further education etc). In the event of any disclosure of unsafe practice *and* reluctance from the participant to receive guidance, then I would be obliged to report this to the relevant governing professional body. This intent was made explicit in the consent form and discussed with the participant before data collection. This approach was intended to secure agreement from the participant before commencement of the study so that, in the event of any substandard practice being exposed, further advice and guidance, either from myself or in terms of signposting the healthcare professional to other sources of information, would be accepted. As a result, the strategy for disclosure did not need to be employed, though individuals were often signposted to guidelines or suggested further reading.

4.2.6 Data Analysis

IPA was utilised to analyse data (Smith et al., 2009). An active role in analysis, through interpretation of data to identify and signify common themes, was taken in an attempt to try to understand the content and complexity of meanings rather than just measuring frequency.

Data analysis was organised within Nvivo 9[®] (2010); whilst this had great advantages of dealing with vast amounts of data in an ordered manner, there was a tendency within the software to count instances within themes, rather than richness of data expressed by individuals. The onus therefore was on me to preserve the integrity of data in relation to individual participants; this was achieved through clear identification of individuals and ideographics as reference points for contextualising comments.

Audio tapes were transcribed at the semantic level; this enabled consideration of all words spoken including false starts, significant pauses, laughs and other features worth recording (Smith and Osborn, 2003). This approach facilitated understanding of participants' perceptions and their interpretation of bodily experiences, including meanings that they assigned to them (Brocki and Wearden, 2006). True to idiographic inquiry, cases were analysed as individuals initially before comparisons were made. As already discussed, findings were influenced by my personal and professional experience as an active part of the analysis. The power of the IPA study can often be judged by the light it sheds within this broader context (Smith and Osborn, 2003).

Seamark et al. (2004) suggest that the overall aim of IPA is to translate emerging master themes into an interesting narrative that may possibly move towards a 'grounded' theory. Whilst the findings may not be generalisable it may be possible to draw tentative conclusions that may be applicable to a wider population. Data were analysed with the IPA assumption that the analyst was interested in learning something about the respondent's psychological world.

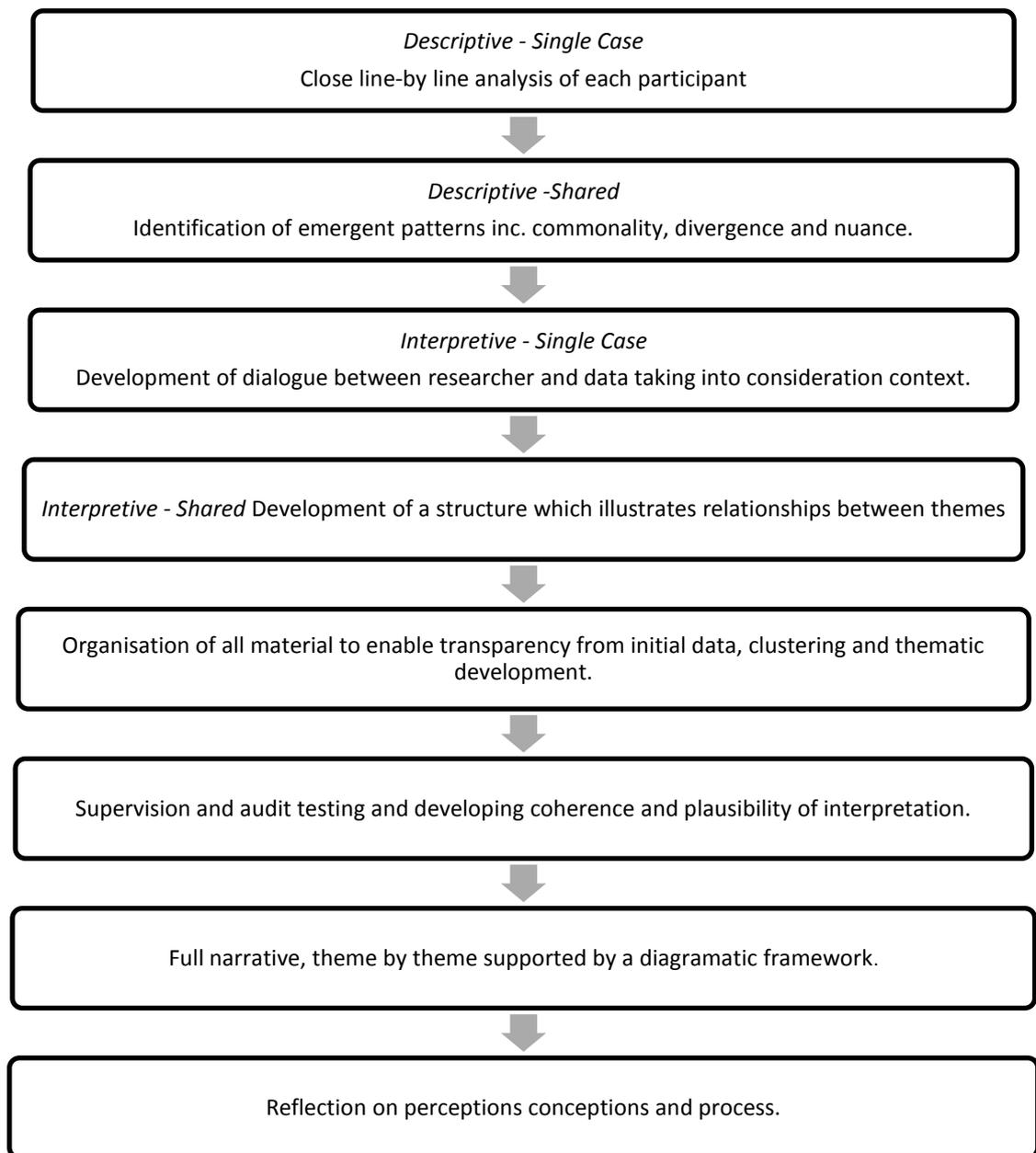
No single method for analysis is prescribed for IPA and it is proposed that a healthy flexibility helps (Smith et al., 2009). In other words there is no right or wrong way, and innovation is encouraged. The focus directs the analytic attention towards participants' attempts to make sense of their experiences; analysis is therefore a joint product of the participants and the researcher – the double hermeneutic.

This involved an interpretative relationship with the transcript, thus obtaining meaning through a sustained engagement with the text and a process of interpretation (Smith and Osborn, 2003). The qualitative analysis therefore was a personal process involving several, though not prescriptive, stages, incorporating principles of understanding participants' points of view and personal meaning in particular contexts.

These stages are characterised by a common process of moving from the particular to the shared; and from the descriptive to the interpretative. Taubert and Nelson (2010) describe their stages of systematic IPA as: preliminary reading; early analysis (initial comments grouped into themes); higher level abstraction (developing connections between themes); subsequent transcripts (testing new emerging themes across cases); consideration of language including vocabulary, use of metaphor and content of speech. According to Smith and Osborn (2003) the macro approach is one of transformation of initial notes into themes through clustering and ordering, and may continue to incorporate data from others with respect to convergences and divergences. In keeping with the iterative process of IPA the analysis continued as earlier transcripts were reviewed in light of any new superordinate themes (Smith and Osborn, 2003).

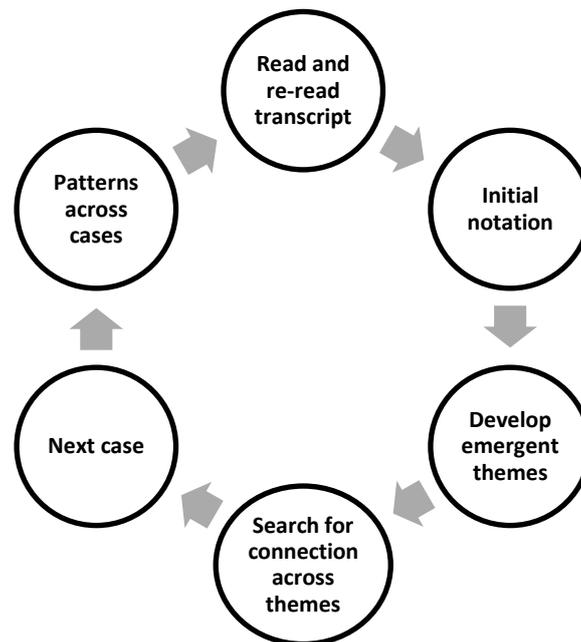
An iterative and inductive cycle was therefore utilised and the stages suggested by Smith et al. (2009) for the novice IPA researcher adopted:

Figure 7: The Stages of IPA (adapted from Smith et al., 2009)



Smith et al. (2009) further suggest six cyclical steps that again are not meant to be prescriptive but may aid first time IPA researchers (Figure 8).

Figure 8: Cyclical Process of Analysis (adapted from Smith et al., 2009)



For this study, the process involved immersion in the data on a single case basis by reading and listening to transcripts concurrently, then re-reading transcripts, making interpretative comments and identifying potential themes in the margins. Subsequent cases were then analysed with existing themes as the basis of interpretation. Numerous re-readings of all transcripts refined the themes and ensured that emerging themes were considered as either new entities or an extension of a theme already identified. Thus the whole process can be considered iterative: continuously returning to the raw data. Emergent themes were identified and organised within Nvivo 9[®] (2010). Figure 9 shows an example of how emerging themes were developed for a piece of transcription from patient 5. Initial notes and analysis are marked in the right hand column, with emergent themes identified in the left margin.

Whilst satisfactory for the purpose of initial individual case analysis, this method proved onerous for the relatively large sample size. Group level analysis was therefore adopted as further suggested by Smith et al. (2009:106). This involved identification of emergent themes at case level whilst simultaneously searching for patterns and connections when considering all cases together, taking care not to overlook divergent themes or cases.

A further challenge with the large sample, in particular with the approach to analysis outlined above, was ensuring preservation of the ideographic detail. This was achieved through selection of abstracts that represented a range of views and were typical: rich with emotion, metaphor or captured imagination, and were taken from particular individuals; thus ensuring group level themes were illustrated at the case level. In addition, atypical extracts were selected to illustrate the complexity and contradictions that appeared between and within cases. This preserved the individual voice whilst at the same time making claims for the larger group.

Smith et al. (2009) suggest that a key issue with larger samples concerns measuring recurrence. This was performed by measuring recurrent superordinate themes in cases. Smith et al. (2009) profess that recurrence should be defined by measuring, for example half, or all, participants: this was achieved by counting occurrences.

4.2.7 Strategies for validating findings

Achieving adequate reliability and validity in qualitative research is judged differently than for quantitative approaches (Smith, 1996) and authenticity rather than reliability is often an issue (Seale and Silverman, 1997). IPA is identified as a creative process and Smith et al. (2009) suggest that criteria for validity need to be

flexibly applied. Key authors also suggest that quality in IPA studies can be demonstrated through engagement with theoretical foundations and methodological approaches outlined in the literature (Smith et al., 2009); this study has drawn from texts by both key authors and those who have already utilised IPA in the field.

In addition a number of procedures were adopted to safeguard and maintain authenticity and credibility. Smith et al. (2009) recommend Yardley’s (2000) criteria for meeting validity in IPA. Yardley (2000) presents four broad principles for quality in qualitative research: sensitivity to context; commitment and rigour; transparency and coherence and impact and importance. Detailed reporting of adherence to these principles for this study is contained in Chapter 8.

Further, Smith et al. (2009) consider the use of an independent auditor. Independent audit was used to ensure that the account produced was a credible one, not in respect of representing ‘the truth’ (Smith et al., 2009: 183), as a number of legitimate accounts could be possible; the audit was more concerned with how systematically and transparently the research has been produced. It is suggested that this particular function could be performed as mini-audits as part of the supervisory process (Smith et al., 2009). For this study the Director of Studies (MO’B) acted as an independent auditor for formal verification purposes. The use of peer debriefing is also recommended to enhance accuracy of the account and ensure that it resonates with others (Creswell, 2014); this debriefing was integral to the supervisory process.

Further suggested criteria for internal validity and reliability are: assessment of internal coherence (is the presented argument internally consistent and supported by the data?), and presentation of evidence (is there sufficient data from participants’

discourse to enable readers to evaluate the interpretation?). Here verbatim extracts in the data analysis provide 'grounding in examples' (Smith, 1996).

Other authors have reported the use of a personal journal (Cheung and Hocking, 2004) as a means of recording the researcher's personal view that might influence findings and responses while collecting data; this proved an invaluable tool in informing individual narratives in the current study.

Brocki and Wearden (2006) however, point out that although IPA is not striving for generalisability, neither is it simply retelling respondents' stories. It is the inductive nature of the researcher discussing their analysis in light of varied existing knowledge that is unique to IPA. Nonetheless, care needed to be taken to minimise researcher bias in the process of selecting themes for analysis (Smith, 1996) and confirmability, member checking and the use of thick description adds to validity (Creswell, 2014). Respondent verification during interviews served to check authenticity of interpretations of experiences (Coolican, 2014). The process of concurrently listening and reading interview data added to the checking of accuracy. All participants were asked if they wished to act as verifiers and two HCPs volunteered. Initial transcripts, together with highlighted observations, were returned to these participants but no additional comments were made.

IPA needs to be considered as an emerging research approach and strategies for assessing markers of good practice, and criteria for how quality of IPA studies can be assessed, have been forthcoming (Smith, 2011).

4.2.8 Reflection and reflexivity

Reflection can be described as a general set of thoughts concerned largely with process and verification (Shaw, 2010). Reflexivity on the other hand is an evaluation of self. It entails adopting self-awareness as a researcher and acknowledging any potential biases that may influence data analysis. Both were important to the current study.

Smith et al. (2009) refer to four layers of reflection in IPA:

- 1) *Pre-reflexive reflexivity* – a minimum level of awareness.
- 2) *The reflective “glancing at” a pre-reflective experience* – intuitive, undirected reflection on the pre-reflective.
- 3) *Attentive reflection on the pre-reflective* – an experience becomes an experience of importance that is significant and requires attention.
- 4) *Deliberate controlled reflection* – also referred to as phenomenological reflection. The conduct of a formal analysis of events which present a phenomenological reflection on spontaneous reflection of what has happened.

In this context it is proposed that this ‘bandwidth’ (Smith et al., 2009:189) of reflection comprises a wide range of related activity. These processes of reflection were applied prior, during and within interviews. In addition, these same layers prompted participants within interviews, thus facilitating self-conscious phenomenological reflection by participants.

Issues of reflexivity affect all approaches to qualitative research and IPA is no exception. In broad epistemological terms reflexivity requires an engagement with

development of super-ordinate themes. An account of reflections and reflexivity undertaken prior, during and after completion of this study are both integral to the narrative and contained within a summary in Chapter 7.

Smith (1996) suggests that ultimately research utilising IPA will be judged on how illuminating it is of particular cases: it should be richly informative and fairly modest in its claims of generalisation. These were important considerations in all stages of the analysis.

4.3 SUMMARY

This chapter has outlined the key philosophical tenets that have underpinned this study and detailed the methodological approach applied. The research design and methods employed have been described, and an overview of methodological considerations has been discussed.

The following chapter presents relevant demographic detail and findings from the analysis of interview data separately for patients and HCPs.

P18 <i>Interviewed alone</i>	M	68	Alone	"Mark on his lung" Congestive heart failure	Normoxic SpO2 97% on air	Home from hospital 2 years ago on LTOT 14 h.p.d. now just when needed – uses 15 mins. twice per day	Pragmatic and stoical man. Uses oxygen 15 mins. twice per day as nobody gave specific instructions. Grateful that it was there when he needed it "if it hadn't been for the oxygen then I probably wouldn't have been here". Relieved doesn't need it now but ok to go back on.
P19 <i>Interviewed alone</i>	F	76	Alone	COPD	Borderline Normoxic SpO2 91% on air	LTOT (on discharge one month ago) and ambulatory 15 h.p.d. but does not use – just ambulatory oxygen now for 2-3 h.p.d.	Very frail emaciated lady clearly breathless on exertion. Accepting of oxygen though not sure of reason for. Voiced some disappointment with how much oxygen had helped – expected more. Feels oxygen has changed her persona and others' perceptions of her. But if she needs it, she needs it. "I don't really like having it, but it does help." Very middle ground.
P20 <i>Wife present</i>	M	74	Wife	Sarcoidosis	Hypoxic on exertion , normoxic at rest SpO2 range 87-93%	LTOT 1 l.p.m x 10 h.p.d. plus 4 l.p.m. on exertion	Wife present at interview. Matter of fact – quite flat. Accepted oxygen as necessity – a means of coping with his disease/breathlessness. Wife similar attitude – they seem to "work with it". Holidays important and would have liked more information. "But we're very, what's the word, pragmatic, we thought ... this isn't going to, you know, alter our lives as ...we'll work with it."
P21 <i>Interviewed alone</i>	F	66	Husband	COPD	Hypoxic - SpO2 84%	LTOT 15 h.p.d x 18 months. Was withdrawn and recently restarted after a chest infection.	Very no-nonsense. Doesn't understand COPD – prefers to think it's "avian" despite smoking history. Feels the oxygen is principally for "breathing better". Has adjusted and accepts oxygen but worries she'll need more (for going out) in the future.
P22 <i>Interviewed alone</i>	F	51	Husband	Interstitial lung disease	Normoxic at rest, hypoxic on exertion SpO2 79-90% self monitors.	Ambulatory 6 l.p.m for approx. 2 h.p.d.	Knowledgeable about disease and oxygen. Pragmatic lady but seemed quite concerned with others' opinions of her on oxygen. "...people get shocked." Grateful to oxygen as an assistant – likened it to a walking stick. Associated it with death initially but now accepted and adjusted.

P23 <i>Interviewed alone</i>	F	62	Alone	COPD	Sats 89% at rest on air. D/C home with O2 at 81%	LTOT 15 h.p.d – takes 8-10 h.p.d	Accepting of oxygen and grateful. Helped her recover. Feels she's become reliant on it and would like a 'back-up' if withdrawn. Believes it is principally for breathlessness so only uses it in day, not night, hence 10 h.p.d
P24 <i>Interviewed alone</i>	M	69	Wife	Asbestos	Mild hypoxia – ok last time	LTOT 15 h.p.d. Manages 10-11 h.p.d	Felt oxygen helps and makes him 'happy'. Reluctant at first but has learnt to adapt & adjust to life with oxygen though refuses to go out wearing it – embarrassed. Talks about oxygen as something alien to his body – 'not mine'.
P25 <i>Interviewed alone</i>	F	71	Daughter & family	?ILD/? Rare lung disease	Severe hypoxia	Two concentrators back to back 24/7	Oxygen changed her life completely but this may be synonymous with diagnosis of rare lung disease. Despite initial resentment now seems to have accepted this as inevitable.
P26 <i>Interviewed alone</i>	F	54	Daughter	COPD Hypoventilation Obesity Syndrome	Sats 91-93% on air in day. ? drop at night - ? what level	O2 3 lpm + BiPAP overnight 12 hours. Plus 3 lpm ambulatory O2.	Overall very complacent and accepting of oxygen. Just seems to accept it as necessary. Doesn't mention BiPAP – maybe she thinks both are one treatment. Very grateful to the oxygen – feels it has helped. Didn't understand how it worked and would like to know more. Alludes to info overload when first put on.
P27 <i>Interviewed alone</i>	M	73	Wife	? COPD Lobectomy age 14	Sats 89-92%	3lpm 12 hours per day + 6lpm ambulatory. Doesn't sleep with	Feels oxygen is very beneficial and necessary. Dependant on oxygen. Cylinder during interview) despite mild hypoxia. Selective with regards which instruction suits hi: likes oxygen for breathlessness but won't take overnight.
P28 <i>Wife present</i>	M	63	Wife	Pulmonary vasculitis / COPD	Sats 92-94%	Off oxygen now – did take 24 h.p.d. for 4 months. Sats improved & taken off	Has had oxygen withdrawn because no longer needs. ? reparative but more likely has responded to treatment following correct diagnosis. Very pragmatic, grateful to oxygen for aiding recovery but also glad to be off it.

KEY: hpd - hours per day

lpm – litres per minute

PaO₂ – Arterial blood oxygen

SpO₂ – Pulse oximetry

Table 9: HCP Demographics and Oxygen Characteristics

INTERVIEWEE PROFESSION	SEX	EXP. YRS.	PRACTICE WITH OXYGEN	OVERALL ATTITUDE TO OXYGEN
HCP1:Paramedic <i>Face to face interview</i>	M	5-10	Administers under protocol & guidelines	Reasonable knowledge. Alluded to a 'darker side' of oxygen, oxygen as potentially detrimental. Differentiated between clinical & psychological breathlessness. Embraces guidelines but thinks overall oxygen does no harm, except in a few.
HCP2:Senior Nurse, Critical Care <i>Face to face interview</i>	F	>20	PGD (patient group directive) for oxygen administration & px	Clearly knowledgeable but focused on critical care setting. Critical of others' practice with regards to oxygen and frustrated by limited opportunities/time to teach. Education a real issue.
HCP3 :Palliative Care Nurse <i>Face to face interview</i>	F	10-20	Advisory role	Good grasp of the use of oxygen in palliative care. Able to see the other non-beneficial effects. Aware of drawbacks for patients and family. Limited knowledge of oxygen in other settings.
HCP4:Student Paramedic <i>Face to face interview</i>	F	<5	Administers under protocol & guidelines	Student in training but also has previous experience in Red Cross. Pretty switched on and pragmatic regards oxygen. Works with guidelines but recounts occasions when deviates.
HCP5 :Respiratory Nurse Specialist <i>Face to face interview</i>	F	>20	Prescriber & advisor. Oxygen Lead	Had her own agenda with regards to the situation with oxygen in practice. Good knowledge with regards respiratory patients but unaware of oxygen issues in other disease areas.
HCP6 :Senior Paramedic / Trainer <i>Face to face interview</i>	M	5-10	Administers under protocol & guidelines Teaching role	Very knowledgeable and provided an educationalists viewpoint. Talked about resistance to change and possible reasons why (lack of rationale/scepticism). Expressed concerns of practice swinging the other way with a too cautious approach. Spoke a lot about pts expectations.
HCP7:Paramedic / Trainer <i>Face to face interview</i>	F	5-10	Administers under protocol & guidelines Teaching role	Reports practice sometimes 'confusing' with multiple changes and mixed messages. Poor practice does persist and conflicts with evidence and current guidelines at times. 'Old school resistance'. Oxygen as a placebo could be useful. Need for more structured training.

HCP8:Paramedic <i>Face to face interview</i>	F	<5 yrs	Administers under protocol & guidelines	Aware of guidelines and dangers of O2 and keen to promote guideline usage. Still disclosed some potential inappropriate. Practice regarding giving 100% to acute asthma despite sats. and breathlessness: 'you'd have to try it'. Spoke of patients on occasion demanding/expecting oxygen. Concern at some first responders (fire) giving oxygen 'willy nilly'.
HCP9:Community Matron <i>Telephone interview</i>	F	10-20	Advises and educates pts as case manager	Interested in O2 herself. Discusses frustrations of pts expectations also tension of mixed messages and pts regard 'doctor knows best'. Reflects on difficulty withdrawing oxygen. Also pts see oxygen as quick fix and will call 999 as a means of obtaining oxygen quickly. Spoke about use of high flow in these situations. Palliative care useful and spoke of difficulties denying oxygen to a dying patient or relatives.
HCP10:Clinic nurse – non-respiratory <i>Face to face interview</i>	F	>20yrs	Uses oxygen for emergency only. Not involve with other method	Some useful insight into the 'lay' HCP thoughts on oxygen. Uses oxygen for fainting. Not aware of any guidelines and doesn't use/have pulse oximeter. Acknowledges own limitation in knowledge. "Worried" regarding the lack of understanding of such a common therapy.
HCP11:Respiratory Nurse Band 6 <i>Telephone interview</i>	F	5-10	Advises ward staff. Involved with HOS	Good knowledge & insight. Talks about difficulties changing practice; general acceptance that oxygen is for breathlessness poses the biggest challenge. Refers to pts psychological benefit & HCPs: "we are as dependent upon it as our patients".
HCP12:CCU Nurse <i>Face to face interview</i>	F	5-10	Administers & titrates oxygen	Knowledgeable & passionate about oxygen. Referred to difficulties advising medics and seniors who were either entrenched in existing practice or too junior (medics) to be assertive; some medics arrogant. Barriers to change identified as time; competing issues and fatigue.
HCP13:Nurse Practitioner walk-in centre <i>Face to face interview</i>	F	>20	Administers oxygen under PGD	Was a student in my class a few weeks previously – this was the first time she had heard of 2008 BTS guidelines and guidance on stroke/MI. Feels O2 given "automatically" for breathlessness. Talked about mixed messages and difficulty keeping up with training. Angry & shocked about the lack of dissemination of guidelines and lack of training. Nurse-led unit.
HCP14:Band 5 ward nurse <i>Telephone interview</i>	F	10-20	Administers oxygen under protocol	Considers oxygen is overused – compares it to her home country in Africa where she trained. Did feel oxygen calmed the breathless patient down and could have a psychological benefit for both patients and carers, especially in palliative care. Spoke of expectations of family – gave case story.
HCP15:Respiratory nurse specialist <i>Telephone interview</i>	F	>20	Advises and administers	Little current experience with oxygen as specialises in asthma. Spoke of difficulties withdrawing and pts DNA if they "get wind" of removal. Pressure from families on occasion. Limitations of awareness of guidelines and alert cards

HCP16:Paramedic <i>Face to face interview</i>	M	5-10	Administers under protocol & emergency	Knowledgeable & experienced with oxygen. Now in leadership role. Articulate about changing practice and barriers faced referring to culture and 'old ways'. Oxygen can be used to make a patient feel better and pts expectations are often shaped by influences such as TV etc. Alert cards – valiant effort but fragmented implementation. Self taught mostly.
HCP17:Community matron <i>Face to face interview</i>	F	>20	Cares for patients with HOT	Non-specialist viewpoint. Feels HOT restricts pts and fosters dependency. Helps HCPs & carers – “makes you feel like you’re doing something productive and useful”. Knowledge clearly limited. Palliative oxygen always useful. Clear insight into own limited knowledge by the end of interview – made her think and will seek education for her & her team.
HCP18:Community Matron <i>Face to face interview</i>	F	5-10	Cares for patients with HOT	Reflected on own lack of knowledge before this role – presumed oxygen was for dyspnoea. Patient dependency and difficulty withdrawing features. Patients use oxygen for breathlessness - synonymous with dying so trying to educate patients is difficult. Seems to understand rationale but then contradicts with an unreserved intention when palliative. Emotive rationale.
HCP19:Community Matron <i>Face to face interview</i>	F	>20	Cares for patients with HOT	Reported poor prescribing of oxygen in community, oxygen synonymous with breathlessness. Also advocated using to reduce anxiety & keep pts at home. Reflected on pts and families resisting withdrawal of oxygen. Thinks a public campaign not warranted “because thank god you know hardly any of us are going to use it”
HCP20: Lung Cancer Nurse Specialist <i>Telephone interview</i>	F	10-20yrs	Advises/Reccs/ Prescribes oxygen	Reflected on pts want & expectation of oxygen. Contradictory practice: only ever prescribes for hypoxia unless individual circumstances such as breathlessness warrant. Feels oxygen reassures pts even if they don't use it. Reflected on her experience using oxygen post op – felt it “comforting”.
HCP21: Pharmacist <i>Telephone interview</i>	F	5-10 yrs	In dependant prescriber / Medicines management	Passionately believes in oxygen being treated as a drug and prescribed. Suggests many HCPs & doctors “don't really feel competent to prescribe & adjust”. Variation in practice exists and fixed ideas esp. In post-op & palliative care – resistance to change. Challenges the pharmacy profession to participate more actively.
HCP22: COPD Nurse Specialist (Band 6) <i>Face to face interview</i>	F	5-10	Assess & F/U HOTS Nurse led clinic	Very rich data. Very knowledgeable but also pragmatic. Psychological benefits to pts: “they just love oxygen”. Misconceptions fostered by ward nurses, medics & especially GPs. Power struggles at times: pts perceive GPs know more/better. Patients may use oxygen to enhance sick role – for both relatives and financial (welfare) benefits. Resistance to withdrawal from both pts and carers. Despite good knowledge of and adherence to guidelines contradicts herself with palliative pts: would always give “doesn't matter whether it works or not”.

HCP23: Pharmacist <i>Telephone interview</i>	F	10-20	Commissioners of oxygen services	Strong views on oxygen. Commissioning role (O2 free to pts on NHS – you have to buy a fan – suggests using some of oxygen budget to fund). Oxygen fundamentally associated with breathlessness. Culture of giving oxygen for emergencies – it’s the thing to do! Role of pharmacist in oxygen changed. Oxygen often for pts, carers, families and HCPs – doing something. Reduced cost of HOTS disincentivised removal. Suggested that oxygen is learnt in context of disease rather than a treatment in itself – that’s a problem.
HCP24: Out of Hours Manager (ANP) <i>Face to face interview</i>	F	10-20	Manages service	Altogether unsure about oxygen. Always used for breathlessness – not aware of any other indication. Felt she had received enough training in the past. Knowledge reflects lack of awareness of oxygen – probably doesn’t see as really important. Has some shared responsibility for training. Reported that the interview raised her awareness and will re-visit adequacy of training.
HCP25: Nurse Consultant <i>Face to face interview</i>	F	>20	Responsible for clinical standards, patient safety, staff training & development	Good insight into oxygen. Aware of issues regarding pats and families wanting oxygen – referred to an ‘emotional attachment’. Pts use to reduce anxiety & breathlessness, referred to placebo effect but also makes them sit down and makes them shut up. Feels some pts use it to validate illness but fully aware of the burden: ‘must be shit’ and describes it as a ‘death sentence’. Mixed feelings re palliative care: ‘you wouldn’t want anybody to die not being able to breathe’.
HCP26: Third year student nurse- <i>Face to face interview</i>	F	<5	Administers oxygen in emergency but always under supervision	Has a vague awareness of oxygen but very little formal training. Perception is being formed through own personal experience: “...and if you give them oxygen, that calms them down”. Aware vaguely that too much oxygen is detrimental but unsure why. Regards oxygen as a drug but not aware of any guidelines.
HCP27: Advanced Nurse Practitioner- <i>Face to face interview</i>	F	>20	Administers oxygen; responsibility for training colleagues	No real views or insight. Administers oxygen according to ‘BNF’ guidelines. Endorses that oxygen often calmed patients down – reflected on personal experience of her farther with emphysema – used oxygen PRN for ‘panic’. Understands perhaps more training needed.
HCP28: General Practitioner <i>Face to face interview</i>	M	10-20	Prescribes and administers oxygen	Sound knowledge & awareness of issues regarding oxygen. A&E background probably influenced this insight. Uses BTS guidelines. Will use oxygen to palliate dyspnoea and spoke of pressure from families to prescribe on occasion. Acknowledges placebo effect. Felt had had enough training but most in A&E experience and self-directed.
HCP29: General Practitioner <i>Face to face interview</i>	M	10-20	Prescribes and administers oxygen	Not particularly knowledgeable; pragmatic. Some resentment regarding changes to px O2 in community. With regards referral: “nobody really knows what they’re doing” explaining variation in practice. HOOF seems to be a barrier to providing what he wants/used to in terms of PRN oxygen or short term emergency oxygen (e.g. over weekend) to keep them out of hospital. “No mechanism to do that now”. Acknowledges placebo effect. Reflects on previous entrenched practice: “anybody & everybody had an oxygen mask on, no matter what”. Definitely didn’t receive enough training.

HCP30: Pharmacist <i>Telephone interview</i>	M	>20	Medicines Management Lead & Advisor (inc. Oxygen)	Very interested in oxygen though personal knowledge seemed a little limited. Clearly feels oxygen is poorly understood by many HCPs and a more structured approach to education and training is needed. Role of pharmacist could be important but “sometimes not well clued up”. Acknowledges placebo/psychological benefit can cause pts to become dependent yet endorses use in palliative care for breathlessness. Highlighted the waste of resource if not clinically indicated.
HCP31: Pharmacist (ILD Specialist) <i>Telephone interview</i>	M	5-10	Independent prescriber	Generally aware of oxygen use in ILD but new to post so still much to learn. Discussed frustration at variance in practice nationally and poor evidence base, esp. Regarding detrimental effects of oxygen on pathogenesis of ILD. Oxygen important for managing breathlessness and the impact of maintaining a ‘normal life’. Thinks pharmacists need to “have a bit more handle on it”. No training to speak of – self taught. Cites “ingrained cultures of nurses” as barrier to correct px & administration.
HCP32: Pharmacist Head of Medicines Management <i>Telephone interview</i>	M	>20	Independent prescriber	Very insightful views. PhD in cognition of chronic disease so aware of existence of beliefs & myths. Generally feels both HCPs and Pts overrate the value of oxygen. Conflict in practice when both pts & HCPs feel its beneficial for dyspnoea. Oxygen synonymous with breathlessness. No appreciation of potential harm from either HCPs or Pts “it’s only good you know”. “I do find myself almost diametrically opposed to some other people’s views.” Part of role is to implement oxygen guidelines - frequently challenged by GPS as proxy for pt & family with regards wanting oxygen. See as a cost-cutting exercise. Pts are let down by HCPs through lack of education and effective communication. Palliative care – could make a moral argument if impacted on pts symptoms; sympathises if rejected because don’t meet criteria.
HCP33: GP <i>Telephone interview</i>	M	>20	Prescribes and administers oxygen	Feels “phased” by oxygen acknowledging own lack of knowledge. Feels he doesn’t have the tools or knowledge base to make objective decisions about oxygen. Talked of issues of patient and carer pressure and dependency. Acknowledged psychological benefits and felt unable to deal with patients ‘wants’ in an informed manner. Talked of “escalating needs, or escalating wants”. No training whatsoever and said it would probably make him “less worried about what I’m doing”. No hesitation re the use in palliative care “actually maybe we don’t use it enough”. Sees it as placebo benefit for pts & relatives though pts expect it will make them ‘better’.
HCP34: GP <i>Telephone interview</i>	F	10-20	Prescribes and administers oxygen	Limited knowledge – usually refers to HOS for assessment of pts. Does prescribe to palliative patients for symptom management. Feels it helps dyspnoea in acute and palliative situations. Acknowledges psychological benefit and that pts can become reliant on it. Has had no training and previously hadn’t given it much thought “it’s just oxygen”. Felt the interview was very thought-provoking and intends to raise some of the questions to colleagues in practice.

For the purpose of reporting findings and discussing patients' perceptions of oxygen in the context of their blood oxygen levels the following definitions have been used:

Hypoxaemia – blood oxygen level below 7.3 kPa or saturations below 88%.

Borderline hypoxaemia - blood oxygen level between 7.3 – 8.0 kPa, or saturations between 88-92%.

Normoxaemia – blood oxygen levels above 8.0 kPa or saturations above 92%.

Participants will be labelled as follows:

Patient participant number – sex (M=male; F= female) – age – principle respiratory diagnosis – blood oxygen level, transcript line number.

Example: P14–F-67-COPD-borderline hypoxaemia, line no. 166)

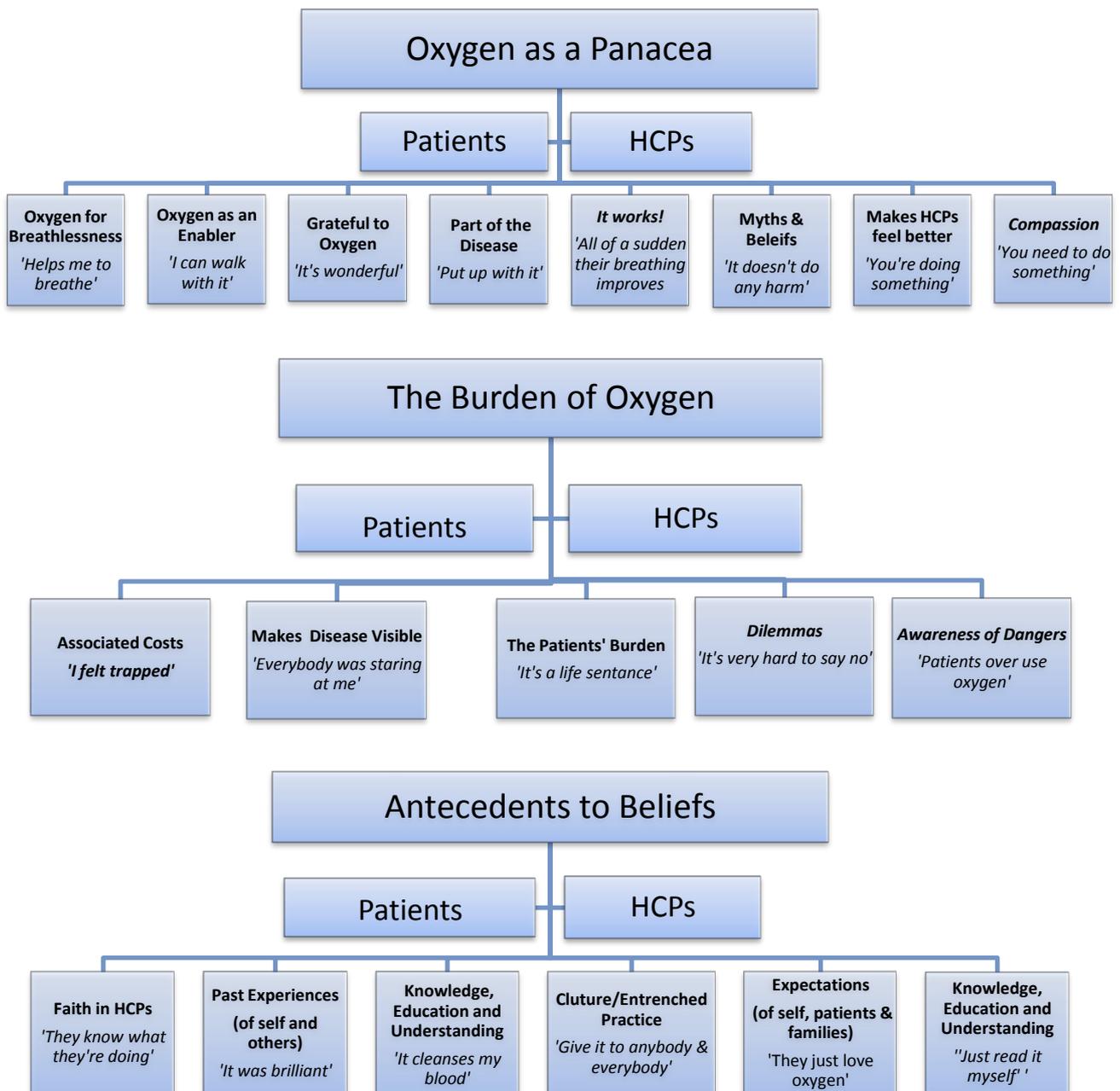
Healthcare professional participant number – professional group – sex (M=male; F= female), transcript line number.

Example: (HCP23- Pharmacist-F, line no. 7-8)

5.3 DATA ANALYSIS

Initial data analysis consisted of exploration of the transcript data, making comments for each individual's interview and identifying emergent themes as detailed in Chapter 4. As emergent themes were identified, superordinate themes were developed discarding any themes that did not directly relate to the research question. Superordinate themes were then grouped into three master themes which were common to both groups of participants: *Oxygen as a Panacea*, *The Burden of Oxygen* and *Antecedents to Beliefs*. The master themes and superordinate themes identified for each group, patients and HCPs, are depicted in Figure 10.

Figure 10: Master Themes and Superordinate Themes for Patients and HCPs



Although superordinate themes differ between both patients and HCPs the results will be reported under the master themes for both groups in order to highlight the similarities and differences apparent.

The focus of the following narrative is to characterise participants overall use, opinion of, and attitude towards oxygen therapy, for both patients and HCPs. In an

attempt to conserve the idiographic, extracts are used to illustrate the themes and demographics to preserve the context of the individual’s record. Reflections on participants’ non-verbal communication and overall attitude towards oxygen therapy are informed by field notes and the researcher’s reflective diary.

5.3.1 Oxygen as a Panacea – Patients

This master theme from the patients’ perspective was developed from superordinate themes: *Oxygen for Breathlessness*; *Oxygen as an Enabler*; *Grateful to the Oxygen*; and *Oxygen as Part of the Disease*. The superordinate themes were developed from the data’s emergent themes. These relationships are depicted in Table 10.

Table 10: Oxygen as a Panacea: Superordinate and emergent themes - Patients

Superordinate Theme	Subordinate theme	No of patients	No of refs.
Oxygen for Breathlessness	<i>‘It helps me to breath’</i>	9	20
	Controls breathing	6	7
	Essential at times	5	5
Oxygen as an Enabler	Fosters independence	6	7
	Helps to do things	9	16
	Helps to go places	14	20
	<i>‘With my oxygen I can walk’</i>	9	14
Grateful to the Oxygen	<i>‘Keeps me alive’</i>	12	16
	<i>‘Makes me feel better’</i>	19	42
	Oxygen works!	19	39
	Wanting oxygen	8	18
Oxygen as Part of the Disease	Compromise	17	26
	Acceptance	15	47
	Others’ Acceptance	9	24
	Ambivalence	10	13

Oxygen for Breathlessness

The superordinate theme *oxygen for breathlessness* was a common recurring topic from all patients' perspective. The theme was constructed from subthemes: '*It helps me to breathe*', '*Controls breathing*' and *Essential at times*.

Patients refer to the oxygen's potential to ease, relieve and make breathing '*better*'. Obviously related to the sensation of breathlessness, patients saw oxygen as an intervention that would enable them to tolerate and manage breathlessness more effectively. At times this was associated with the mechanical action of breathing:

'You know, to breathe deeper, to get breath in.' (P14–F-67-COPD-borderline hypoxaemia, line no. 166)

This patient was not currently on oxygen but stated she would like it. The extract referred to when she'd had oxygen as an in-patient in the past. Overall, reflecting on the interview data and as recorded in the researcher's reflective diary, this patient appeared to 'enjoy' the patient role and seemed to dwell on pessimism. She complained about the lack of attention from family members and seemed to hold resentment about that. It was clear nonetheless that she felt oxygen had helped her breathing.

Others viewed the relief from breathlessness as a more holistic concept, referring to overall benefit and oxygen as comforting:

'It just releases me - you know, I'm not gasping for my breath all the time. It gives me that bit of comfort.' (P15–F-72-emphysema–normoxaemia-SBOT, line no. 76-77)

This frail, elderly woman used oxygen for approximately two hours per day *'unless my breathing gets really bad and I have to put it on'* (line no. 208). Overall she was ambivalent about oxygen, accepting it as part of the disease and using it as a support to increase her confidence. Oxygen seemed to make her feel secure: *'it's knowing you've got that backup to help you.'* (line no. 237-238).

Others also made reference to using oxygen as a back-up and how it helped them to *Control breathing*:

'I start to get as though my breathing, I'm breathing through a filter, like cotton wool, and it's not going in properly, and then I think well I'd better put it on, and when I put it on it eases that. So when I get that feeling I know then to put the oxygen on.' (P20-M-74-sarcoidosis- normoxaemia /exertional hypoxia, line no. 120-123)

Other patients, despite being on LTOT for chronic hypoxia and prescribed oxygen for 15 hours per day, use oxygen for control by helping them overcome panic:

'You do panic and as I say you sit down and sit quiet, all you can do is sit quiet, while you're sitting quiet you're gulping you know. Whereas when you've got this oxygen it's not as severe, you still get breathless but you're able to control it better.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 380-383)

The final sub-theme *Essential at times* refers to patients' reliance on oxygen not only as a crutch for support, but also at times for their very survival, when their breathlessness feels as though it is heralding their demise:

'Well I can't, I'm fighting for breath and I just sit there and I can feel myself panicking, and they say don't panic, don't panic, but you can't really, you haven't really got much choice ... and they say it's alright, it won't kill you ... it's not a very good existence.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 243-251)

'When they had to call the ambulance out there, I was gasping for air. I was sat outside in the garden suffocating. I was saying "give me oxygen, give me oxygen." I just couldn't breathe.' (P28-M-63-pulmonary fibrosis- normoxaemia, line no. 68-71)

The latter extract is from a patient with normal oxygen levels (saturating between 94-98%). He didn't currently have oxygen though he had previously had it and it had been withdrawn. Disappointed at the withdrawal, a full explanation had been given to him by the respiratory team caring for him. Although reluctant at first he has since accepted that there is no need for oxygen routinely. He has since purchased a portable pulse oximeter and monitors his readings twice daily and when breathless – during the interview he showed the spreadsheet that he uses to record his oxygen saturations. Whether he was observing his readings in order to question the decision, or waiting for the saturation to dip in order that he may once again receive oxygen, was unclear. Either way the use of emotive words like '*suffocating*' give an insight into the depth of despair that patients experience when dyspnoeic.

Oxygen as an Enabler

A further dimension that appears to form the concept of oxygen as a panacea for patients is that of enablement. The sub-themes that formed to develop this superordinate theme are: *Fosters independence, Helps to do things, Helps to go places* and '*With my oxygen I can walk*'.

Patients clearly see oxygen as an aid that enables them to be generally more active and participate in activities of daily living:

"I'm very grateful for it, it allows me to go out and about and carry on a normal life and I just really consider it as somebody would consider a walking stick so it's an aid" (P22-F-51-ILD- normoxaemia /exertional hypoxia-ambulatory oxygen, line no. 8-10)

Collectively these attributes appear to foster independence. Whether this is through increased confidence:

“I suppose I feel liberated in the sense that I can do things now” (P22-F-51-ILD- normoxia /exertional hypoxaemia-ambulatory oxygen, line no. 287)

Or through increased mobility:

“If they didn’t give me oxygen, I’d be sat in that chair or in the bed, I’d be practically house bound and I don’t want that.” (P27-M-73-COPD-borderline hypoxaemia-LTOT and ambulatory oxygen, line no. 9-11)

This man felt his oxygen was very beneficial, using it for both breathlessness and preventing breathlessness. He seemed very dependent on oxygen however, both physically and psychologically, despite having only mild hypoxaemia.

On a practical level, undoubtedly oxygen from the patients’ perspective *helps to do things*. For the majority of patients this referred to housework – routine chores such as changing beds, cleaning windows and hanging washing. Routine chores that are taken for granted by the majority, but for patients with chronic dyspnoea the inability to perform these everyday tasks can rob them of independence, sometimes with devastating psychological effects. Oxygen appeared to enable small increases in activity that made a huge difference to autonomy:

Interviewer: *‘Do you think that the oxygen therapy has changed the way you do things?’*

‘Certainly has yes, it’s changed a lot because for example, what did I do this morning? I did some jobs, only little things and I started breathing a bit heavy so I had it on and it made me feel a different person. It did the world of good to me.’ (P13-M-89-emphysema-normoxaemia-SBOT, line no. 272-274)

The patient above did not require oxygen for low blood oxygen levels therefore the

benefits probably manifest in the placebo effect, either physiologically through airflow or psychologically as an active intervention. Further dialogue reveals that oxygen in this case may indeed be used to allay fear; this fear appears to be rooted in the experience of dyspnoea:

'Well it makes life a lot easier. Obviously when I've had it I can go and do tiny little jobs which I was probably frightened of doing, and being short of breath but after the oxygen I felt I can do a few more little jobs.' (P13-M-89-emphysema-normoxaemia-SBOT, line no. 117-119)

From another perspective:

'It lets you do things that, well you probably would do them but you'd be worried about doing anything in case [pause] Oh yes it sets you up you know, you know you've got to it and you'll do it, whereas without [oxygen] you take 2 or 3 days worrying.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 454-461)

Other patients refer to oxygen reducing tiredness which in turn enabled them to do *'small things'* (P6-M-73-COPD-hypoxaemia-LTOT, line no. 339), whilst for others it is about performing the most fundamental functions such as bathing and showering. Often it is their inability to perform these basic hygiene needs that cause patients, and relatives, distress. This distress in turn appeared to aggravate frustration, as coping strategies prove less and less effective, and alternatives prove unsatisfactory. For some patients in these situations oxygen can make all the difference:

'Oh god yeah I wouldn't be able to do it without the oxygen.' (P10-F-55-COPD-normoxaemia-ambulatory, line no.108)

In addition to enabling patients to do more, oxygen can liberate and *helps to go places*. A majority of the patients interviewed (fourteen) made reference to oxygen in this regard. Often this was in a general manner; when oxygen had

facilitated everyday outings in order maintain some form of normality in routine, such as regular trips to the post office, to the local town or hospital appointments. For others it enabled them to use methods of transport effectively, such as mobility scooters:

Yes, but I put the oxygen in my basket on the front of it, and I'm all right. I only use it 'till I'm settled on the scooter. Turn it off then.' (P15-F-72-emphysema-normoxaemia-SBOT, line no. 343-344)

Several patients referred to activities that, although not necessarily essential, enhanced their quality of life; gardening was one such popular pastime, '*Quite handy, I can get up and down the garden with it*' (P26-F-54-COPD-hyoxaemia-LTOT and ambulatory oxygen, line no. 150). For others oxygen offered the opportunity to attend more significant events that were a fundamental part of their life:

'I've had two brothers die within 6 weeks, so I was able to go to the funeral taking a back-up with me you see, with my little cylinder and I was able to go to Wales with it, you know ...' (P11-M-80-bronchiectasis-borderline hypoxaemia-LTOT, line no. 572-574)

The participant above, although prescribed LTOT for 15 hours per day, actually admitted to only using it for six hours. It was clear from the interview that he has little understanding of his disease or the oxygen therapy but accepted the oxygen for what it was and wouldn't like to lose it. He did not see the point of using the oxygen for fifteen hours, particularly overnight, when, in his opinion, he needed it for performing activities and enabling him to go out and about as needed.

The final sub-theme concerning oxygen as an enabler refers to the fundamental task of walking: '*I wouldn't be able to walk two houses down without it.*' (P22-F-51-ILD- normoxaemia /exertional hypoxia -ambulatory oxygen, line no. 312).

This theme occurs commonly with some patients, probably those who are more severely affected and disabled by their chronic lung disease. It suggests that for them, oxygen is an essential cornerstone of their therapeutic regime without which they would not only be housebound, but also immobile:

'With my oxygen I can walk, provided I don't over exert myself, I can walk a fair distance. I can go out to the kitchen, I can go out to the car, I can virtually walk around 20 – 30 metres at a time then I'd have to stop and get a little rest. But apart from that if I didn't have it I wouldn't be able, I'd walk out to the car and back again and I'd be coughing and spluttering.' (P7-M-60-IPF hypoxaemia-LTOT and ambulatory, line no. 23-27)

For this patient, on oxygen 24 hours most days, it is a crucial part of his treatment. This man clearly relied on oxygen totally and although still severely limited in his mobility, was nonetheless grateful for even the small respite from disablement that oxygen provided.

Oxygen also provided an opportunity to exercise. For some this was related to exercises at home:

'So I do my exercises in the bedroom, so I have the oxygen on to do my exercise because without it I wouldn't be able to exercise.' (P10-F-55-COPD-normoxaemia-ambulatory, line no. 14-16)

For others it allowed visits to external exercise classes such as aqua aerobics or simply just being more active with grandchildren.

Evidently oxygen is used by patients to facilitate activities and seems to enhance their quality of life significantly as a result.

Grateful to the Oxygen

Given that oxygen is used for relief of breathlessness and as an enabler, it is hardly surprising that the majority of patients were very *grateful to the oxygen*. This superordinate theme was constructed from identified subthemes: *Oxygen works*, *'Makes me feel better'*, *'Keeps me alive'* and *Wanting Oxygen*.

The majority of patients interviewed alluded to the notion that *oxygen works!* This idea was either expressed directly, although without specific reference to what it is achieving:

'... only that it works, it really, really does work'. (P17-M-77-lung cancer-normoxaemia-no oxygen, line no. 91)

'Well it works, and I don't know how it works...' (P28-M-63-pulmonary fibrosis-normoxaemia, line no. 7-8)

Or, for others, it was related to how it eased their breathing – *'The relief, the relief of my breathing.'* (P15–F-72-emphysema–normoxaemia-SBOT, line no.236), but still with the emphasis on the power of oxygen *working*, rather than just relieving breathlessness as discussed earlier:

'I mean when you're fighting for air it's like drowning, so you're really pushing yourself and you try and get oxygen in but you don't feel you're getting anywhere, you're not getting sufficient air to relieve the problem, what I'm trying to say is it's very, very difficult it really is, so I know that oxygen works because that's happened.' (P17-M-77-lung cancer-normoxia-no oxygen, line no. 104-109)

Some patients regarded oxygen in an abstract way, describing its merits and their gratitude for it without relating it to symptoms *per se*:

'It does me the world of good.' (P13-M-89-emphysema-normoxaemia-SBOT, line no.15)

'All I can say I know it's done me a power of good using it.' (P24-M-69-asbestosios- borderline hypoxaemia-LTOT, line no. 218)

The majority of the patients quoted here had normal blood oxygen levels; the oxygen then was clearly offering them something over and above relief of hypoxia. This abstract regard for oxygen working was seldom related to clear rationale: most patients were ignorant as to how oxygen actually worked, many stating that they didn't want or need to know.

In addition to stating that oxygen simply works, many patients related to the fact that oxygen *'Makes me feel better'*:

'Feet up, let's have a rest, and I feel comfortable and I know it's going to make me feel better in half an hour.' (P2-F-75-emphysema- hypoxaemia-LTOT, line no. 112-113).

Whether this respite was related to relief of breathlessness (which may have been achieved by oxygen or just resting) or compliance with the prescribed therapy (during interview this patient reported that she was very compliant and adhered to all advice given – despite the fact that she had been instructed to take her LTOT for 12 hours per day rather than 15), it is clear that oxygen is a central part of her therapeutic regime.

This vague notion of *feeling better* was further referred to by several patients suggesting that oxygen makes them feel happier:

'Well, what shall I say? [laughing] it makes me feel well and happy and joy, it makes me, makes a better life for me all round.' (P13-M-89-emphysema-normoxaemia-SBOT, line no. 264-265)

Another stated:

'I don't know really. It sounds a bit stupid, but you feel... happier. That sounds stupid I know, but....' (P24-M-69-asbestosios- borderline hypoxaemia-LTOT, line no. 178-179)

Energy-giving was another related term used by patients. *'Well as I say it gives you that big boost gives a bit more energy'* (P18-M-68-heart failure-normoxaemia-SBOT, line no. 193-194). This male patient, who lived alone, revealed during the interview that he had no idea of his diagnosis; he suggested that his heart was failing but was unaware of anything else. He had worked down the *'pit'* for decades and it is likely that he had COPD, but this couldn't be confirmed. He had been given oxygen when he came out of hospital nine months previous and reported that although initially informed to use oxygen for 14 hours per day, nobody had followed him up. He had therefore decided on a regime that suited him: he used 15 minutes of oxygen twice a day. His last recorded saturation was 97% and plans were in place to remove the oxygen – he wasn't aware of this.

The notion of gratitude to oxygen can be summarised by one particular patient: *'Oh yes it's made a big difference to my life, yes. I think it's wonderful.'* (P1-F-78-OHS-hypoxaemia-LTOT, line no. 309). This elderly female patient, who was hypoxic, seemed to embrace the patient role, accepting her limitations and oxygen as part of the disease process. She accredited oxygen as having helped her a lot: she had no worries about oxygen although she didn't understand exactly what it was for or how it worked; neither did she want to know. Fundamentally she had no reservations about oxygen therapy: *'I love it!'*. (Line no. 82)

These vague notions of oxygen working, making them feel better, happier and giving energy, are contrasted on several instances by patients reporting a much

more elementary gratitude to oxygen: *'It's keeping me alive.'* (P5-M-66-emphysema-borderline hypoxaemia-SBOT, line no. 185).

This is either related to mortality itself – *'I'd have been dead'* (P1-F-78-OHS-hypoxia-LTOT, line no. 82), and in reference to not having oxygen: *'well you might as well put me in the cemetery!'* (P11-M-80-bronchiectasis- borderline hypoxaemia-LTOT, line no. 679). Or for other patients it was related to longevity:

'Well I'm hoping it will help me to live a little bit longer and help to give me a bit more life that I feel as if I don't have at the moment.' (P14-F-67-COPD-borderline hypoxaemia-no oxygen, line no.170-171)

These vague statements did not suggest any underpinning knowledge to support the claims, and when asked to clarify none could expand on the rationale that oxygen could prolong their lives. One exception to this was a relatively young female who gave the following explanation:

'erm...well it's helping my organs isn't it...it's helping me live longer...and it's helping me to do things that I couldn't do without it, like going outside, and just general things in the house...it is a life saver for me.' (P10-F-55-COPD-normoxaemia-ambulatory, line no. 564-566)

Interestingly this patient was normoxic and in fact only used ambulatory oxygen for approximately two hours per day. Despite her understanding that oxygen was preserving her organs, in this case it seems the insight into physiology was misinformed.

Expanding further on the analogy of oxygen as a friend, some patients referred to *wanting oxygen*. This reference was usually from patients who had oxygen and feared that it may be removed (remarkably some patients needed reassurance during the interviews that this was not the reason for my visit):

'Oh god I don't want you to take it away yet I'm not ready yet I don't think' (P23-F-62-COPD- borderline hypoxaemia-LTOT, line no. 703)

'Oh! I couldn't do without it I'd just [laughing] DONT TAKE it away' (P22-F-51-ILD- normoxia /exertional hypoxaemia-ambulatory, line no. 374)

One patient in particular (P17-M-77-lung cancer-normoxaemia-no oxygen), together with his wife, saw the interview as an additional means of lobbying for oxygen therapy to be provided. He recalled having used oxygen in the past and it was very helpful; he now feels he *'needs it'* in order to manage his symptoms. He had had an oxygen assessment which was normal. He disagreed, again reflecting on the benefit he had previously experienced: this belief seemed genuine, and both he and his wife reported that they would *'fight the system'* (Line no. 444) if required.

'It might well have come now to the stage where I'm out to beat the system if you like. I want to be in a position to, to, I know I've got a problem, and I now want to beat the problem, it's as simple as that ... when I went national service I signed on for the brigade and I managed to get through.' (Line no. 432-437)

Here he regarded getting oxygen as a challenge similar to that of joining an elite arm of the national forces. He was determined not to be defeated and was pleading at times in an effort to influence the decision:

'... but when you've gone two hours and you're still struggling, not quite as much but you're still struggling, then it's a little bit isn't it. So I need that little bit of help, and that's all I've asked for really, that's all I would like, and I'm sure it would make a hell of a difference, I'm sure it would, 'cause I can't do any more than I'm already doing, I've done it all.' (Line no. 513-518)

Despite rationalised explanations it was profoundly evident that this patient, and his wife, strongly believed that the provision of oxygen would help him to manage his symptoms and disease. This man had lung cancer and therefore possibly a short life

expectancy; the quest for oxygen was the dominant theme during this 40 minute interview.

Overwhelmingly patients viewed oxygen in a positive manner; regarding it as a friend at times, a friend they were extremely grateful to, and at times, reliant on.

Oxygen as Part of the Disease

The final superordinate theme for patients regarding oxygen as a panacea addresses the issue that many patients consider oxygen as part of their disease. This relates to both *compromise* and *acceptance* in relation to the therapeutic nature of oxygen, together with *others' acceptance*. Finally, this overarching theme considers *ambivalence*: this may be a stage in the process of adaptation or it may signify a juxtaposition when patients are aware of both the advantages and disadvantages of oxygen.

Compromise and *acceptance* were both commonly found in the data. Whether patients feel the need to compromise in order to accept the therapy wasn't entirely apparent, however both sub-themes illustrated a stoical attitude displayed by the majority of patients in the study. Sometimes this *compromise* referred to the physicality of the therapy:

'I feel... a bit tied down. You know, over your nose and... ear. Pipes are all over the place and that, you know. But, I just get on with it, you know. Make the best, make the best of it. And finally I go to sleep, until the morning.' (P24-M-69-asbestosios- borderline hypoxaemia-LTOT, line no. 121-123)

'Yes I've got to sort of live with it. The night time therapy is very difficult to get your head around, because you've got these tubes in there and you roll over and you get your arm stuck in it. It depends, some nights I go upstairs and go to bed upstairs, or most of the nights I sleep down here because I just can't be bothered going upstairs.' (P7-M-60-IPF- hypoxaemia-LTOT and ambulatory, line no. 565-560)

Other patients referred to change in lifestyle in order to accommodate the oxygen:

'We got over the shock. I think it was a shock because we're pretty active, adventurous, you know. We've driven all over the world and all over Malaysia and what have you. We knew we wouldn't be able to ... and France. But we work round it.' (P20-M-74-sarcoidosis-normoxaemia /exertional hypoxia, line no. 426-429)

'No, as I say, it does it yes, when you first get it you think, oh I'm not putting that on going out, but slowly you find you've got to do, you've no excuses, you've got to wear it, otherwise you get that tired that you're not enjoying yourself, so that's the way I look at it.' (P6-M-73-COPD-hypoxaemia-LTOT, line no. 210-213)

Either way patients often referred to a need to *'put up with it'* (P14-F-67-COPD- borderline hypoxaemia-no oxygen, line no.135), *'because you have to put up with these things otherwise you'd be dead'* (P16-M-66-sleep apnoea-hypoxaemia-LTOT, line no. 498). Again the relationship with mortality is expressed, suggesting that the sacrifice is worthwhile.

Acceptance was evident by the majority of the patients interviewed. At times this was related to treating the disease: *'it was just a case of I was ill and it made me better and that's fine.'* (P1-F-78-OHS-hypoxaemia-LTOT, line no. 432-433); *'I thought, "well that's it because the lungs are damaged" ...'* (P20-M-74-sarcoidosis-normoxaemia /exertional hypoxia, line no. 45-46).

Some patients related this acceptance to potential benefits: *'Well - I didn't mind if it was going to give me that relief.'* (P15-F-72-emphysema-normoxaemia-SBOT, line no. 44). It wasn't always clear what individuals thought those benefits may be. It could be related to symptoms as above but at other times understanding

of the benefits was vague: *'If it's going to make me better, that's it, that's fine by me'*. (P5-M-66-emphysema- borderline hypoxaemia-SBOT, line no. 291).

Pragmatism also featured in interviews, an attitude that was evident in several patients; which no doubt helped acceptance of oxygen: *'Well it's just one of those things isn't it, if you need it you're not going to say "no I don't want it".'* (P14-F-67-COPD- borderline hypoxaemia-no oxygen, line no.124-125); *'I just accepted it and got on with it do you know what I mean.'* (P9-F-68-COPD- borderline hypoxaemia-LTOT, line no. 435-436). This latter patient took oxygen for 24 hours per day despite only mild hypoxaemia which would not warrant this. From the interview it was apparent that she had limited understanding of her disease and oxygen therapy, but had been prescribed oxygen so was now just willing to accept it as part of her illness. She discussed her reluctance to take it off, even for short periods, and kept it on throughout the interview.

Others' acceptance was an important consideration for many patients. This acceptance isn't inevitable and the embarrassment and stigma so often attached to oxygen will be discussed further when considering its burden. When acceptance and positive reactions by loved ones, and members of the general public, were evident, however, patients liked to acknowledge it:

'And as for going out and people looking at you, you, actually people have been very, very kind.' (P19-F-COPD-normoxaemia- ambulatory, line no. 8-9)

'... but I tell you something, since I have had it and I've gone out with my, you know, my mobile on, people look at you differently, in a different way. And they're nicer to you.' (P23-F-62-COPD- borderline hypoxaemia-LTOT, line no. 75)

The final sub-theme of *ambivalence* was expressed by several patients. This either manifested in the juxtaposition of emotions:

'Well no, I mean, I'm still chatty, I'm still (in takes of breath) you know, I feel okay, I don't feel down or anything like that, the only thing is, I said to you before was, I don't like it, I don't like it, it restricts me.' (P4-M-62-COPD-hypoxaemia-LTOT, line no. 285-287)

'I don't know I think I was a bit put out because I'd seen, all I'd seen is pictures of people with a thundering big tank and pipes and it horrified me actually. I thought "oh my lord!" You know, "do I need all that", and then when it was explained you can use one of these and how it works and it, it's just marvellous really.' (P21-F-66-COPD-hypoxaemia-LTOT, line no. 175-180)

Or perhaps a dawning of realisation regarding the magnitude of the therapy and its impact on the future, perhaps for some tempered with disappointment:

'I don't really think it conjured up anything to be quite honest. Just thought – oxygen... "right, I'll be able to get around" [laughs] I suppose you think, it's gonna be a miracle, you're gonna go round and everything's gonna be alright you know? You don't realize that's it not gonna be alright, it only helps. It's not a cure.' (P19-F-COPD-normoxia- ambulatory, line no. 219-223)

'I don't know. You've got to, I think it's like you're going to get this miracle, you know, it's gonna make you feel... hundred percent, but you've just got to take it slow and easy and, you know.'(P24-M-69-asbestosios- borderline hypoxaemia-LTOT, line no. 236-238)

For some, despite the realisation of the significance, optimism comes through:

'I just thought I'd be sat here for the rest o' me life on oxygen but like I said they've turned it down a bit now, so I know I'm getting somewhere.' (P26-F-54-COPD-hyoxaemia-LTOT and ambulatory, line no. 286-287)

'I don't know, I just felt that I wouldn't be able to get on with life as I was worrying over you know, whether am I going to be an invalid and I'm not going to, yuno, get on with life how I wanted to, but I've learned to live with it now.' (P12-F-73-emphysema-normoxaemia-SBOT, line no. 127-128)

This last quote came from a female patient who had previously had LTOT but

following re-assessment the concentrator had been removed and replaced with a cylinder for use when needed. She clearly regarded oxygen as an enabler and a friend; she stated that she missed it and would be happy to have it back at any time.

All but one of the patients interviewed in this study viewed oxygen in a positive light, to varying degrees. Their attitude and reported affirmative attributes of oxygen did not seem to relate to either the modality (i.e. LTOT or SBOT) or whether or not they were hypoxic. Many of the patients additionally reported the drawbacks and burdens of oxygen, but these were always considered as secondary to the overwhelming regard for oxygen as a panacea. The one patient who was an exception (P3-F-71-COPD/asthma-normoxaemia-no oxygen) will be discussed in greater depth later (page 212).

5.3.2 Oxygen as a Panacea – HCPs

This master theme from the HCPs' perspective was developed from superordinate themes: *It works!*; *Myths and beliefs*; *Makes HCPs feel better* and *Compassion*. The superordinate themes were developed from the data's emergent themes. These relationships are depicted in Table 11.

Table 11: Oxygen as a Panacea: Superordinate and Emergent themes: HCPs

Superordinate Theme	Subordinate theme	No of HCPs	No of references
It works!	Vital for life	6	9
	Oxygen for breathlessness	24	45
	Oxygen for anxiety	11	14
	They improve!	6	11
	Psychological benefit	20	35
	Placebo effect	9	11
Myths & Beliefs	It's just oxygen	12	19
	It doesn't do any harm	8	12

	More is better	8	14
	It's given to everyone & anyone	12	13
	Wonder drug	6	12
Makes HCPs Feel Better	Something is being done	7	7
	Quick fix	4	7
	Makes the job easier	3	9
Compassion	Comfort	15	27
	Do Anything & Everything	12	14
	Family Benefit	7	10

It works!

This superordinate theme in relation to HCPs' perception of oxygen therapy was constructed from the sub-themes: *Vital for life*; *Oxygen for breathlessness*; *Oxygen for anxiety*; *They improve!*; *Psychological benefit* and *Placebo effect*. These sub-themes seem to represent the voices of the various HCPs as they attempt to articulate the utility and efficacy of oxygen. These perceptions were at times expressed in the first person, at other times they were as the third person; this will be clarified throughout the narrative. At times the responses came across as a rationale for using oxygen, at other times as a defence for not adhering to guidelines; again, this context will be clarified.

The sub-theme *vital for life*, surprisingly was one of the least highlighted aspects of oxygen. Terms such as '*vital for living*' (HCP21-Pharmacist-F, line no. 12), '*without oxygen you die don't you?*' (HCP25-Nurse Consultant-F, line no. 78) and '*essential for life*' (HCP13-Nurse Practitioner-F, line no. 4) seemed to summarise that, despite wide ranging and complex opinions of oxygen, fundamentally it is a basic requirement for metabolism – in the context of both chronic and acute clinical presentations.

For one student paramedic her reflections on oxygen placed it firmly in the context of resuscitation:

'It's - for me it's used, for me in a crisis, if a patient's having a crisis - without it you've got the potential for death. And what a way to go - to be able to have hypoxia till you die is not a nice way, so for me it's the life-saving side of it.' (HCP4-Student Paramedic-F, line no. 5-8)

From a purely physiologically based justification as seen above, HCPs then moved to another, what the majority considered elementary, rationale for using oxygen: *breathlessness*. This notion of using oxygen for breathlessness was presented from the patients' perspective:

'It makes breathing easier for them, I think. Yes, makes it easier for them.' (HCP14-Nurse-F, line no. 195)

The perspective of HCPs themselves was also discussed, both in the first person:

'So you know, whatever the cause of the breathlessness a bit of oxygen can only be beneficial.' (HCP32- Pharmacist-M, line no.114-115)

'... a palliative care patient when they have dyspnoea we use it, yeah dyspnea patient when they have some malignancy of the lungs we use it.' (HCP28-GP-M, line no. 13-14)

And in the third person in reference to the observed or common practice of others:

'There is this sort of just overarching feel that the minute somebody is breathless that they need oxygen.' (HCP23- Pharmacist-F, line no. 7-8)

'A GP will ring and say "we've got a patient, erm, very breathless, needs some oxygen"' (HCP22-Respiratory Nurse-F, line no. 94-95)

The last statement came from a respiratory nurse who was involved in oxygen assessment clinics and well informed with regards to contemporary oxygen guidelines. She had very strong opinions about oxygen: when to give it and when not

to, but despite her knowledge and compliance to guidelines she also voiced frustration that sometimes, despite trying all other approaches to managing breathlessness, the patient still ended up on oxygen – a delay that often resulted in a greater cost in terms of finance and distress, to both patients and their families: *'They just love oxygen'* (HCP22-Respiratory Nurse-F, line no. 74).

This insight into the dilemmas presented when using oxygen for breathlessness was observed with others; this student nurse seemed to demonstrate a critical understanding of oxygen therapy during the interview. It was as if she realised that oxygen had been given for breathlessness automatically despite the lack of apparent hypoxia:

'... often they can't take a breath, but I'm sure I've seen sometimes patients who were breathless but their oxygen saturations, they were more or less all right.' (HCP26-Student Nurse-F, line no. 92-94)

In addition to reporting the use oxygen for breathlessness, many HCPs reflected on oxygen as a useful treatment *for anxiety* induced by breathlessness and fear:

'I think it reduces their anxiety, I think it calms them down. They feel less stressed.' (HCP18- Community Matron-F, line no. 234)

'Some types of patients who are chronically ill can become very anxious and dependent on something to help them and that might be an oxygen mask that makes them feel more secure.' (HCP2-Critical Care Nurse-F, line no. 329-333)

In addition to discussion of the utility of oxygen for specific symptoms, some HCPs just claimed non-specifically *'And they would always improve.'* (HCP1-Paramedic-M, line no. 309-310). This senior paramedic was well versed in the BTS (British Thoracic Society) emergency oxygen guidelines (BTS, 2008) and reported

that he would always titrate to oxygen saturations. He then went on to contemplate that sometimes he would also give oxygen anyway despite normal saturations. He recalled previous experience:

'Going back to those two patients that you'd managed to calm down, and also the things that they're feeling, shortness of breath, I know it's actually mentioned in the guidelines, the evidence is it doesn't do anything for them but unfortunately it does, it does do something for them, it might not do anything clinical for them but it does do something for them.' (Line no. 560-565)

The majority of HCPs interviewed recalled how oxygen seems to have *psychological benefits* for patients. These benefits in the main were related to how patients come to depend on their oxygen and often use it as *'a crutch'* (HCP12-Cardiac Nurse-F, line no. 291). One respiratory nurse précised this phenomenon:

'They just become very dependent on it and very anxious if it is removed, even if they only take it for five minutes every hour because that is what they were told to do six years ago, someone saying to them well that five minutes has not been of any use, you don't need the oxygen, I can prove you don't need the oxygen with the blood results, your blood levels are as good as mine, there's a psychological element of "oh I need it, it helps me breathe, I need it to keep well, it keeps me out of hospital".' (HCP5-Respiratory Nurse-F, line no.119-125)

And from a GPs perspective:

'You wonder though if there's some ... in some cases patients go dead panicky if they don't have it, you know sometimes they can become reliant on it, and I'm not sure then how much you know it's helping, you know physiologically you know to address any problems or whether it's more of, there's more of a psychological element to it maybe than helping breathlessness.' (HCP34-GP-M, line no. 186-192)

Others felt that it offered patients some form of insurance policy:

'The problem has been I think that people psychologically get attached to it, even though they don't use it at home much at all, they don't want to give it up just in case.' (HCP11-Respiratory Nurse-F, line no. 203-205)

The reference to psychological benefit on the whole was obscure but a few participants did refer directly to the potential placebo effect that oxygen may have:

'Oh! I think there is a reassuring element, so what some people might call a placebo response perhaps, but there is a reassuring element that they're actually getting oxygen.' (HCP30- Pharmacist-M, line no. 49-51)

'They are anxious because they are short of breath, it makes the patient feel like something's being done about it, maybe it's the power of placebo I don't know.' (HCP21-Pharmacist-F, line no. 240-242)

One GP in particular, although acknowledging a placebo effect, did express his own doubts regarding how much could be attributed to this, and how much was physiological benefit:

'Well I'm sure there is a placebo effect as well, having a mask on with oxygen, but I've never been able to quantify that compared to how much they are actually getting from the oxygen per say.' (HCP29-GP-M, line no. 68-70)

Overall, all HCPs interviewed regarded the beneficial effects of oxygen as wider-reaching than just correction of hypoxia or an acute intervention. They described the use of oxygen in order to calm patients down, reduce dyspnoea, enable daily activities, or non-specifically it just helps patients:

'Sometimes you might just give them a little bit, just to settle them down because that's what they want, and then take it off them.' (HCP7-Paramedic-F, line no. 256-258)

Myths and Beliefs

In an attempt to identify resistant practice and cultures, sub-themes related to existing beliefs and myths were constructed. These sub-themes were: *It's just*

oxygen; It doesn't do any harm; More is better; It's just given to everyone & anyone and Wonder drug.

Terms such as '*innocuous*' (HCP3-Palliative Care Nurse-F, line no. 245) and '*treated a little bit too casually*' (HCP23- Pharmacist-F, line no. 13-14) uncover a perception that at times oxygen is regarded as commonplace and therefore unlikely to be dangerous. When considering oxygen in this manner HCPs either gave their personal views:

'You can't really have too much oxygen in your body.' (HCP26-Student Nurse-F, line no. 74)

'It would just pink you up a little bit and you might actually feel a little bit better ... and even if we did go back to the days of giving oxygen for all, it's not necessarily going to be a really, really bad thing, just only to a few patients.' (HCP1-Paramedic-M, line no. 333-334, 771-772)

Or expressed this existing viewpoint through others' attitudes:

'I think perhaps, perhaps people, people don't think of it as a therapy ... it's just oxygen, you know [laughs] ... and maybe it's that, that kind of feeling about it, you know, they don't treat it in the same way as they would other drugs.' (HCP34--GP-M, line no. 387-395)

'I guess people think it's just oxygen and what harm can it do. Everyone needs oxygen a bit like everyone needs water; everyone needs to breathe the air that we breathe.' (HCP21-Pharmacist-F, line no. 137-139)

Coupled with the perspective of *its just oxygen* is the notion of *it doesn't do any harm*, again expressed as the respondent's personal opinion:

'I don't think it harms the patient. No, I don't think so.' (HCP14-Nurse-F, line no. 215)

'Everyone's always improved on oxygen because at the end of the day, if you didn't need it, in terms of, apart from COPD, if you didn't need it, then it wouldn't do you any harm.' (HCP1-Paramedic-M, line no. 331-333)

'If my patient honestly does need it, then I will give it, but sometimes I just think for that short period of time that we have them, it's not going to do any harm to them.' (HCP4-Student Paramedic-F, line no. 434-436)

On occasions, this belief is attributed either to the past:

'when we first started, it was just thought by everyone, "oxygen's brilliant it doesn't do any harm" it was, "throw it at everyone" it was really good.' (HCP7-Paramedic-F, line no.352-354)

Or to the ideas of others:

'it's something that is misunderstood by junior staff who think that it's not harmful.' (HCP2-Critical Care Nurse-F, line no. 15-16)

Following on from this the notion that *more is better* and, despite knowledge of guidelines, sometimes the old philosophy overrules:

'... because you know if you had someone with an MI with sats. of 96 but looked like shit I would still give them oxygen.' (HCP7-Paramedic-F, line no. 38-41)

From the interview data there appears to be an existing culture of giving oxygen *to everyone and anyone*, a deep-seated reflexive practice that was not dominant in any one given profession. This practice was reported in both the present and past tense:

'It's 'one size fits all' kind of drug ... unfortunately a lot of people are still 'one fits all' or of that opinion that one fits all, even some healthcare staff.' (HCP1-Paramedic-M, line no. 548-551)

'My overall view is that it's just given to everyone and anyone.' (HCP17-Community Matron-F, line no 9)

'A lot of people you've seen over the years, certainly in A&E, put oxygen masks on 'cause anybody and everybody had an oxygen mask on no matter what.' (HCP29-GP-M, line no. 70-73)

Fundamentally oxygen was often regarded as a *wonder drug* in the context that its benefits were multifaceted: it was safe for the majority, freely available and *'an all-round good egg'* (HCP25-Nurse Consultant-F, line no. 8). Tempered with this however was awareness that perhaps opinions were, on occasion, overrated:

'And sometimes all the health professionals have a view over and above the current evidence face of the value of oxygen.' (HCP32- Pharmacist-M, line no. 21-22)

Some illumination regarding persistent beliefs, myths and practices has been found in the data analysed. Essentially HCPs appear to be faced with past experiences of oxygen working, and complacency arising from the routine use of, and prolific availability of, oxygen.

Makes HCPs Feel Better

Evidence was found that oxygen was sometimes administered for the benefit of the healthcare professional as much as the patient. Sub-themes: *Something is being done*, *Quick fix* and *Makes the job easier* all pointed to attributes of oxygen therapy viewed by HCPs in a positive manner. Reference to patients feeling like *something is being done* was made by several HCPs. This was always related to the patients themselves, but on occasion the mutual benefit to the HCP was acknowledged:

'I think they [patients], like health professionals, feel something's being done, because patients expect something to be done and when it's not done can feel very abandoned, and isolated if they feel things aren't being done, devalued even sometimes.' (HCP3-Palliative Care Nurse-F, line no. 341-344)

This perspective was articulated from a palliative care nurse. During the interview she displayed an astute insight into the drawbacks of oxygen and recounted the negative impact that oxygen can have on both lifestyle and family relationships. Yet in this context she still regarded oxygen as beneficial because *something is being done*; benefits which were attributed to both the patient and the HCP.

The notion of oxygen as a *quick fix* came predominantly from nurses. This was often reflecting on referrals to respiratory nurses to do oxygen assessments on patients waiting to be discharged from hospital. It was reported that often managers and medics saw oxygen as a solution to hypoxaemia rather than investigating the causes of hypoxaemia. Other HCPs reported oxygen was often used as a quick fix for breathlessness for self-care: *'they just see it as that short sharp fix of ... they've struggled from the bathroom so that's going to help them'* (HCP22-Respiratory Nurse-F, line no. 21-23), or for relatives to manage episodes of dyspnoea: *'They've seen their loved ones breathless so they, the first thing is a quick fix, it's a quick fix to get them to calm down with a bit of help'*. (HCP9-Community Matron-F, line no. 266-268)

Likewise there was reference from a critical care nurse that oxygen is used in a similar context to manage patients' falling oxygen levels:

'So a quick fix maybe to turn up the oxygen percentage and that might satisfy you for a short amount of time but then the patient will continue to deteriorate underneath.' (HCP2-Critical Care Nurse-F, line no.42-44)

The idea that oxygen can be used, either to provide reassurance that something is being done, to facilitate recovery, or to provide relief from

breathlessness or anxiety, all leads to the prospect of *making the job easier* for HCPs. This frank disclosure was only reported by three individuals (two paramedics and a respiratory nurse) but may offer insight into a mind-set that exists:

'Without kind of ... it sounds really awful but it makes your job easier because you've given them something.' (HCP1-Paramedic-M, line no. 569-570)

In particular, individuals cite such aspects of care as the patient's co-operation, improvement of condition, or the patient's remembering that it was effective last time:

'Last time the crew gave me oxygen it worked.' (HCP6-Paramedic-M, line no. 93)

In addition oxygen was seen as a means to facilitate discharge or keep patients from returning to the GP's surgery:

'... they just want that patient out the surgery and not to keep coming back for that same complaint, so "give it them".' (HCP22-Respiratory Nurse-F, line no. 101)

The notion of oxygen as a therapy for the HCP, though not expressed by the majority, introduces the concept that doing something, especially something as visible and tangible as administering oxygen, can be as gratifying for HCPs as it is for patients.

Compassion

The overarching theme of compassion contained sub-themes of *comfort*, *do anything and everything* and *family benefit*. Most of the dialogues recorded here were in the context of palliative care. Most regarded the addition of oxygen therapy

to a patient's palliative care regime as beneficial, even if this contradicted their own previously held prudence and recognition of evidence-based guidelines.

As may be predicted, most healthcare professionals regarded the comfort of the patient as prime importance: *'Make them as comfortable as possible'* (HCP10-Nurse-F, line no. 439). This desire seemed to override all previous opinions regarding cautious and judicious use of oxygen. Often an awareness of effects other than the purely physiological was expressed:

'...if the patient was palliative and it eased their symptoms or they felt reassured, their anxiety dropped...' (HCP12-Cardiac Nurse-F, line no. 91-92)

The notion of death was clearly central in the minds of healthcare professionals when considering the use of oxygen in the palliative context and often seemed synonymous with the management of dyspnoea:

'You wouldn't want anybody to die not being able to breathe...it must be awful to die with a sense of breathlessness, it must be so frightening...' (HCP25-Nurse Consultant-F, line no. 130-132)

Such remarks often exemplified empathy and a reflective approach to practice, as previous experience of death and breathlessness was regarded as the antipathy of a peaceful death. With regards to the utility of oxygen, some healthcare professionals referred to potential effects, although clearly not all were based on physiological rationale:

'...it initiates some form of euphoria...' (HCP16- Paramedic-M, line no. 300)

When discussing the value of oxygen for the normoxaemic patient, logic and reason were often in conflict with caution:

'...if it's making them comfortable then it would have a purpose' (HCP27-Nurse Practitioner-F, line no. 123)

This conflict of thought was epitomised by one participant who expressed strong beliefs regarding the use of oxygen only to correct hypoxia, yet they would nevertheless use it in palliative circumstances:

'You know it doesn't matter whether it works or it doesn't work, nothing else is going to help is it; I'd give it'. (HCP22-Respiratory Nurse-F, line no. 682-683)

The approach to palliative care that was often expressed was the idea that the healthcare professional must do their utmost to relieve symptoms, whatever the cost, *to do anything and everything*:

'If it was my mum she would have all the oxygen.' (HCP10-Nurse-F, line no. 422-423)

Resentment regarding the bureaucracy of ordering oxygen however was expressed, and policies were seen as a barrier that had to be circumnavigated in order to optimise care for seemingly needy individuals:

'...without having to go through all the rigmarole of the form and the referral and this, that and the other.' (HCP29-GP-M, line no. 155-156)

Often oxygen, in the context of palliative care, was regarded as a panacea without drawbacks. The notion of patients being at a stage when there is nothing left to lose allowed oxygen to be considered as a final attempt at palliation: *'...in a way you've shot your last bolt.'* (HCP33--GP-M, line no. 54). Others regarded it as an expectation, something that always happens:

'some doctors see it as a tick box, that this patient's got a malignancy so we will give them this drug, we will get the Macmillan nurses in and put oxygen in.' (HCP5-Respiratory Nurse-F, line no. 147-148)

Family benefit. The notion of expectation is referred to further when considering the family and carers of patients receiving palliative care. Although often aware that what they were doing was treating the family rather than the patient, healthcare professionals regarded this as a justified approach.

'...and sometimes of course with the oxygen you're treating the relatives aren't you?' (HCP23- Pharmacist-F, line no. 352)

The notion of actively treating the family in addition to the patient was usual and was often encompassed within the philosophy of palliative oxygen. At times it was intimated that providing oxygen therapy could be more for the psychological benefit of the carer than the physiological benefit of the patient.

'You don't want the family to be in distress.' (HCP9-Community Matron-F, line no. 384-385)

The use of oxygen was also seen to be a protective strategy against complaint or accusation. When considering the family, this Community Matron (HCP9-Community Matron-F) reflected:

'... it's the relatives, because they see them struggling for breath, ... I've been in situations where the patient's relatives are saying "they've done nothing to help them", so they've [GPs] given the oxygen.' (Line no.373-377)

The majority of respondents showed prudence with oxygen and cautious administration was paramount in most circumstances. In the context of palliative care however all HCPs would paradoxically default to the compassionate stance of 'just give it'.

Whatever the more subtle discussions and revelations, overall the majority of HCPs and patients perceived oxygen, above all else, as a panacea.

5.3.3 The Burden of Oxygen – Patients

Almost overwhelmingly then, both patients and healthcare professionals regarded oxygen in a positive manner. It was seen as a universal remedy, a solution, certainly to breathlessness, and an adjunct to self-care. This viewpoint however was not held heedlessly, in that all study participants also recognised that oxygen as a therapy was not in itself benign and highlighting the burden of oxygen seemed important to both groups.

For patients the burdens of oxygen were only expressed in relation to domiciliary therapy. Seemingly because of the impact that this would have on their lifestyles and body image, whereas oxygen in the acute situation was regarded as a temporary measure and therefore drawbacks were transient.

It has already been identified that the vast majority of patients saw oxygen as a very positive therapy, even if drawbacks were apparent and expressed, on balance the overall perception was affirmative. All, that is, except one patient (P3-F-71-COPD/asthma-normoxaemia-no oxygen). This lady was quite emotive in her negative expressions of oxygen. She had LTOT for a period of 6 months following hospital discharge for an acute exacerbation of her COPD. The therapy had now been removed following a re-assessment which showed that she had normal blood oxygen levels. She spoke passionately about when she had the oxygen '*it had ruined my life completely*' (line no. 29). She reported that she couldn't handle adapting to the oxygen and that she thought her '*life was over.*' (line no. 21).

Though she was the extreme and the exception in that she had absolutely no positive comments to make about oxygen, most other patients also felt that there were downsides to having oxygen therapy. For patients, issues were identified from

the interview data and grouped into common sub-themes; from these the superordinate themes were constructed: *Make disease visible* and *Associated costs*. These themes are depicted in Table 12.

Table 12: The Burden of Oxygen: Superordinate and Emergent themes: Patients

Superordinate Theme	Subordinate theme	No of HCPs	No of references
Makes disease visible	Associations with death /severity	8	15
	Permanency	8	12
	Embarrassment	20	32
Associated costs	Trapped	12	17
	Resentment	13	37
	Dependency	10	16

Makes Disease Visible

This superordinate theme was constructed from the sub-themes: *Associations with death and a sign of severity*, *Permanency* and *Embarrassment*.

Patients interpreted the introduction of domiciliary oxygen therapy as a *sign of disease severity*: ‘*I know I’ll be getting worse won’t I?*’ (P19-F-COPD-normoxaemia-ambulatory, line no. 612), and potential future worsening:

‘*I know the time will come probably when I will need it more, but I don’t want to think about it.*’ (P10-F-55-COPD-normoxaemia-ambulatory, line no.117-118)

Both these patients had normal blood oxygen levels and used ambulatory oxygen only. Another recalled: ‘*I didn’t realise how ill I was before.*’ (P5-M-66-emphysema- borderline hypoxaemia-SBOT, line no.38). Again on SBOT only, this patient with normal blood oxygen levels regarded the introduction of oxygen as a

sign of decline in disease status, a perception misplaced given his moderate disease. During the interview he was very accepting of oxygen and was willing to compromise his lifestyle in order to accommodate what was essentially an unnecessary intervention.

For other patients oxygen was more overtly *associated with death* itself:

'I think because it's associated with end of life you do think "oh no I'm going to die, I'm going to die".' (P22-F-51-ILD- normoxaemia /exertional hypoxia-ambulatory, line no. 42-43)

The idea of *permanency* and how it relates to disease trajectory came across from several patients: *'I'm never going to get rid of this now, this is my life.'* (P3-F-71-COPD/asthma-normoxaemia-no oxygen, line no. 96-97). This was the patient described earlier who did not adapt to oxygen at all. She reported feeling depressed at the prospect of always having to use the oxygen and the impact that this had on her life.

Other patients reflected on permanency and used expressions such as *'you're stuck with it now'*, (P19-F-COPD-normoxaemia- ambulatory, line no. 497). For one particular man the introduction of oxygen was initially considered as a temporary measure:

'I just took it for granted, it was going to be a temporary thing and then they said "no, this is not going to be temporary".' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 415-417)

The realisation appeared to be when the concentrator appeared:

'Well we went to the hospital and the doctor there said I'm sending you home and I'm going to arrange oxygen for home, but it'll only be a temporary thing; but it's never, it's not going to be temporary, because at first they brought little

cylinders and then suddenly we had this machine that plugs in.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 389-392)

Associations with death and the idea of permanency on occasions appeared to influence the embarrassment that patients felt. This particular patient got upset during the interview when reflecting on how wearing the oxygen made her feel:

'Well you think you're not like other people. [pause - upset]...I suppose that's what lot of the disabled people think [pause]...cos it's like being disabled isn't it, but not..losing a limb or an arm or anything like that. But yes I feel as though I'm different from other people.' (P19-F-COPD-normoxaemia-ambulatory, line no. 395-396)

For many patients the oxygen concentrator, tubing, cylinders and interface were unwelcome outward signs of their disease and a source of discomfiture. People didn't like to use oxygen in public, *'... cause people are obviously looking at you'* (P11-M-80-bronchiectasis- borderline hypoxaemia-LTOT, line no. 374). At times an emotional consequence was perceptible:

'I felt that everybody was staring at me, and some of them do it now, you know, and it does upset me a bit when people stare.' (P12-F-73-emphysema-normoxaemia-no oxygen, line no. 135)

Patients described strategies for covering up their embarrassment: *'I kind of...if I'm in town or anything, I kind of look down..but you get used to it.'* (P10-F-55-COPD-normoxaemia-ambulatory, line no. 298-299). Others described how they would try to hide the apparatus, even at home:

'If anybody comes I take my wire out. So that must say something, mustn't it? I just stick it, I stick it down there and, yeah I don't sit here with my wire in. So I think that must be something to do with it. Do I not want people to know? Well, they can't not know can they really but it's still not stuck up my nose ...' (P21-F-66-COPD-hypoxaemia-LTOT, line no. 561-565)

One particular patient, who had since had oxygen withdrawn, reflected on his experiences of wearing oxygen in public quite bitterly:

'You want to go in the shop for something and try not to be conspicuous with it and people look at you, thinking "should you be out of hospital, you should be in bloody hospital mate". [They] keep away, you'll have some bloody disease they don't want to catch anything so [they] keep away from you.' (P28-M-63-pulmonary fibrosis- normoxaemia, line no. 293-301).

Associated costs

In addition to making the disease more visible, patients expressed other associated costs to living with oxygen therapy. These were grouped under the sub-themes *trapped*, *resentment* and *dependency*.

The perception of feeling *trapped* by oxygen was expressed in different dimensions. For some this was the physical restriction that wearing oxygen had; the following patient had normal oxygen levels but despite this used oxygen when undertaking activities. He regarded oxygen overall as an enabler but he still expresses anxiety arising from the physical constraints:

'I didn't like it, I had the wires going up the stairs and I felt trapped in a way.' (P10-F-55-COPD-normoxaemia-ambulatory, line no. 98)

'I feel... a bit tied down. You know, over your nose and... ear. Pipes are all over the place and that, you know. But, I just get on with it, you know. Make the best, make the best of it. And finally I go to sleep, until the morning.' (P24-M-69-asbestosios- borderline hypoxaemia-LTOT, line no. 121-123)

Feeling physically trapped was just one reported frustration that led to patients voicing feelings of *resentment* regarding their oxygen. This was also related to the physical intrusion of the oxygen and its equipment:

'the oxygen's arriving and then he wheeled in with that you know, I thought oh my god, you know, and the cylinders and the big cylinder that goes under the stairs ...' (P20-M-74-sarcoidosis-normoxaemia /exertional hypoxia, line no. 397-398)

'I was gutted. Absolutely gutted. I thought it's 'déjà vu' this, my mum. And I didn't, well I wasn't happy at all 'cause I expected one of those cylinders. And I thought I don't want, you know, my, I'm house proud, I didn't want one of those cylinders in my living room.' (P23-F-62-COPD- borderline hypoxaemia-LTOT, line no. 598-601)

Resentment was also related to the impact of having the oxygen, or being informed for the first time that oxygen was to be put into the home:

'Didn't want it. That was it. Whole attitude was just didn't want it I didn't want my life to change. It was going to change, but I was the last to find out.' (P25-F-71-ILD-hypoxaemia-LTOT, line no. 101-102)

Some patients expressed frustration with the inconvenience and intrusion into everyday life:

'You get a bit frustrated don't you if you're honest, at times you say, this bloody oxygen, you know. Sometimes I get fed up because I've used it perhaps that day and I've had it outside while I've been walking around, taking it off, putting it on, I'll come here back home, I'll put the concentrator on and then I'll want to go in the back garden, put that on again, want to go out the front, put it on, I want to go upstairs, put it on and I ... bloody thing! You know, I get frustrated that way.' (P20-M-74-sarcoidosis-normoxaemia /exertional hypoxia, line no. 437-445)

One particular patient spoke in a particularly poignant way about his resentment regarding the presence of oxygen: *'I do resent it a little bit, it's invading my privacy.'* (P4-M-62-COPD-hypoxaemia-LTOT, line no. 135)

The third sub-theme that represented the costs associated with oxygen was that of *dependency*. This was expressed either as a fear of dependency:

'Well sometimes you think, eh well "oh I better get it off", in case you get too used to it you see.' (P11-M-80-bronchiectasis- borderline hypoxaemia-LTOT, line no. 617-618)

Other patients seemed to reluctantly accept that they already were dependant:

'Well I think I am dependent on it. I think once you start using it you're dependent on it, ... you've got no choice.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 526-528)

For patients, oxygen therapy posed several drawbacks but these were usually tempered with the benefits and advantages of oxygen. For all but one patient the positive aspects still far outweighed the negative ones.

5.3.4 The Burden of Oxygen – HCPs

HCPs were also considerate of the burdens related to oxygen therapy. Sometimes these were expressed as an *awareness of the dangers* associated with oxygen; sometimes they were related to *the patients' burden*; the third superordinate theme identified was one that caused *dilemma* for the HCP themselves.

These superordinate themes and contributing sub-themes are depicted in Table 13.

Table 13: The Burden of Oxygen: Superordinate and Emergent themes: HCPs

Superordinate Theme	Subordinate theme	No of HCPs	No of references
Awareness of dangers	Dangers of smoking	10	16
	Oxygen as a poison	8	14
	Trips, falls and hazards	2	3
The patients' burden	Changes to patients' lifestyle	10	20
	Dependency	7	13
	Side-effects	4	7
	Cost	4	9
Dilemmas	Controversy	8	13
	Doubt	9	11

Awareness of dangers

HCPs, as expected, seemed to express a greater awareness of the dangers associated with oxygen than patients did. These were grouped into sub-themes of the *dangers of smoking, oxygen as a poison, and trips, falls and hazards*.

Deliberation about the *dangers of smoking* was the commonest occurring sub-theme. Sometimes this was with regards to the safety of the patient, sometimes the safety of others, or even themselves:

'And he was sat there with a massive grey big gas fire blazing, with an oxygen cylinder sat in front it, and a fag! He was a heavy smoker and you just think, if you don't blow yourself up in the house, [laughs] you're going to end up killing yourself.' (HCP4-Student Paramedic-F, line no. 143-146)

Some HCPs reflected on the consequences of smoking: *'you know we've had a few patients that have had burns to their faces and things from having a smoke with it on.'* (HCP17-Community Matron-F, line no. 207-208) For others the consequences have been more devastating:

'There are patients who smoke on their oxygen, who cook with their oxygen next to the naked flames and we have had a number of deaths, nasty accidents.' (HCP5-Respiratory Nurse-F, line no. 311-312)

The potential poisoning effects of oxygen were the second commonest reported concern, though not one particular individual referred to it as 'a poison' as such. These references to the potential detrimental effects to the patients' metabolism were sometimes expressed vaguely: *'sometimes there's always the danger of kind of giving it and them not needing it.'* (HCP1-Paramedic-M, line no. 536) For other HCPs the dangers were well articulated:

Furthermore, they felt, or had experienced, that dependency can affect daily activities and ultimately quality of life. This in turn can affect a patient's reluctance to give oxygen up if deemed necessary or indeed to comply with the prescribed regime.

This is, on occasion, related to a patient's belief that oxygen is keeping them alive:

'They've realised they can't do much without it and rely on it so heavily that they feel that they can't do anything without becoming breathless and they're going to die if they can't catch their breath. I think it is fear of dying' (HCP18- Community Matron-F, line no. 102-105)

Sometimes this is related to a vicious cycle of dyspnoea – panic – dyspnoea, in which case the oxygen was felt to exacerbate this:

'In my experience, when patients are put on oxygen, sometimes after a time they can feel panicky if it's not on, and actually it just induces panic and fosters a further dependency.' (HCP3-Palliative Care Nurse-F, line no. 73-75)

The subsequent impact that this then had on patient's quality of life was at the forefront of many HCPs thoughts: *'I think patients often sometimes do become dependent on oxygen'* (HCP33--GP-M, line no. 50-51); *'... often tend to rely on it to the exclusion of quality of life'* (HCP17-Community Matron-F, line no. 7).

Healthcare professionals are often aware that oxygen may bring about helplessness. The expressed concern that the health carers themselves may be contributing to this dependency is evident, and clearly gives rise to predicaments in daily practice; knowing what to do for the best is a quandary that these healthcare professionals faced on a regular basis.

The issue of *side-effects* for patients was surprisingly not very commonly highlighted, but was a concern expressed by some HCPs. This consisted of a myriad of issues from haphazard use as they take oxygen, prescribed as LTOT, for relief of

because of the risk assessments, you know, but in the scheme of things, it's not, not huge.' (HCP23- Pharmacist-F, line no. 552-556)

This pharmacist had very strong views on both oxygen and costs and dwelled on the topic at greater length than any other individual. In her commissioning role she suggested that since more recent changes in the oxygen providers' contract, falling costs have reduced the incentive for judicious prescribing.

For others, cost was seen as a driver and perhaps intimated that this was something that they needed to be seen to be doing:

'Yeah, yeah, definitely, cost-cutting is the main thing, isn't it, 'cause we know how much money we've saved with the under users, so the way the NHS is, you know we've got to watch all our budgets and each people, we'll all be responsible for our own budgets now.' (HCP22-Respiratory Nurse-F, line no. 648-651)

Some were more defensive of the need to consider cost; again, the pharmacist quoted below was considering the prescription of oxygen in the context of his role in Medicines Management and as a prescriber and advisor for oxygen prescription. He was quite firm in his opinion that if the patient does not meet the criteria then oxygen should never be prescribed:

'... it's not really going to be justifiable in terms of the cost. Now I know it does come to cost but unfortunately that is what the NHS runs on and the money that we spend, if it's not appropriate it is denied to patients with other clinical needs. It's seen as cost cutting.' (HCP32- Pharmacist-M, line no. 93-96)

The interviews clearly showed HCPs were aware of drawbacks of oxygen, an awareness that often posed dilemmas in clinical practice and decision making.

At other times it was a way of handing decisions over to somebody else, letting them take control and tell them what to do: *'No. I'm glad someone will think for me.'* (P25-F-71-ILD-hypoxaemia-LTOT, line no. 217).

Other excerpts demonstrate a reverence to superior knowledge:

'Well my attitude to that was well you're the expert you know what you're talking about so I'll do whatever you say so.' (P16-M-66-sleep apnoea-hypoxaemia-LTOT, line no. 333-334)

'I just took it that they know what they're doing.' (P1-F-78-OHS-hypoxaemia-LTOT, line no. 348-349)

Past Experiences

Patients frequently reflected on the past during the interviews and their previous experiences with oxygen. These were either *personal experiences*, *experiences of others* on oxygen or influences from *social media*, in particular television (TV).

Personal experiences on the whole centred on acute care and in particular emergency services and ambulance transfers:

'As soon as I collapsed they phoned for the ambulance, oxygen on, and I was taken to the hospital and all the time in the hospital I had oxygen, day and night.' (P8-F-75-COPD-hypoxaemia-LTOT, line no. 161-163)

When prompted to talk further how this made her feel the same patient replied:

'Relieved you know. Because I used to be always fighting for my breath and phoning the ambulance. Because the ambulance comes straight away and they give you the oxygen, they sedate you but they don't say right we're going, they take you to the hospital and then it's up to the doctors there whether you stay, or you get sent back.' (Line no. 421-425)

One patient demonstrated bitterness regarding the general misconception that most people on oxygen were smokers or ex-smokers. She had idiopathic pulmonary fibrosis, and at 60 considered herself quite young. Overall, she was grateful to the oxygen (she was currently awaiting lung transplantation), but her experiences of others on oxygen were negative:

'And then there's obviously, there's also the dark, not the dark side of it, there's also the side of it that annoys you whereas you've got people who are on oxygen with chronic either emphysema or whatever and really, they're far higher flow rates than I am, smoking! That's the annoying thing. And these guys, you know some of the horrendous stories they tell you, where they've got people with face masks on and they drill little holes in the face mask so they can get a fag in. And they've got oxygen blasting in at about 10ltrs per minute, which is like a hurricane really up your nose.' (P7-M-60-IPF-hypoxaemia-LTOT and ambulatory, line no. 735-742)

During interviews patients would often reflect on perhaps what had influenced their perceptions of oxygen and the media was a common theme identified. In particular this was one individual's reflections on what they'd seen on TV: *'I've only ever seen it on the telly.'* (P26-F-54-COPD-hyoxaemia-LTOT and ambulatory, line no. 175)

This viewing on TV, mostly soap operas, gave some patients information and allowed them to feel knowledgeable when oxygen was given to them:

'I've obviously seen all, you know, you watch all the medical programmes and Holby City and all this and you see them with the nasal cannula and everything else like that.' (P7-M-60-IPF- hypoxaemia-LTOT and ambulatory, line no. 321-323)

For some these comparisons were more poignantly associated with death:

'Anyway it come up just after the, at the end of the advert thing, Mrs so and so died two days after making this thing like you know, and yet, I must admit it

worried me a bit you know ... So when I saw this advert of this women with this machine the same as what I've got ...' (P4-M-62-COPD-hypoxaemia-LTOT, line no. 234-235)

Others reported using the internet as a source of information; this was on occasion to supplement education and advice given to them from HCPs. At other times it was reported in the absence of sufficient information:

'I think we found it out for ourselves by going on the internet and doing a lot by ourselves.' (P21-F-66-COPD-hypoxia-LTOT, line no. 508-509)

Knowledge, Education & Understanding

This superordinate theme was constructed from commonly aired answers to questions directing patients to consider their knowledge and understanding of oxygen, and the kind of information that they receive. The sub-themes identified are *how oxygen works, information, mixed messages and patient knows best.*

When asked directly *'Do you understand how oxygen works?'* patients gave an array of answers. Some demonstrated a sound insight and understanding of their disease whilst others thought they knew but their understanding was clearly misinformed:

'Well it is helping my heart as well...it does help 'cause without the oxygen your heart has to pump faster to get the oxygen round so the oxygen does help me that way. ... it's helping my organs isn't it...it's helping me live longer...and it's helping me to do things that I couldn't do without it, like going outside, and just general things in the house...it is a life saver for me.' (P10-F-55-COPD-normoxaemia-ambulatory, line no. 68-70; 564-566)

The fact that oxygen improves lung function and acts as some form of bronchodilator was expressed by some patients, with explanations such as:

'Well to me, I've always thought oxygen was to help open your pipes up, it's the only thing I can call them.' (P14–F-67-COPD- borderline hypoxaemia-no oxygen, line no. 158-159)

When referring to what his GP had told him the oxygen was for, one patient replied: *'... to help me to open the passages to me.'* (P15–F-72-emphysema–normoxaemia-SBOT, line no. 48). For some the connection to easing breathing was also made apparent:

'Well it is eh opening your bronchioles isn't it love, you know helping you breathe more easily.'(P11-M-80-bronchiectasis- borderline hypoxaemia-LTOT, line no. 83)

'Well as far as I know, to do with, as I say it's to help me with my breathing, because my breathing's not, well I wouldn't say it was shallow, but apparently there's not enough oxygen getting down to the, wherever it goes to.' (P4-M-62-COPD-hypoxaemia-LTOT, line no. 89-91)

Many patients seemed to understand that the oxygen was needed in their blood, and though their comprehension seldom went further it was clear that they understood the relevance of the blood gas levels and the monitoring of oxygen saturations. Others had totally misunderstood the relevance: *'Well it's cleansing your blood ...'* (P11-M-80-bronchiectasis- borderline hypoxaemia-LTOT, line no. 99); *'It's strengthening me.'* (P21-F-66-COPD-hypoxaemia-LTOT, line no. 422)

Some patients expressed an opinion that too much emphasis is put on understanding and that frankly it all goes over their heads:

'They talk about sats and blah blah blah, but thats to me over me head cos they know more about what they're talking about and I don't , no, I don't know whether I didn't get or I didn't listen or I didn't want to listen. I don't think I paid, the first time I went I don't think I paid attention enough because.' (P16-M-66-sleep apnoea-hypoxia-LTOT, line no. 246-249)

Others simply saw no need to know:

'If you have this real need to breathe properly then I don't think you give it an awful lot of thought at all, all you want to do is get relief full stop, it's as simple as that. I don't think you start trying to analyse things or think in terms of you just need, you just need the relief and if you can get that relief it makes one hell of a difference.' (P17-M-77-lung cancer-normoxaemia-no oxygen, line no. 211-215)

Others simply didn't know: *'Well I don't know really what to think about it, it does, put it this way, it does its job it does what it's supposed to do and that's all I know about oxygen.'* (P18-M-68-heart failure-normoxaemia-SBOT, line no. 216-217)

Sources of information received by patients also varied. Obviously impacting to some extent on their subsequent levels of knowledge and understanding, patients reported finding out from HCPs, the internet, books and pamphlets; for many they reported that it was simply guesswork:

'It was installed the day before I came out of hospital there was nobody here to explain everything to me. And then [name omitted] adjusted it, you know, later. So I didn't have a lot of explanation at all originally.' (P13-M-89-empysema-normoxaemia-SBOT, line no. 18-21)

This man reported having to work out how to use the oxygen himself. He said he'd had no instructions; he was just aware of the necessity and presumed he needed it. He did have normal oxygen levels and it could not be established why exactly oxygen had been prescribed in this instance. In the absence of any specific instructions he had formulated his own regime, 10-15 minutes twice per day, in the hope that that was sufficient.

Other patients complained of overload, too much information and an inability to take it all in: *'Sometimes when they talk it just goes over my head cos I'm thinking you assume I know.'* (P16-M-66-sleep apnoea-hypoxaemia-LTOT, line no. 257-258)

'Well they give you that much stuff all at once and you'll start reading it and then you think "oh I'll read that later", and then before you know it you've got a stack o' things that you haven't read [mmm].' (P26-F-54-COPD-hyoxaemia-LTOT and ambulatory, line no. 249-252)

Others were grateful for the care and attention given by respiratory teams in particular:

'Well, the oxygen nurses, they've kind of been positive with me, they've explained everything and the one that takes me in the physio, she's helpful, she tells me what I can do and what I shouldn't do, doesn't she. So over the three years we've gathered that much information and spoke to that many people and had it explained that I think now we know.' (P20-M-74-sarcoidosis-normoxaemia /exertional hypoxaemia, line no. 464-469)

'Well she explained everything to me, I mean up until then I had no idea about oxygen therapy, no idea at all.' (P9-F-68-COPD- borderline hypoxaemia-LTOT, line no. 284-285)

Some patients did not want to know why oxygen was needed:

'I probably didn't want to know to be quite honest with you, I thought well it's there, okay I'll use it, you know, if I've got to use it I'll use it.' (P4-M-62-COPD-hypoxaemia-LTOT, line no. 365-367)

But many were just unsure: *'I understand very little except its release when I'm exhausted and fighting for breath.'* (P8-F-75-COPD-hypoxia-LTOT, line no. 151-152)

For some patients it became apparent that they had been given *mixed messages*:

'That I'd go up to the hospital and they'd do all the checks. I think it was borderline really because one of the other nurses, when I rang up, said if it had been me I would have kept you on it. And I did stay off it until the doctor says go back, go on it, so then you don't know what to do.' (P21-F-66-COPD-hypoxaemia-LTOT, line no. 27-33)

consultants are like that, some of the nurses are like that.' (HCP2-Critical Care Nurse-F, line no. 471-475)

Some myths were evident: *'I used to hear that oxygen was a good cure for a hangover.'* (HCP1-Paramedic-M, line no. 720); *'We were always told if we arrive at work with a hangover you should sit in the back of the ambulance and have a bit of oxygen to clear your head.'* (HCP7-Paramedic-F, line no. 327-329)

A junior nurse who was born and trained in Africa felt fundamentally that oxygen in the UK was overused. Reflecting on the contrast in the use of oxygen in developing countries she stated: *'We have access to oxygen back home, but you don't use it the way we use it here. I don't know why'* (HCP14-Nurse-F, line no. 172-173). She did however feel that it was useful in calming down breathless patients and could have a psychological effect on carers as well as patients.

The issue of *power relations* was voiced as both a concern and an irritant by several participants. A pharmacist trying to introduce and standardise the practice of prescribing oxygen reflected:

'If the patient is fully oxygenated without oxygen then they don't need it post op if their saturations are 98%, ... but the surgeons and the anaesthetists disagree with that, they want a target range of, ...we have a special chart for them now which is a target range from 96 to 100 percent, so that is a third target range that has been introduced for that group of patients because they refuse to accept 94 to 98 as being acceptable, they want their patients to have 96 to 100 post op because that's what they believe to be true and right.' (HCP21-Pharmacist-F, line no. 210-218)

Likewise not only did the following scenario, described by an acute nurse, show her annoyance, she also recalled how it made her feel inadequate. When describing a patient she was caring for she recalled:

'An anaesthetist just came in and was really quite rude and couldn't understand why I didn't have her [the patient] on a hundred per cent oxygen ...really quite flippant quite annoyed with me for not keeping her on a hundred per cent oxygen, she [the patient] was a known CO2 retainer and she was retaining even on the two litres, we took her up to CCU and the sister just whacked on a re-breathe at a hundred per cent and she [the sister] said why didn't you just increase her oxygen ...she made me feel stupid but even though I knew that I was in the right.' (HCP12-Cardiac Nurse-F, line no. 245-254)

Sometimes this power relationship was directed to interprofessional rivalry.

Reflecting on a patient's attitude to oxygen:

'It's a block isn't it, you know they've had it for so long and their GP gave it them ... 'cause the GP's a GP, and you're only a nurse — not a nurse with a special interest — you're a nurse, and he's a GP, and he's trained for all them years so how can you know more than him; it's just not possible, and "I like my GP, my GP gives me anything I want ... including oxygen" ... like I know, I know I'm only a nurse.' (HCP22-Respiratory Nurse-F, line no. 501-506)

On occasion these interprofessional power conflicts could perpetuate *mixed* messages, particularly to patients:

'It's different professionals from different backgrounds interacting with that patient and those professionals have different approaches ...I think the priorities are different in those circumstances but obviously the patient, doesn't always understand. [The patient receives] mixed messages that are not necessarily from healthcare professionals, it's more over a lifetime.' (HCP3-Palliative Care Nurse-F, line no. 40-58)

In particular, specific professional conflicts are perceived between nurses and doctors:

'I've experienced it when somebody's prescribed it and you've said no and that you don't need it that they tend to just don't listen to you and the GP goes and prescribes it anyway, you have just basically been undermined really... what the doctor says is right and the nurses are basically there to help the doctors.' (HCP9-Community Matron-F, line no. 334-340)

'They come into the hospital, they're prescribed medication, they're given oxygen and then the nurse is coming and saying right you don't need that and they're thinking, "well last time I saw the doctor the doctor said I did need it", but now they don't need it because their saturations are fine, so I've come into contact with a few patients that have been a bit confused about that.' (HCP15-Respiratory Nurse-F, line no. 55-60)

Dwelling on the philosophical annotations that she made, this palliative care specialist nurse went on to consider the practical aspects for the patient:

'But for our patients one of the difficulties is that there are so many different health professionals involved with this group of patients, they might be going to, a number of different hospitals, different consultants, different... GPs and accessing out of hours, so it can become quite cluttered.' (HCP3-Palliative Care Nurse-F, line no. 146-150)

Other individuals considered the implications of mixed messages for the HCPs themselves:

'It seems like there's a lot of misconceptions and hearsay, wrong beliefs around oxygen.' (HCP21-Pharmacist-F, line no. 206-207)

'The oxygen specialist nurses they seem to have conflicting answers, you could send them two patients with exactly the same illness and they'd say yes to one and no to the other one.' (HCP29-GP-M, line no. 30-32)

Some recognise the potential sources of the confusion related to equipment and lack of standardisation:

'Myself and a lot of other paramedics find that all different percentage oxygen masks are quite confusing and when they say, "oh we will have 28 % through this mask" or "they'll have 43 through this mask" or "all we have are Hudson masks or 100 percent mask"...erm: and then if the patient has got their own nasal cannula...' (HCP7-Paramedic-F, line no. 173-177)

'I've done a lot of advanced life support, everything was, we stick a hundred per cent oxygen on everything and obviously you've got to be, careful with,

yeah you give it for hypoxia but obviously not to over oxygenate people, so I find it very, very confusing sometimes.' (HCP13-Nurse Practitioner-F, line no. 16-19)

One GP seemed to sum up his perception of prescribing domiciliary oxygen quite succinctly: *'It's fairly well dealt with from a practical point of view, it's just nobody really knows much about what they're doing.'* (HCP29-GP-M, line no. 24-25)

Some individual HCPs seemed to hold views on where the origins of patients' misconceptions may lie. Media, as already discussed in relation to patient's own recognised antecedents to beliefs, was cited: again in particular TV:

'It's tricky because the public are sometimes misguided by conceptions that are conveyed on television or what not and that's going to be very, very difficult to change.' (HCP16- Paramedic-M, line no. 346-348)

'You know they say they have read something in the newspaper and they are taking up the same misconceptions.' (HCP5-Respiratory Nurse-F, line no. 410-411)

The HCPs' interviews lasted over 30 minutes for the majority. This allowed a dialogue to be developed and a candid approach to discussion ensued for many of the participants: this didn't differ whether the interviews were face to face or over the telephone. Occasionally participants would recall scenarios that involved poor practice. Confidentiality was always maintained by participants during these disclosures and the case studies were always relayed in the context of reflection and learning from past practice, rather than criticism. This student paramedic remembered an incident in practice following the delivery of a patient to A&E:

'... and we said do you want us to change him to a different mask for you or is he fine on a 100% mask? And they say "stick him in a cubicle and we'll get a doctor to him shortly". So we put him in a cubicle with his 100% mask on... He still had the 100% mask on when we took the next patient in, which was

probably about an hour, hour and a half, and he still had a 100% mask on then. And we were wondering is that on because they've just not bothered changing it and looking at his sats levels and altering things, 'cause they're all general medicine doctors, aren't they, in A&E, none of them are respiratory doctors, so maybe none of them have actually thought about readdressing his oxygen and bringing it back down.' (HCP4-Student Paramedic-F, line no. 541-555)

At times this was related directly to the perceived lack of knowledge and understanding of others:

'I was very intrigued and interested to see these patients been slapped on oxygen and the nurses really had very, very poor knowledge of oxygen therapy of how to instruct the patient to use it, it was almost like the patient was breathless 'cause they were exacerbated and... I think that's very poor and in the past we've had patients then discharged home on oxygen or the GPs have given them oxygen because they've asked the GPs, because they've told the GPs they're breathless and the GPs have said oh well we've give you some oxygen now.' (HCP19-Community Matron-F, line no. 139-147)

As one respiratory nurse summed up regarding oxygen therapy:

'It's misused, it's misunderstood, it can be lifesaving but also its life threatening if given incorrectly.' (HCP15-Respiratory Nurse-F, line no. 7-8)

These short renditions give some insight into contemporary clinical practice and the cultures and rituals that appear still to exist. What drives these practices appeared, from within the interview data, to be largely governed by both expectations and knowledge.

Expectations

Expectations seemed to play an important part in influencing both the way HCPs behaved and what they perceived with regards to prescribing and administering oxygen. These expectations, mostly influenced by *patients' beliefs*,

came from several different directions: *expectations of patients; expectations of family & carers and expectations of self.*

Patients' beliefs featured prominently in the interviews; in particular that patients felt oxygen was for breathlessness; it was a cure for their disease; and the notion that patients had fixed ideas which were difficult to influence or change through patient education.

Oxygen for breathlessness was a belief that HCPs had concerning patients: *'to cure that breathlessness, it's just oxygen and there's no other way to cure, to do it, and they won't be persuaded.'* (HCP22-Respiratory Nurse-F, line no. 45-46), or as a broader belief in the general population:

'I believe if you ask any member of the public, the vast majority, if you said to them "what do you think would help someone's breathlessness", they'd probably say "oxygen".' (HCP19- Community Matron-F, line no. 95-97)

The notion of the curative nature of oxygen was expressed further: *'they [patients] regard it as some kind of cure for their disease'* (HCP17-Community Matron-F, line no. 6). A respiratory nurse offers a perceptive theory of why many patients believe in the curative properties of oxygen and the dilemmas posed by patients who really believe that they are being deprived of an important intervention:

'I think they believe it's the oxygen that's got them better ... 'cause when they've come back in six weeks' time numerous patients have been quite shocked that they don't need the oxygen anymore, they, they, they'll say "but we do ... we do, I can't, I can't live without that", and then you've got, morally thinking, "oh God ... they've got to go home without this now".' (HCP22-Respiratory Nurse-F, line no. 388-393)

Many HCPs recounted how they felt when some patients developed very fixed ideas with regards their oxygen, often associated with a desire to have it and keep it;

the same respiratory nurse stated: *'They just love oxygen!'* (HCP22-Respiratory Nurse-F, line no. 74).

This love of oxygen and the status of their oxygen levels can become obsessive and lead to an over-reliance on emergency services:

'I have got a patient who lives in one of them very old long terraced houses and he has his pulse oximeter on his neck, you know it comes on a little string and when he walks to the toilet he'll measure it and when he walks back he'll measure it, and naturally it drops when he's exercising, and then he'll phone for emergency help and say his sats are only you know, eighty six or whatever.' (HCP17-Community Matron-F, line no. 80-84)

No doubt these patient-held beliefs and fixed ideas lead into, and influence significantly, *patient expectations*. These expectations themselves manifest different dimensions, and every HCP interviewed mentioned this aspect; it was the most prevalent finding in all the data from both HCPs and patients. The reasons for this level of expectation were multifaceted, including it is what always happens:

'I think probably that's always been the way, you know people expect you to give them oxygen as soon as they become breathless that's what they need.' (HCP13-Nurse Practitioner-F, line no. 224-225)

Whether this customary practice has led to patients always wanting oxygen was difficult to decipher, but overwhelmingly all HCPs agreed that generally patients want oxygen: it is seen as a good thing to have, a useful adjunct to treatment, and something that will fundamentally help them manage a very distressing symptom. As this paramedic recounts:

'And if they'd had previous experiences with oxygen, that's what they wanted and because you didn't realise anything more you would give it to them because, let's face it, they're saying it makes them better. You'd walk in the house and the first thing they would say is "can I have, I need oxygen, my doctor tells me I need oxygen", so it could just be a mild cough, or chest infection but because they've been told that there's a dysfunction of the lungs

they want more oxygen because they feel that there's no oxygen going into them and then when you give it they improve. That's all they're concentrating on "I can't breathe, you need to help me, "I can't breathe, you need to help me by giving me the oxygen" and that's, it's just that cycle going round until at some point you pop that oxygen on and then they'll tell you everything.' (HCP1-Paramedic-M, line no. 302-311)

Faced with such a scenario any HCP would find it extremely difficult to follow guidelines to the letter. A similar tale from a palliative care nurse:

'I think when they're breathless they automatically, they, many of them seem to, expect that it comes, always that you always get oxygen if you're feeling breathless.' (HCP3-Palliative Care Nurse-F, line no. 28-30)

It can also become a defensive action:

'I found that patients, again, because in the past they've received oxygen therapy as per standard, kind of sometimes expect it again, to get oxygen, you know oxygen always helps, and if they're not receiving anything, well why have they not received it this time.' (HCP6-Paramedic-M, line no. 20-26)

In the palliative care scenario to deny oxygen could be even more of a conundrum, and was observed as an emotional cost to the HCP:

'Patients seem to want to have oxygen a lot more often than they perhaps actually need it but they find it quite comforting and reassuring if they've got it, so we do tend to prescribe it occasionally to people in the community 'cause I tend to see people settling mostly and we sort of prescribe a low dose.' (HCP20-Lung Cancer Nurse-F, line no. 5-7)

In contrast to the compassionate approach offered above other HCPs claimed that on occasion patients used oxygen to validate their illness:

'I think it's a prescription isn't it in a sense and we've talked about the psychology of why patients want prescriptions, ...it sort of validates the severity of their illness, that if the breathlessness is so bad that they need oxygen then it's, you know, it's really bad, you know or has he got to that stage yet when he needs oxygen ... everyone signs up to that almost the

patient the carers the doctor, it's a mutual kind of, cycle that they've got into.' (HCP3-Palliative Care Nurse-F, line no. 285-292)

'I think that would take a large part of her identity away, because she actually is quite happy to sit on it 24 hours a day.' (HCP19- Community Matron-F, line no. 124-125)

Sometimes this was related to eligibility for state benefits:

'It makes them look sicker ...We've got quite a lot of patients at the moment, with regards to the benefit reform, the oxygen gets them a high rate of disability ...yeah, so we've got a lot of patients at the moment who are saying, "well they're going to stop my benefits if you take that oxygen off me".' (HCP22-Respiratory Nurse-F, line no. 432-442)

Bearing in mind all the discussion regarding patients' desires and expectations for oxygen it is hardly surprising that for patients who have been prescribed oxygen therapy unnecessarily, or have since improved and oxygen needs to be withdrawn, HCPs can, on occasion, encounter problems:

'... and you're trying to explain "we're going to take it off you", you know "we're going to go through a series of tests" ... it's quite a shock 'cause they've kept that little oxygen box there and everyone's done everything for them, 'cause when they get breathless they're going to have their oxygen, even though they don't need it. It's, it's a massive, massive catalogue of events ...' (HCP22-Respiratory Nurse-F, line no. 454-459)

Often the pressure put on HCPs from patients is in collusion with others and expectations from families and carers (*'we do get a lot of pressure from family'* - HCP19- Community Matron-F, line no. 127) featured significantly:

'I think em they're watching their relative, or the person they're caring for struggling and they have it in their head that when we get the oxygen — not "if" we get it, "when" we get it — this will make it, their life so much easier?, 'cause they've not got to watch them struggling then, 'cause that's obviously not a nice thing to have to watch.' (HCP22-Respiratory Nurse-F, line no.139-142)

Sometimes this was alluded to as an extension of the caring role to include families and carers:

'... and sometimes of course with the oxygen you're treating the relatives aren't you rather than the patient. You know, because the relatives are very upset by seeing somebody who's breathless and just by putting something like a fan there doesn't actually meet their needs and it's a bit like, I always call it 'the relative factor', it always appears in all sorts of situations, people treat patients for the relatives not for the patient.' (HCP23- Pharmacist-F, line no. 352-359)

The potential threat of withdrawal seemed to exacerbate these expectations and was reported to elicit quite emotive responses from both patients and families:

'We've had families ringing up or will come into clinic and say "you ... why do you want to take that off ...", you know "why do you want to take that off him?". We've had patients even saying "well I'll pay for it then if that's the case, don't take it off me, I'll pay for it" ... "why do you want to ... why do you want to take it off me ... why?", and I say "it's not me personally ... I'm just saying that you don't need it, so it promotes your independence if you don't need it", you know "we've got pulmonary rehabilitation we can refer you to there"... "I can't do an exercise class, I need my oxygen"' (HCP22-Respiratory Nurse-F, line no. 477-486)

In addition to expectations from patients, families and carers, HCPs also seemed to have *expectations of themselves* that, on occasion, influenced their decision making. For some this came in the form of their own beliefs and personal experiences of receiving oxygen:

'I can imagine it feels quite nice if you're on oxygen for a period of time ... I just remember when I've had an operation and I've had oxygen it feels quite comforting.' (HCP20-Lung Cancer Nurse-F, line no. 243-247)

For some it was an apprehension about oxygen prescribing because of lack of confidence:

Overall, education and training regarding oxygen therapy was perceived by the HCPs themselves to be lacking. An *ad hoc* or DIY approach prevailed and it was evident that, as a result, levels of knowledge and insight varied; at times this disparity in knowledge was reported to result in unsafe practice.

5.4 SUMMARY

The findings reported here capture the common features that recurred during the interviews from 28 patients and 34 HCPs as the interpretative analysis strove to portray perceptions from both sets of individuals; both within, and across the two groups. The major themes *Oxygen as a Panacea*, *the Burden of Oxygen* and *Antecedents to Beliefs* were common to both groups of participants; however the superordinate themes that were constructed to inform these were different between groups. Fundamentally, both patients and HCPs overwhelmingly regarded oxygen as some form of cure-all, a universal remedy whose merits sometimes were overstated when compared to the actual experienced effects. Principally this was directed to the use of oxygen for breathlessness. For patients this veneration of oxygen resulted in them often accepting it into their lives, and as part of their disease. For HCPs the recognised benefits of oxygen at times conflicted with their considered and informed opinion, and this caused dilemmas in practice which at times required difficult decisions and led to an emotional cost to caring. There was evidence conversely that the administration of oxygen can, at times, be as beneficial for HCPs as it is for those receiving the therapy. Both participant groups were aware of the burden that oxygen frequently brings, and whilst not the dominant attribute for all but one patient, these associated costs were ever-present and had a significant impact on existing perceptions.

In an attempt to understand the origins of perceptions, potential antecedents to beliefs and common practices were interrogated. Again differences between groups were apparent: for many patients an unquestioning faith in HCPs prevailed, often in concurrence to their experiences in the past, both personal and of others, and their knowledge and understanding of what oxygen is actually for and does; the majority did not appear to think about rationale at all. For HCPs an entrenched culture of giving oxygen to '*everybody and anybody*' was evident, influenced by expectations of patients, families and carers, and themselves. A dearth of formal training and education was reported, leading to a DIY approach to education.

The following chapter will draw conclusions from these discoveries, synthesise them with what is already known, and suggest aspects of the findings that may be worthy of further research.

CHAPTER 6 – DISCUSSION AND SYNTHESIS OF FINDINGS

6.1 INTRODUCTION

This chapter contains a discussion of the study's main findings and synthesising it to existent literature. Through establishment of underpinning similarities and divergences, new emergent knowledge will be highlighted.

Three overarching master themes were identified: *oxygen as a panacea*, *the burden of oxygen* and *antecedents to beliefs* all common to both groups, though superordinate themes differed.

Under each overarching master theme patients' perceptions will be considered first, then HCPs' perceptions, and, in terms of shared and variant features, leading into a combined overall summary of the study's main findings.

6.2 OXYGEN AS A PANACEA

The overarching master theme of oxygen as a panacea was common and dominant in both participant groups. The construct varied for patients and HCPs but for the majority oxygen was perceived as a positive therapeutic intervention.

6.2.1 Oxygen as a Panacea – Patients

Overwhelmingly patients report benefit from oxygen and regard it as a positive addition to the treatment of disease and management of symptoms. As individual cases were précised, initial analysis found that five patients were overall extremely positive with regards to their oxygen; one patient was negative (P3), but the vast majority (sixteen) seemed to have adopted a middle ground consisting of acceptance, compromise, adjustment and compliance. There seemed to exist, a

process of adaptation with benefits weighed against drawbacks – the outcome of this deliberation was as individual as the patients interviewed.

Three superordinate themes were identified from analysis of patient interviews constituting the overarching master theme. These are summarised in Table 16.

Table 16: Oxygen as a Panacea – Patients: Superordinate and ordinate themes

Superordinate Theme	Ordinate theme
Oxygen for Breathlessness	<i>'It helps me to breath'</i>
	Controls breathing
	Essential at times
Oxygen as an Enabler	Fosters independence
	Helps to do things
	Helps to go places
	<i>'With my oxygen I can walk'</i>
Grateful to the Oxygen	<i>'Keeps me alive'</i>
	<i>'Makes me feel better'</i>
	Oxygen works!
	Wanting oxygen
Oxygen as Part of the Disease	Compromise
	Acceptance
	Others' Acceptance
	Ambivalence

Without doubt patients perceive oxygen as a positive intervention. Patients expressed a belief and almost a reverence to oxygen, feeling grateful, enamoured and indebted. They considered oxygen as a friend in one form or another; a friend they were very grateful to have. In particular this related to oxygen in regard to, or belief in, its ability to quell or control dyspnoea. Enablement seems corollary to this reported relief of breathlessness which in turn reinforced the gratitude that patients

felt towards the therapy. For many patients the consequence of this gratitude towards oxygen is that they accepted and even embraced it as part of their disease.

Oxygen for Breathlessness

Patients' reported use of oxygen for relief of breathlessness was particularly prevalent. It is possible that in certain situations taking oxygen requires patients to sit still, perhaps for longer than usual, and focus on controlling breathing; its use in this manner acting as an adjunct or prompt for breathing control. In situations like these the oxygen probably serves patients in several ways: physiologically it may well relieve the work of breathing if any degree of hypoxia is present, in addition a cooling effect may also stimulate trigeminal nerves to slow breathing, finally the oxygen probably acts as a psychological support, reassuring the individual that an intervention to relieve their discomfort is being administered. Indeed, the ritual of putting the oxygen apparatus on may in itself constitute a placebo effect that results in subsidence of panic.

This placebo effect has previously been acknowledged (Booth et al., 1996; Lewis et al., 2003) but there is no empirical evidence to isolate the psychological effects from other physiological benefits. Several authors (Booth et al., 1996; Lewis et al., 2003; Bruera et al., 2003; Booth et al., 2004; Philip et al., 2006; Abernethy, 2010) have demonstrated that patients' dyspnoea can be improved with both air and oxygen, but with no significant difference between those who were hypoxic and those who were not. The current study suggests that there was no relationship between hypoxaemia and patients' overall acceptance or attitude to oxygen, though the evidence is not sound. This correlation has not been depicted in the literature before and therefore adds an important dimension.

The placebo effect will be an important concept to consider in the context of this study. Goldacre (2009) refers to the placebo effect as socially constructed. Benedetti et al. (2011) describes, not a single, but many different placebo effects, and mechanisms of expectation, anxiety and reward are all involved. In addition there is a variety of learning phenomena including Pavlovian conditioning (learned behaviour), cognitive and social learning with different social stimuli such as words and rituals (of the therapeutic act) which may alter brain chemistry (Benedetti et al., 2011). These factors could contribute to the response to oxygen and the notion that whatever made symptoms better when they were at their worst, must have been the reason for recovery. This then leads to expectations and reinforcement of expectation, which in turn may result in repeated patterns of behaviour. In the case of oxygen, this may be precipitated by HCPs' behaviour, in that when respiratory patients are acutely ill oxygen is usually administered. In this scenario there could also be an additional link whereby anxiety is modulated by expectations and placebo interventions (Benedetti et al., 2011).

While there is common understanding amongst patients that oxygen is given for dyspnoea, there is, also, a recurring lack of clarity regarding the rationale for why it was initially prescribed (Booth et al., 1996; Fraser et al., 2006; Gruffydd-Jones et al., 2007; O'Neill et al., 2005). It is possible that expectations may have an influence on perceived benefits and become a self-fulfilling prophecy. If expectations however are unrealistic then this could counter benefits and indeed result in a lack of compliance to prescribed regimes of oxygen.

Patients' understanding of the rationale for a prescribed medication has been linked to efficacy (Roberts et al., 1993), and unreasoned optimism (Wynne, 1989), factors which may influence perceived benefits and therefore expectation. There is

also a possible link here with mastery: if patients feel that they have some form of control over disease manifestations, their perception of illness and psychological disposition in terms of their outlook can be adjusted (Scharloo et al., 2007). Whichever way this is considered it was clear in the current study that expectations are important and central to an existent culture regarding the use of oxygen for dyspnoea.

Oxygen as an Enabler

The perception of oxygen as an enabler was another recurrent theme which seemed inextricably linked with symptom relief. As already highlighted oxygen efficacy does not appear to relate to patients' blood oxygen status, suggesting it may also influence patients' confidence, autonomy and sense of wellbeing, in turn enabling patients to maintain activity levels which would perhaps not otherwise be possible. This strategy appears to promote independence and enhance self-efficacy, and as a consequence patients often demonstrated an emotional attachment to their oxygen. For some this was incongruous in that oxygen enabled, through increased confidence and independence, yet dependence on oxygen perversely constrained activity. Similar contradictory consequences of oxygen have been identified elsewhere (Ek et al., 2011), creating independence through dependence in this way somehow seems inapt.

Oxygen as an enabler was a similarly important finding in the literature. The use of oxygen to enable performance of activities, through both the relief of and mastery of dyspnoea (Jaturapatporn et al., 2010; O'Neill et al., 2005; Adams, 2008; Cicutto and Brooks, 2006; Fraser et al., 2006; Neri et al., 2006; Goldbart 2013; Arnold 2011), and to actively manage disease (Cornford, 2000; Berg, 1996) has

been reported. This was identified as important in fostering self-management (Cullen and Stiffler, 2009).

Self-care and shared decision making are regarded as central to management of chronic disease; gaining insight into perceptions and respecting the patient's perspectives is therefore important (Kaptein et al., 2009; Wortz et al., 2012). In addition, domains of self-management have been identified as a psychosocial resource for dealing with chronic illness (Brooks et al., 2014) and positive beliefs about the effects of illness result in a better quality of life (Scharloo et al., 2007). Clearly, empowering patients to take control of dyspnoea and increase activity levels through self-management strategies will have beneficial effects to overall psychosocial wellbeing, and oxygen has been found, in the current study, to impact significantly on this.

This finding can be further linked to illness behaviour and experiences. Psychological and behavioural factors when linked to perceived severity and intractability of illness can be regarded as important. Patient education as an effective vehicle for interventions to modify these behaviours has been suggested (Kaptein et al., 2009) but should focus on addressing the patient's expectations in addition to improving care (Wortz et al. (2012). The current study highlights the importance of patients' belief in, and expectations of, oxygen and how these affect the overall attitude to self-management and mastery of disease manifestations.

Grateful to the Oxygen

Patients clearly exhibited a gratitude towards oxygen, which given the empowerment of enablement and symptom control, holds little surprise. Fundamentally, oxygen seemed to make patients '*feel better*' and these cognitive

benefits can be related to principles of cognitive behavioural therapy (Coventry and Gellatly, 2008). If a patient is optimistic and feels that, through the use of oxygen, their internal locus of control is enhanced then overall attitude towards illness, illness perception and their future will be affected. Generally oxygen for the majority was a positive addition to their therapeutic regime, despite lack of appreciation of why it was prescribed, how it worked, or countenance of drawbacks.

Findings showed that oxygen is regarded as synonymous with life and living, and therefore can be seen to represent a shield against death. Many patients expressed the sentiment that oxygen was keeping them alive and indeed that it was essential in this respect; a response elicited from patients receiving different regimes of oxygen and, on occasion, as an anticipatory need. The notion of oxygen keeping patients alive has been similarly reported elsewhere (Adams,2005; Arnold et al., 2011; Ring and Danielson, 1997; Lai et al., 2007; Jaturapatporn et al., 2010; Hasson et al., 2008).

It is hardly unexpected then, given all the perceived benefits, that patients in this study were often found to *want oxygen*; a finding not seen elsewhere. For one patient in particular, P17, this was an imperative goal. Despite normal oxygen saturations (93% on room air) he reflected on how helpful oxygen had been in the past. Although referred for assessment by his GP he did not meet the criteria for prescription, his interpretation: oxygen had been declined. Since his breathlessness was now worsening it seemed logical to him that if oxygen had worked previously it should help now, possibly even more so. He referred to a need to '*fight the system*' in order to convince HCPs that he needed oxygen: he saw the study interview as a further opportunity to put pressure on the *system* requesting that I write to the GP and hospital supporting his case. This desire for oxygen for both him and his wife

seemed overbearing to them and highlights a lack of clear communication between them and the HCPs caring for them, but also possibly between HCPs themselves.

Counter to this *want*, was a fear of withdrawal of oxygen; several patients remarked on this possibility during interviews and needed some reassurance that this was not the purpose of my visit. This fear of withdrawal is not evident in the existent literature and consequently is reported here for the first time. The previous lack of reference to withdrawal may be because few studies have been conducted since the reorganisation of domiciliary oxygen services in the UK (BTS, 2006) when widespread re-assessment of patients often led to recommendations for withdrawal. This finding further highlights the importance of clear communication regarding both the rationale for oxygen and future expectations for the patient.

Fundamentally patients in the current study wanted and/or expected oxygen; particularly during a crisis. This may be inextricably linked to their perception of oxygen as a panacea or as a result of psychological dependency linked to the placebo effect. Of course, for some this could have been related to physiological benefit through the correction of hypoxia – but this was difficult to extrapolate during interviews as patients saw benefit from oxygen in both acute and stable non-hypoxaemic phases of their disease sequelae. This esteem in turn manifests in their gratitude and want, probably contributing significantly to their ability to accept oxygen as a necessity in order to tolerate the consequences of their disease and adjust lifestyle.

Oxygen as Part of the Disease

Experiences with oxygen differed for all individuals but acceptance seemed inevitable for the majority. This acceptance was often expressed by means of

compromise, ambivalence and just getting on with things. Acceptance from others, both families and carers, and the general public, was also an important feature.

Compromise and acceptance incorporated both physical inferences and lifestyles changes and were often articulated as '*putting up with it*'. The forfeits were expressed as worthwhile in relation to benefits and the relationship with death and living served as a constant reminder to many that the sacrifice was worth it. This identified pragmatism shared similarities with the literature, as seen in the synthetic constructs of *adaptation, compromise and trade-off*, all leading to the idea of impartiality and oxygen as a mixed blessing (Cullen and Stiffler, 2009; Cornford, 2000; Earnest, 2002; Jaturapatporn et al., 2010; Ingadottir and Josphottir, 2006; Ring and Danielson 1997; Wrench, 2012).

Acceptance from others too was deemed to be important. In the literature this came across only as a negative domain (to be discussed later), however the current study exposed more positive connotations. This was evident in patients reporting others' reactions to seeing them with oxygen eliciting sympathy: '*people have been very, very kind*' (P19); '*they're nicer to you*' (P23). For others oxygen was expressed as a public symbol, reiterating findings found elsewhere in a negative sense (Earnest, 2002; Williams, 2007). In the current study however, this was regarded as a positive sign: '*This shows him I'm ill*' (P1); a validation of illness. This can be corroborated by Parsons' theory of the sick role (Parsons, 1951). Parsons viewed sickness as a response to social pressure which permitted avoidance of social responsibilities (Lubkin and Larsen, 2009). A view expressed elsewhere as 'illness as an occupation' (Herzlich and Graham, 1973:126). In this way oxygen can be regarded as a metaphor for disease – a very visible sign of severity and endorsement for what is often an invisible illness. Harrison et al. (2014) identify a

similar concept through meta-synthesis of pre-existing literature that explored patients' responses to acute exacerbations of COPD. They recognised that by making breathlessness visible to others, patients could communicate the seriousness of their condition. In this context, considering the relevance of hope and imagined futures in patients with long term conditions, illness can be considered as an extension to identity (Brooks et al., 2014). Oxygen can be symbolic of illness in this compartment.

Overall patients' positive disposition regarding oxygen therapy may well affect behaviour and compliance, not only with oxygen, but with other disease management interventions. A link between mortality, reduced hospital admissions and positive health outcomes has been found to be independent of active drug or placebo arms in several RCTs (Simpson et al., 2006; Vestbo et al., 2009), supporting the concept of the *healthy adherer* (Hays et al., 1994). This would suggest a bias activating other positive behaviours or indeed that compliance is a character trait. This is not a new concept: in 1983 Morgan et al. demonstrated that attitudes and beliefs outweighed effects of mood and lung function capacity during functional assessment, suggesting that psychological interventions aimed at increasing confidence and reducing fear may reduce disability. Those involved in provision of pulmonary rehabilitation programmes are well aware that benefits go much deeper than physical fitness. A similar concept could be related to oxygen in that, through beliefs in its attributes and reliance on it, patients may be exhibiting the characteristic trait of *healthy adherer*.

These illness perceptions have been shown to relate to quality of life (Scharloo et al., 2007). By understanding how patients interpret and experience their illness, HCPs can integrate illness beliefs into contemporary approaches to self-

management, such as pulmonary rehabilitation (Lacasse, 2006a; Puhan, 2011) and cognitive behavioural therapy (Coventry and Gellatly, 2008). Focusing on strengthening beliefs in personal control and correcting erroneous beliefs that manifest in the reliance on oxygen, may prove a useful strategy in altering patients' perceptions and expectations.

Interestingly, in contrast to the optimistic dominance found in the current research, Clancy et al. (2008) reported *only* negative findings from their phenomenological study of existential experiences of COPD patients and their carers, though this focused on the disease as a whole rather than just oxygen. Perhaps the wider burden of disease is the reason why so many patients in the current study viewed oxygen as an overwhelmingly positive therapy when used to fight disease and symptoms.

To summarise, patients clearly regard oxygen as a panacea. It appears to play a vital part in the management of dyspnoea, but this does not relate to blood oxygen levels for all patients; this is the first time that this has been correlated to perception. This in turn enables them to participate in a more active and independent lifestyle, impacting positively on quality of life and reinforcing patients' *want* for oxygen; a unique finding in this study. How oxygen entwines with patients' lives appears to consequently inform their perception of illness, control and attitude to disease and for many was regarded as positive validation of their illness, a further unique contribution to knowledge. Patients are grateful for the crutch that oxygen symbolises and are willing to put up with its intrusive nature and accept it as part of their disease. Although potentially underlying physiological benefits underpin this positive regard for oxygen it is clear that psychosocial perspectives likewise play an important role.

that oxygen is beneficial to patients, in some manner, was universal. HCPs reflected on the utility of oxygen and deliberated during interviews whether or not this was due to psychological manifestations, including the placebo effect. Sometimes this notion of efficacy was cited to justify using oxygen, at other times it defended against not adhering to guidelines, and was related to individuals' personal behaviours and observed practice in others. The use of oxygen for the management of breathlessness was similarly found in the majority of studies reviewed (Abernethy, 2005; Atiş et al., 2001; Barr et al., 2005; Brearden et al., 2013; Neri et al., 2006; Roberts et al., 1993; Stringer et al., 2006).

An awareness of the placebo effect seems embedded in historical practice (Chapter 2) and was linked to the notion of oxygen being harmless. This was also observed in the CIS; where nurses acknowledged the psychological effects of oxygen and the symbolic benefit (Roberts et al. 1993). In the current study HCPs were likewise aware of the psychological dependence that oxygen could foster, and related this to the management of anxiety in addition to potential placebo effects. But HCPs found this difficult to quantify, often revealing doubts regarding what factors actually played a part in subduing the patient's breathlessness. During these conversations HCPs often reverted to highlighting the fact that *it just works*, at times questioning the importance of knowing the mechanism.

Myths & Beliefs

Irrespective of sound knowledge, an individuals' justification for resistant practice and cultures was related to existent myths and beliefs that feed into persistent rituals. Some with limited knowledge, for example HCP26, a student nurse, made direct naive comments substantiating these myths: '*You can't really*

have too much oxygen in your body'. Otherwise the majority of HCPs, although knowledgeable, reported habitual practice as persistent in others and uncertainties regarding oxygen exist. Whether relating poor practice to others was a result of the inherent bias in the study population – individuals with an interest in oxygen – or it was careful circumnavigation of disclosing their own personal persistently poor practice, is not clear.

Either way, it was obvious from interviews that out-dated practice endures and over-rules guidelines in certain circumstances, perpetuating existent uncertainties. This in itself would point to a culture of entrenched practice at an organisational level that is difficult to change despite an individual's knowledge and understanding of oxygen therapy. This was particularly evident in acute situations when giving oxygen appeared to be a reflexive practice. A custom rooted in history as outlined in Chapter 2, the perception being: the greater the dyspnoea or the sicker the patient, the greater the need for oxygen. Widespread accessibility of oxygen possibly perpetuates this situation and acts as a barrier to implementing change.

Overuse and misunderstanding of oxygen therapy by HCPs is common (Downs, 2003; Troosters, 2004; Calverley, 2005; New, 2006; Tin, 2002), although rationale appears elusive. It has been intimated previously that a culture may exist whereby oxygen is given automatically to patients who present as critically ill or dyspnoeic (New, 2006; BTS, 2008; Austin et al., 2010); this is the first time that articulation of this culture, underpinned by beliefs, misconceptions and myths, has been captured and reported as empirical data.

Social constructivism is said to be based on these norms (Creswell, 2007) and can be used to formulate why an individual's perceptions form; social norms theory therefore helps to see why group perceptions persist and are bigger and wider than the individual. Utilisation of IPA in the current study has enabled individuals' understanding and positionality of the experience of oxygen therapy – whether a patient or a HCP – as a socially constructed phenomenon to reveal the existence of these social norms with regards to oxygen therapy. In other words how reality is constructed and, for individuals, how subjective meanings – negotiated both socially and historically – are formed through interaction with others.

It is however possible to change norms. The societal attitude to smoking over the last few decades is one such example and similar multipronged approaches to the growing issue of problematic social drinking are being currently applied. It has been suggested that false consensus and misperceptions mutually reinforce and self-perpetuate social norms (Berkowitz, 2004) and in order to break this cycle there is a need to provide accurate normative feedback. In the past this has required large co-ordinated campaigns targeting all affected parties; for oxygen this would be HCPs, patients and society as a whole in order to target the socially constructed perception of oxygen as a universal remedy. To date, small projects have attempted to initiate changes in oxygen prescribing in emergency situations at local levels but repetitive audits have shown that although improvements have been made, resistance is evident (Davidson et al., 2011; Lee et al., 2013; O'Driscoll, 2014). These past attempts have been singularly focused on HCPs through provision of education and changing the social norm of oxygen administration. Perhaps to have greater effect campaigns need to simultaneously target patients and the wider population. Likewise similar approaches with regards to domiciliary oxygen are

necessary. In the past, attempts to control domiciliary oxygen prescribing, including palliative oxygen, have focussed on financial inducement (RCP, 1999; BTS, 2006; IMPRESS, 2011; NHSImp – Lung, 2012). Potentially, highlighting detrimental effects and drawbacks to all involved parties, and therefore bringing it back to the immediate prescriber-patient relationship, may help to incentivise alternative strategies to the use of oxygen therapy in a broader context.

Compassion

The final superordinate theme relating to oxygen as a panacea for HCPs is *compassion*. Most HCPs in this study were well informed regarding oxygen therapy. Despite this, and without exception, all healthcare professionals interviewed indicated that the use of oxygen in a palliative care situation was always permissible. This paradox was true even for respondents who had generally aired caution and reserve when using oxygen in other normoxaemic patients, reverting, within the palliative scenario, to the default position of '*just give it*'. This stance could be seen as a resignation of inevitability. Faced with a patient suffering from intractable dyspnoea, together with concerned and often distraught families, HCPs will predictably opt for any means available to alleviate suffering. If the outcome is as predictable as death, it is hardly surprising that HCPs resort to oxygen as an intervention, sooner, rather than later.

These findings add to existing literature supporting the prevalence of oxygen to relieve dyspnoea and provide comfort (Abernethy, 2005). Roberts et al. (1993) suggests that oxygen was often given to provide psychological support to patients and carers; the current study supports this and endorses the idea that, in addition, HCPs may indeed even be prescribing oxygen to appease their own frustration and

guilt regarding not being able to offer any curative treatment for the underlying condition.

Compassion is an important emotional response; for most HCPs it is possibly an innate reaction connected directly to their vocational occupation. Superimposed on this, and evident from the data, is the issue that no-one wants to be seen as the '*bad guy*' for withholding oxygen, with the potential to cause further distress to patients and families. This is a wider issue in palliative care, and analogies with when to stop futile radiological imaging and chemotherapy can be drawn. This inherent need to do something and pacify patients, families, carers and even colleagues, can often overwhelm HCPs. This innate protective kindness probably influences patients', carers' and colleagues' perceptions regarding the need for oxygen and further endorses oxygen as a panacea; a cyclical predicament. One could argue that there will always be a need to try something else with intractable dyspnoea by the very nature of its obduracy. This finding can be endorsed by similar recorded frustrations by family physicians who found that controlling dyspnoea is a significant challenge: "*you run out of tricks*" (Young et al., 2012:e405).

It seems oxygen is given to comfort patients and carers, and enables HCPs to feel that they are doing something. Clearly education of HCPs will be a central catalyst to initiating change in this culture and mindset. This will require not only dissemination of guidelines and evidence but also promotion of fundamental principles of oxygen physiology in order to inform decisions regarding what is best for patients. This in turn will foster confidence and hopefully break the habit of intuitive practice of treating all that is breathless with oxygen. Relief of dyspnoea can be considered a human right (Currow et al., 2014) but this should not be at the expense of other aspects of the patient's care and comfort.

So it can be summarised that oxygen, for HCPs, is regarded as much as a panacea as it is for patients. This appears to be related to its effectiveness in controlling dyspnoea, relieving anxiety and helping the HCP to do something tangible to intervene for both acute clinical presentations and intractable dyspnoea. Practice seems to be based on tradition and an existing culture is evident. The cycle itself appears to become self-perpetuating and practice and expectation is endorsed through continuation of the norm. The current study serves not only to further illuminate the positive perceptions that HCPs have of oxygen, but also to detail the broad spectrum of perceived benefits including, importantly, those related to helping HCPs themselves.

6.3 THE BURDEN OF OXYGEN

In contrast, but juxtaposed, to the prevalent perception of oxygen as a panacea, both patients and HCPs showed an awareness of drawbacks and burdens that oxygen may impose. Again the ordinate themes for each cohort differed but awareness of negative aspects, to some degree, was apparent for all participants.

6.3.1 The Burden of Oxygen – Patients

Oxygen as a panacea, for the majority of patients, was the most prevalent perception, but for many there appeared an additional forfeit and the burden was not insignificant with acknowledged alteration of lifestyle and body image. Two superordinate themes were identified from the analysis of the patient interviews forming the overarching master theme. These are summarised in Table 18.

potentially impact on individuals' ability to maintain independence and achieve integration into mainstream society. Thus oxygen can be regarded as a stigma, in relation to which Goffman (1963) refers to the 'self isolate' (p24), who, lacking daily intercourse with others, can become suspicious, hostile, anxious and bewildered; responses observed in certain individuals in the current study. Although initial resentment at the intrusion that oxygen imposed was obvious for several patients, nonetheless, for the majority, this was latterly overcome to the point of acceptance.

A further related negative aspect expressed by patients was that of permanency. Again, patients were found to resent the intrusion of oxygen and the revelation that this was a perpetual fixture. In particular this response was most evident and extreme in P3, the female patient who had not accepted oxygen at all and felt quite bitter about the invasion of both oxygen and its imposed limits. Oxygen was for her, and several others, seen as an intruder. The difference for this particular patient was that she did not compromise and accept oxygen. The irony of course in this particular instance was that oxygen had been prescribed as a treatment for dyspnoea and was not needed for correction of hypoxaemia.

Permanency, as such, was not evident in the literature but connotations can be found when considering the synthetic constructs of fear, especially of the expected decline and what oxygen represented in terms of inevitability. This was particularly poignant when related to memories of others (Earnest, 2002; Clancy et al., 2009) and perceived consequences that followed the introduction of oxygen.

Associations with declining disease, death and the idea of permanency all seem to relate, directly and indirectly, to the final ordinate theme of *embarrassment*. The current study revealed that embarrassment was common. This was at times

Table 19: The Burden of Oxygen – HCPs: Superordinate and ordinate themes

Superordinate Theme	Ordinate theme
Awareness of dangers	Dangers of smoking
	Oxygen as a poison
	Trips, falls and hazards
The patients' burden	Changes to patients' lifestyle
	Dependency
	Side-effects
	Cost
Dilemmas	Controversy
	Doubt

Awareness of dangers

HCPs were aware of the dangers associated with oxygen, more so than patients. In particular, the dangers of smoking and the potential combustible features of oxygen were prominent, especially in relation to domiciliary oxygen therapy, drawing on anecdotal examples and expressing concerns in relation to safety of patients, themselves and others. This expressed frustration may be motivated by an on-going contention that exists regarding whether indeed to prescribe domiciliary oxygen to smokers (Lacasse et al., 2006b) and variations in practice exist (Lee et al., 2011). This theme was not found in any of the reviewed literature regarding perceptions, possibly because of a contemporary emphasis on safety (resulting from re-organisation of domiciliary oxygen services {BTS, 2006}) or possibly because of existent contention which may serve to negate open discussion.

HCPs were also aware of the dangers of over-oxygenation, although how well this was articulated varied amongst individuals; a finding supported by others (Considine et al., 2005; Considine and Botti, 2006). In this study, those with underpinning knowledge were much more confident in their renditions of applying

guidelines. For others, answers were ambiguous and reflected an unsound knowledge base. Individuals' confidence in articulating dangers were clearly related to understanding and justification of recommendations, a trend that is probably transferred into clinical practice.

Both the issues of deliberating with regards to patients' continuation to smoke and the potential to invoke hyperoxaemia manifested as HCPs own anxieties regarding decision making in the clinical field. These aspects were portrayed as important to clinicians and will be discussed later in the context of dilemmas.

The patients' burden

Additionally, HCPs were mindful of the patient's burden, including changes to the patient's lifestyle, development of dependency and side-effects. This posed further tensions for HCPs trying to promote the patient's physical activity and social integration, yet knowing that oxygen was restrictive and had a negative impact on quality of life. In addition, HCPs expressed awareness of the potential effects on mood for the patient; heightening depression and raising awareness of impending death were cited as examples. Although previous literature has highlighted these burdens (Booth et al., 2004; Brearden et al., 2013) *per se*, this is the first time that this awareness has been shown to influence HCPs' perceptions.

Dependency and how this further affects patients' lifestyles together with the psychological impact also raised concern. It was felt that oxygen could induce helplessness and presented a quandary for HCPs advising patients. Side-effects were familiar and awareness of additional burden, particularly in palliative care contexts, was apparent. Dependency was also recognised in a similar manner to the fear of addiction expressed by patients, but accepted by HCPs as a psychological

dependency rather than a physiological one. HCPs even felt that oxygen could contribute to patients' anxieties because of the fear of it not being available or within reach. This was also reiterated when discussing how some patients feared oxygen being withdrawn, further endorsing dependency.

Several HCPs related these drawbacks to issues of compliance in patients and this was related to difficulties encountered when a patient's understanding of the purpose of oxygen was at odds with the HCP's. Rather than following a prescribed regime, HCPs reported that patients, confused by mixed messages, often defaulted to taking oxygen for breathlessness – resulting in over or under use.

The issue of financial cost, in particular the implications for cost-saving, was raised by a few individuals but was not seen as a priority. One individual (HCP23) with responsibility for commissioning services reflected on the issue that more recent changes to oxygen supplier contracts had in fact disincentivised judicious prescribing in the community. Another participant reflected that maybe consideration of cost was something that they should be doing, but in the context of compassion, it was often discounted. This unique finding would suggest that government strategies to reduce overall cost of oxygen prescribing may not feature as highly to clinicians as they do to commissioners of services.

Dilemmas

Data from HCPs demonstrated that drawbacks were clearly an important consideration. In the context of oxygen as a panacea this clearly posed clinical *dilemmas*. This issue was particularly poignant when oxygen use in palliative care was discussed.

When a patient's blood oxygen remains normal, yet dyspnoea is persistent and intractable, an argument presents itself which leads to contention and confusion in practice. This poses a dilemma for HCPs who, faced with conflicting advice and information, strive to provide optimum care for the dying patient. This study has illuminated this previously intangible perspective of professional dilemmas regarding oxygen. Controversies regarding oxygen seem ubiquitous in practice as reported by participants, in particular in relation to criteria for prescribing oxygen, when ambiguity in addition to conflict of opinions was discussed.

Erroneous beliefs were also apparent, again more frequent in relation to palliative oxygen; HCPs questioned whether oxygen may prolong life in these circumstances and possibly protract suffering. The emotional cost of these deliberations was obvious, with HCPs reflecting on the consequences of refusal. Doubts regarding the efficacy of oxygen with regards to its role in palliation were also evident and scepticism was exposed; sound knowledge and understanding sometimes serving to compound the issue rather than clarify it. HCPs were aware of ethical issues and the deception of, or collusion with, patients was referred to in the context of what the HCP believed, and what they did in practice. If the two were antagonistic then it was clear that an emotional cost was incurred by the individual. The anxiety whilst debating these dilemmas was at times quite tangible within interviews. The more informed the HCP was, the worse the anguish became; a finding that has not been reported before.

It seems patients and families often expect and welcome oxygen but the overwhelming perception of it as a solution to dyspnoea can conflict with HCPs' own doubts and experiences. Brearden et al. (2013) highlighted that specialist palliative care nurses felt sometimes that there was an additional need to manage

expectations of families, caregivers and other clinicians. It was reported that it was sometimes easier to initiate oxygen to '*treat the caregiver's anxiety*' (p270) despite no clinical indication. Since patients and carers regard oxygen as synonymous with life, denial of oxygen may be hard to defend. Given that one of the overriding concerns regarding death for a respiratory patient is their fear of breathlessness and suffocation (Gardiner et al., 2009) the situation is worsened.

It appeared in the current study that there was often an irresistible need for HCPs to *do something* when caring for a patient with intractable dyspnoea; the drivers for this appear to be both external: to appease patients and relatives who believe in, expect and welcome oxygen; and internal: in that it helps HCPs feel better about themselves in their caring role. Issues such as collusion and deception were evident and at times caused HCPs to question their own professional integrity. HCPs often felt frustrated and did not know what else to do.

Insight into inconsistencies of oxygen prescription and administration in palliative care were evident and has been reported elsewhere (Abernethy, 2005; Stringer et al., 2004). Additionally, frustrations of family physicians treating dyspnoea in the palliative care context generally have been reported: '*weighs you down emotionally*' (Young et al. 2012:e404), but the finding of propensity for clinical dilemmas and related emotional cost, in relation to the use of oxygen for dyspnoea, is unique.

Likewise dilemmas are presented to HCPs when administering oxygen in the emergency situation. Guidelines suggest that oxygen should now, contrary to tradition and long-established historical practice, be withheld in certain categories of patients. Clearly for some individuals this seemed counter-intuitive and indeed

threatened the reliability of decisions, compounding pressure experienced in the clinical field. Variables such as expectation and pressure from patients, carers and colleagues were cited to influence decisions, especially when HCPs lack confidence in enforcing guideline recommendations. Austin et al. (2010) identified a similar problem when analysing their RCT data to find that adherence to study protocol was often breached, more so in the titrated (56%) rather than the high-flow (21%) oxygen arm of the study. This finding supports the existence of, and exposes, an entrenched culture and stubborn values which, at times, impede HCPs ability to comply to guidance; an original finding.

These aspects of practice in relation to oxygen have not been reported previously. This study is the first to reveal that HCPs often face deliberations in making difficult decisions regarding oxygen therapy and are influenced by extraneous variables; an emotional cost is evident.

6.4 ANTECEDENTS TO BELIEFS

In an effort to expose potential causes and circumstances that lead to common perceptions and misconceptions, the interview schedules probed potential influences, opinions and beliefs in an effort to understand why individuals perceived oxygen the way that they did. Some enlightenment with regards to *antecedents to beliefs* was uncovered, giving rise to a third master theme and exposing some possible influencing factors that may precipitate persistent erroneous beliefs and poor clinical practice.

6.4.1 Antecedents to Beliefs – Patients

For patients, these potential antecedents were organised into three superordinate themes which are summarised in Table 20.

Table 20: Antecedents to Beliefs – Patients: Superordinate and ordinate themes

Superordinate Theme	Ordinate theme
Faith in HCPs	Faith in HCPs
Past Experiences	Personal experiences
	Others on oxygen
	Social media
Knowledge, Education & Understanding	How oxygen works
	Information
	Mixed messages
	Patient knows best

Faith in HCPs

Faith in healthcare professionals was an important finding, supporting similar previous literature (Jaturapatporn et al., 2010; Earnest, 2002; Cicutto and Brooks, 2006; Adams, 2005; Habraken et al., 2008; Lai et al., 2007; Ring and Danielson, 1997). Although not reported by all, for those individuals that expressed their trust in HCPs, the concept came across powerfully. These patients appeared to put total trust in the HCP, alluding to superiority and adopting a subservient attitude: ‘*you’re in charge*’ (P5). At times this was relayed as deferral of decision-making, letting another do the thinking and take responsibility for choices. HCPs were regarded as the ‘*experts*’ who knew what they were doing; a deference that will be discussed further in context of HCPs’ knowledge and understanding.

Faith in HCPs was similarly noted by Harrison et al. (2014) in relation to COPD patients' needing to be *saved* at times of acute dyspnoea. This stemmed from fear and incompetence at self-management and respondents often felt that in order for their needs to be addressed, hospitalisation was required. Hill Bailey (2001) included the perceived need for oxygen and faith in HCPs related specifically to '*The Rescue*', when urgent care was needed in the face of the fear of impending death. This identified passivity may reflect patients' lack of self-efficacy and control over the situation. It seems that if available in the home, oxygen is utilised to control breathless up to a point, but when acuity intensifies and panic sets in, the patients' coping strategies are quickly depleted; a deferral to HCPs which usually manifests in a visit to the GP or call to emergency services.

The propensity for this faith in HCPs can be further associated with compliance and act as a motivator for self-care. It can also be related to non-compliance through misinformation or mixed messages. In this situation patients regarded the HCP as the expert; trust was evident and appeared to be built on faith, not only in the individual clinician, but also faith in their knowledge and familiarity with the therapy. It was rare within interviews for patients to question HCPs' knowledge and understanding.

Past Experiences

Past experiences certainly influence patients' perceptions of oxygen and reflections on their own previous care and that of others known to them were common. In particular these seemed to centre on acute care, especially emergency transfer to hospital. Patients discussed relief; a finding that is analogous with feelings of safety found in the literature (Ring and Danielson, 1997; Lai et al., 2007;

Jaturapatporn et al., 2010; Hasson et al., 2008). No insight into tangible reasons for this feeling of safety were however apparent in the literature; the findings here endorse faith in the HCPs as a potential source of this perception. For a patient experiencing acute dyspnoea, their fear can be somewhat quelled by the presence of a clinician, an ability to hand over their care, indeed their destiny.

Expectation was also identified as an antecedent related to past experiences. Patients reflected on oxygen as a symbol of acuity and administration was regarded as the norm. This was also relayed in their reflection of others receiving oxygen: it worked, it salvaged them, it was synonymous with recovery. Findings similar to *keeping alive* identified within the literature (Adams, 2005; Hasson et al., 2008; Jaturapatporn et al., 2010; Lai et al., 2007; Ring and Danielson, 1997) and in *memories of others* (Berg, 1996; Clancy et al., 2009; Earnest, 2002; Gardiner et al., 2009; Williams, 1993).

It has been suggested that other people are often used as a reference point against which patients judge themselves; a social comparison against which hope is fostered (Brooks et al., 2014); a finding evident in the current study through numerous recollections from patients regarding what happened to others receiving oxygen in an emergency.

But death was also a prominent feature and oxygen for a few was seen as synonymous with demise. Cultural beliefs, both patients and HCPS, are obviously a powerful influence on attitudes to oxygen. Stevenson et al. (2014) discussed these attitudes whilst exploring barriers to acceptance of oxygen in Malawi. Many patients and parents of sick children often refused oxygen for pneumonia, a common cause of death. A perceived association with death in the study was a recurrent theme, and

cited as a reason for refusal of oxygen. Past experiences and hearsay were the main factors that influenced this; when the previous experience was positive, oxygen was viewed as tantamount to saving life and the attitude was altered. Within the present study similar influences were apparent: real life reflections had both positive and negative connotations depending on the particular memory of the individual. This confirms that previous experiences are powerful influences on perceptions.

When reflecting on media the same dichotomy of oxygen as a life-saver and a representation of death was portrayed and patients cited influences such as television soap operas, advertisements and medical dramas. The internet also featured as an additional source of information either to supplement, or in the absence of replace, information provided. Reflections on how these various resources influenced perceptions were as diverse as the individual experiences. Nonetheless, the potential for media messages to influence perceptions and commonly held beliefs may be important for challenging common misconceptions.

Knowledge, Education & Understanding

Fundamentally the majority of patients in this study failed to demonstrate a sufficient knowledge of oxygen or the rationale for prescription. The majority took the default position of presuming that oxygen was given for breathlessness. Some claimed that they didn't want, or feel the need, to know, others just didn't want to think about it. It could be that these predispositions are in fact further signs of the shift of responsibility to HCPs. Others had totally misunderstood the relevance and imagined/envisioned physiological effects such as cleaning the blood or opening up the airways as being responsible for beneficial effects. Whether these misconstrues were a result of misinformation – from several potential sources such as HCPs,

social media, rumour from others or simple guesswork – is not clear from either the literature or the findings presented here. When presented at a local respiratory nurse forum this finding was disputed by the fact that patients are provided with the necessary information from various sources such as the oxygen supplier – there was no excuse for not knowing. Further interrogation of the data revealed that rather than not being provided with information, patients just did not think, or did not want to think, about oxygen; a feature not previously seen in the literature.

Reasons for this lack of comprehension were not entirely forthcoming, though information overload was identified as a barrier to understanding for some. Possibly the use of jargon and medical terms contaminate patients' ability to understand. Additionally, lower health literacy in COPD has been associated with poorer health status and higher health-care utilisation (Omachi et al., 2012).

Unpublished government surveys on home oxygen reported by the NHS Lung Improvement Agency (2008) suggest that patients do not always consider oxygen as a treatment, as they do with other drugs. This was identified as a barrier to implementing guidelines regarding emergency oxygen therapy, citing patients' attitudes and culture towards oxygen as an influencing factor; however no empirical evidence was presented.

Patients also reported mixed messages and this potentially impacted upon their understanding, confusion and ultimately perception. On occasion this resulted in patients doing what they thought best in the face of conflicting advice. Ultimately this approach resulted in non-compliance, either in terms of under-use or over-use of prescribed oxygen.

From the literature we know that patients' knowledge and understanding is important and can influence compliance and patients' feeling of safety in respect of oxygen for relief of dyspnoea (Peckham et al., 1998; Godey et al., 2012). Likewise lack of knowledge can add to patients' anxieties and fears (Gruffyd-Jones et al., 2007). Health beliefs therefore can be considered important in the context of what influences perceptions. Godey et al. (2012) have demonstrated that education has the ability to alter patient's compliance regarding LTOT through the identification of problems and implementation of interventions. Patient's perception of illness and treatment therefore can be seen as a target for modulation by any form of education programmes or interventions.

So, when looking for possible antecedents that inform patients' perceptions of oxygen, the picture is not entirely clear. Knowledge, education and understanding are key, and some enlightenment in examining these aspects can be found. Although some patients understand the principles of oxygen and the rationale for prescribing very well, these were a minority. Fallacies were evident that may lead to hyperbolic expectations and justify the intrusion of oxygen. The vast majority of patients interviewed were unsure of what oxygen did or why it had been prescribed; for many, oxygen was not warranted under current guidelines. Many reverted to the default position that it was for breathlessness.

Patients' perceptions of oxygen have clearly been influenced by media, personal experience and memories of others, in particular related to paramedic interventions. It is likely that because these interactions are the most dramatic they are also the most memorable.

Knowledge and education generally appeared lacking and a unique finding in relation to this was that patients *don't think* or *don't want to think* about oxygen; whether this reflects the wider population of respiratory patients cannot be verified. Regardless of sources of information or influences on perception, however, faith in HCPs was for the majority absolute. This may be associated with the age range of patients, mostly elderly and for whom deference to authority may be reflective of an established social culture.

6.4.2 Antecedents to Beliefs – HCPs

In an effort to uncover potential antecedents to beliefs for HCPs three superordinate themes were identified. These are summarised in Table 21.

Table 21: Antecedents to Beliefs – HCPs: Superordinate and ordinate themes

Superordinate Theme	Ordinate theme
Culture	It's what always happens
	Historical practice
	Power relations
	Mixed messages
	Social media influences
	Poor practice
Expectations	Patients' beliefs
	Expectations of patients
	Expectations of family & carers
	Expectations of self
Knowledge, Education & Training	Lack of knowledge
	Lack of education & training
	Do it yourself education
	Guidelines

Culture

Several ordinate themes were identified that may potentially influence existent HCP perceptions of oxygen therapy. Closely related to first response in emergency care, HCPs referred to a presiding culture of historical practice. This refers back to reflexive practice discussed earlier, where oxygen is given automatically and instantaneously to critically ill patients. Perception of benefit, even with normal blood oxygen levels, and fear of the danger of hypoxaemia, appears to drive common usage of high concentration of oxygen for all medical emergencies: *it's what always happens*. The common practice reported in the literature of the use of oxygen for dyspnoea supports the existence of such a culture (Abernethy, 2005; Barr et al., 2005; Roberts et al., 1993). Brearden et al. (2013) additionally highlighted behaviour of other HCPs in emergency care: *'the first thing they do [in the ambulance] is put oxygen on'* (p270).

This practice was also extrapolated to the breathless patient and HCPs reported how repetitive application of oxygen in clinical settings reinforces perceived purpose and heightens desire from patients. Commonality with the synthesising argument of *oxygen for symptom relief* in the literature CIS is seen, further emphasising the prevailing and widespread use of oxygen for breathlessness in both the acute and chronic care settings. Consideration of HCPs' previous experience, especially when oxygen *worked*, served to reinforce this perception. A parallel with an aging workforce, out of touch with clinical updates and set in their ways, was made by some participants.

The liberal use of oxygen may be as a result of its easy availability in most healthcare settings. Accessibility was reflected on by an African nurse (HCP14), who

recalled that oxygen was rarely used in her home country, possibly related to the scarcity and need to ration.

Power struggles between professional groups were evident and highlighted barriers to initiating change. Indulging different professional groups often complicated initiatives rather than facilitate dissemination. Similar problems with adherence to, and adoption of, revised guidelines have been reported as problematic and evidence of an entrenched culture has been alluded to in both emergency respiratory care (BTS, 2008; Austin et al., 2010) and other specialist areas (Burls et al., 2010).

Challenging different professional groups also proved to be problematic, in particular when a hierarchy was perceived, for example nurses and medics. Interprofessional rivalry was also considered to have an effect on the way change was implemented; similarly professional rivalry was reported to influence individual HCP's relationships with patients, at times impeding trust through mixed messages. These mixed messages are obviously potential sources of confusion and may serve to influence practice in a contrary direction; according to one GP, HCP29: '*nobody really knows what they're doing*'.

Hill Bailey et al. (2004), in an ethnographic study of nurses caring for COPD patients experiencing an acute exacerbation, identified the adoption of *common care templates*, described as a uniform cascade of care behaviours. This referred to unchallenged or inappropriate patterns of care and beliefs about particular illness behaviours and fixed templates of care that were adopted in response to these behaviours. This is analogous with the reflexive and '*one size fits all*' response of giving oxygen in an acute presentation of breathlessness, seen in the present study.

Myths and beliefs, as discussed previously, may also contribute to the current state of practice. In particular HCPs reflected on obscure practices such as using oxygen and egg white for pressure sores and receiving oxygen themselves for the treatment of alcohol related hangovers – on occasion recommended by seniors. These experiences clearly had an impact and it is possible that they have influenced current perceptions.

So, it is evident that the entrenched culture, often alluded to elsewhere as contributory to persistence of poor practice, does indeed exist and serves to influence how oxygen is perceived by HCPs. It can be seen that this culture is not a set of fixed beliefs as such; it is nebulous, growing from factors that impact, influence and inform practice. Thus to change culture it will be necessary to address multiple facets of practice, including perceptions of patients and HCPs regarding oxygen.

Expectations

Expectations are recurring throughout the identified themes. The concept appears in various guises throughout patients' perception of oxygen as a panacea and also as potential antecedents for patients as they recall past experiences of themselves and others. Patients' beliefs and fixed ideas with regard to justification and efficacy of oxygen have a significant impact on their expectations, and will ultimately influence HCPs' practice. This theme was therefore also represented throughout the HCPs' perceptions of oxygen as a panacea and the burden of oxygen. In some form or another every HCP interviewed referred to expectations for oxygen.

These expectations were likewise reported in the literature, especially in relation to families and carers (Stringer et al., 2006; Ring and Danielson, 1997;

Currow et al., 2008). It also confirms that on occasion oxygen is probably being prescribed to treat the carer as much as the patient, a finding particularly related to the use of oxygen in end of life care in the current study.

In addition, expectations of self were significant and reflection on the use of oxygen, both personal and when used for patients, was clearly influential to beliefs. It has been reported previously that HCP decision making is influenced by factors other than knowledge (Considine and Botti, 2006) and that expectations probably feature highly in numerous pretexts. For some in this study, especially GPs, the whole notion of prescribing oxygen was associated with worry and this expectation to know more was clearly an issue. Whether this admission of lack of knowledge influenced perceptions directly is obscure, but it could be a contributory factor to non-compliance with guidelines; if this issue seems complex there may be a tendency to avoid it.

Knowledge, Education and Training

The issue of knowledge, education and training is another recurring feature throughout the thesis. Overwhelmingly, all HCPs interviewed believed that they had not received enough education and training regarding oxygen therapy, throughout their careers. Given the significant prevalence of this finding, a lack of knowledge may be apparent in the wider HCP population though this cannot be confirmed. The small mixed cohort included in the present study, however, are a respiratory-interested group, therefore a bias in the form of enhanced awareness regarding the amount of training deemed necessary is likely. On the other hand this skew of findings could in fact serve to expose an even greater need for education, otherwise subdued by a lack of insight.

Notwithstanding this inherent bias however, differences in practice and knowledge were apparent. Sub-group analysis of different professions was not undertaken formally in the current study; however it was evident that levels of knowledge specific to oxygen, and certainly to guidelines, varied. Specialist respiratory nurses, paramedics and pharmacists represented the most knowledgeable individuals in this small sample, whereas GPs and non-specialist nurses had the least insight. Uncertainties also existed, particularly regarding toxicity of oxygen, voiced by several participants within interviews, relating to themselves and others.

It has been reported elsewhere that education of HCPs, regarding oxygen, is lacking (Hammersley et al., 2012; Hughes et al., 2012; Glaab et al., 2006). This observation is not new: in 1944 it was reported that commonly the only education available to HCPs, with regards to oxygen, was that available by the supplying companies themselves – some two and a half hours per year (White, 1979). Some may argue this is significantly more than is available today.

With a background of scarcity of formal training and education, HCPs in this study reported a prevailing do-it-yourself (DIY) culture where self-motivated and interested individuals have sought their own access to education; a finding unique from the literature. The effect that this *ad hoc* approach to education has had on inconsistent standards and practices is not clearly apparent, though conjecture may cite this as a possible contributory factor, countering against attempts to raise and standardise clinical practice. It has been proposed that fundamental changes to education of HCPs, including novel approaches to teaching clinical physiology (Beasley et al., 2007), are needed. A further approach would suggest that HCPs may need to be taught to tolerate permissive hypoxia, which is to be comfortable with

lower level of saturations (MacIntyre, 2013). These are examples of approaches which may serve to counter the reflexive nature of injudicious administration of oxygen, reported so frequently in this study: the most motivated were the best educated.

Poor understanding and continued injudicious practice with regards to oxygen therapy has previously been highlighted (Downs, 2003; Troosters, 2004; Calverley, 2005; New, 2006; Tin, 2002). One of the prime observations in the literature was inconsistency of beliefs and clinical practice, both between and within professional groups, especially regarding the indications for oxygen in relation to its use to relieve or palliate dyspnoea (Glaab et al., 2006; Atiş et al., 2001; Barr et al., 2005; Pepin et al., 1996). This inconsistency has been reiterated within this highly selected group of interested, and for the majority, knowledgeable individuals.

Context of the prevalence of oxygen therapy needs to be borne in mind. This is not a rare or highly specialised intervention; the majority of, if not all, HCPs will come across oxygen therapy at several stages in their professional careers. It could be argued that the higher level of knowledge observed in the current study was expected given the specialist and interested parties. The level of inconsistent practice and obscurity however is worrying and given that the majority of oxygen will be administered or recommended by non-specialists, safe clinical decision making is obviously jeopardised.

Guidelines (BTS, 2008; JRCALC, 2013; BTS, 2014) have been devised to address such inconsistencies in practice and to ensure an evidence-based approach. The current study explored how HCPs considered oxygen guidelines in the context of their practice; the majority considered these valuable and reported that

they help to direct clinical decision making. The same *ad hoc* and inconsistent approach, perceived in the context of education, was however also related to guideline dissemination. On occasion these dissemination strategies were implicated to heighten confusion and were perceived to be a result of lack of communication of related rationale, especially when significant changes in clinical practice were implicated. Again, for motivated individuals this often resulted in a DIY approach to finding out more; but motivation would need to be inherent and elevated to propel this. For the one undergraduate participant there was no awareness of the existence of guidelines – a finding that could mirror the majority population of non-specialist HCPs in the wider healthcare community. Given the historical entrenchment of decades of practice regarding oxygen therapy, it seems reasonable that justification for change needs to be paramount in order to nurture autonomous professionals.

Implementation of guidelines has been identified as problematic across a range of clinical practice areas. Mickan et al. (2011) identified patterns of leakage in the utilisation of clinical guidelines considering awareness, agreement, adoption and adherence as a suggested pathway. The authors concluded that leakage increases proportionately along the continuum, outlining a complex process that requires deeper investigation at each stage. The findings here corroborate this in respect of how awareness and adoption vary amongst HCP groups and clinical settings (paramedics in pre-hospital settings being much more knowledgeable and familiar with guidelines than GPs in primary care, for instance). This degree of leakage regarding oxygen guidelines is also reflected in several published audits (Dodd et al., 2000; Howell, 2001; Hickey, 2007; Wijesinghe et al., 2010; Sundaram et al., 20013; O'Driscoll, 2014).

Some improvements in practice have since been demonstrated with the use of electronic prescribing (Nasir and O'Driscoll, 2012; Peplow et al., 2013), an aspect not commented upon by participants in the current study. All these approaches highlight difficulties implementing initiatives when practice is grounded in tradition, supported by beliefs and perceptions, and resistant to change. There is a clear need, endorsed by the findings here, for sustained, multidimensional and continued educational initiatives to maintain and build upon improvements; difficult with a mobile workforce and evident barriers.

Barriers to implementation of change have been cited in the current study: including entrenched culture, expectations, myths and misconceptions, lack of knowledge and education, and a need for compassion. Similarly a local survey (published as a poster) exploring barriers to enhancing practice regarding emergency oxygen therapy cited: habit, too many policies, guidelines are unclear, always used to treat breathlessness, lack of training and oxygen is not interesting (Parenehewa et al. (2013); all familiar aspects endorsed in the current findings.

Periselneris et al. (2012) in a UK survey of 113 medical, nursing and pharmacy staff, exposed professional attitudes that may also pose barriers to implementing oxygen prescription. The authors found that 75% of doctors felt oxygen would be given despite what the prescription stated; amongst nurses 44% admitted to rarely or never signing for oxygen on ward drug rounds; the result: doctors don't prescribe oxygen as they believe nurses will ignore the prescription. Interestingly, 40% of pharmacists felt that it wasn't their role to check oxygen. In the current study all five pharmacists interviewed (with an oxygen interest bias) felt that oxygen therapy was very much part of the pharmacists' role, and that the pharmacist community should be challenged to participate more actively in addressing poor and

inconsistent practice. It is clear that attitudes will need to be addressed as part of any change strategy.

Social norms theory can be applied further to the issue of knowledge and education and some useful concepts can be aligned with practice regarding oxygen therapy. Knowledge is said to be normative; deriving from what is considered standard. Clinical practice is a complex of norms. Knowledge however is acquired from others and practices are said to be social in character, existing before the individual (Wallace, 2009). Knowledge is therefore based on experience and experience of others (inclusive of empirical knowledge) that is passed on. Thus in order to implement change regarding oxygen, clinical practice in a much wider context than respiratory care needs to be challenged in order to affect and alter common perceptions.

Knowledge and understanding therefore are deemed important and the relationship with clinical practice is clear. Transfer of this knowledge to patients is part of the therapeutic relationship, but it can be contested as beneficial if knowledge is not grounded in evidence but in misplaced beliefs and misconceptions. Findings here are suggestive that the *faith in* HCPs that patients have with regards oxygen, on occasion, may be poorly placed.

6.5 SUMMARY OF DISCUSSION

This discussion chapter has attempted to consider the study's main findings in the wider context of published literature and clinical practice, highlighting unique contributions to knowledge (summarised further in Chapter 8). It must be remembered however that literature directly relating to and exploring both patients' and HCPs' perceptions of oxygen therapy was almost non-existent. Therefore

Regarding the data itself and the findings that the analysis produced, the first revelation was that patients don't actually *think* about oxygen; I was asking them to consider aspects of their disease and treatment that were not familiar to them. This relates well to the notion of the interview being 'phenomenological' in the sense that the researcher is facilitating the participant to provide an account of their reflection; the interview is in fact self-conscious phenomenological reflection by the participant (Smith et al., 2009). In relation to my study, I was facilitating participants to consciously reflect. I was then conducting the fourth layer of formal reflective phenomenological analysis on the patients' layered set of reflections – the double hermeneutic.

But this seemed somehow counter-intuitive to making them feel at ease and comfortable and I was conscious that by making them contemplate issues that had previously been unconscious, I may have compounded the issue of 'public' portrayal. The interview itself is considered an important 'site' for the construction of knowledge, and the researcher and participant often construct this knowledge together (Hand, 2011). Smith et al. (2009) refer to this as 'meaning-making'. In this context there is further endorsement that my knowledge and insight were necessary in order to help patients construct this previously un contemplated awareness. As noted in my diary, I was hearing familiar stories, from both patients and HCPs, that I'd heard many times over the years and was not eliciting any responses that I hadn't expected.

Diary entry, 03.10.11: P5 '*Patients don't "think" about oxygen therapy. Am I not probing because I'm hearing familiar stories? No unexpected responses.*'

Clancy (2013) suggests the need to be mindful in these situations, to identify and interpret participants' accounts correctly and separate them from personal

experience, rather than imagine what is understood. It was useful to remind myself again of the principle of the double hermeneutic in IPA: '*The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world*' (Smith et al., 2009: 53). Being attentive of this whilst conducting interviews and undertaking the analysis was a challenge, but one which I did feel was kept central.

Many HCP participants reported perceptions in the context of their opinion of others' practice rather than their own. At first I was sceptical about using this data as I felt that it didn't record personal perceptions. As I got more immersed in the data however, and confidence grew with interviewing, I realised that these *were* their perceptions, even if relayed through the third person; in fact, what HCPs were referring to was the existence of cultures. Smith et al. (2009) refer to these cultures as essentially 'frameworks for meaning-making' (p194). In order to understand these meanings the researcher can be said to require a certain level of cultural competence, further endorsing my position in the research.

Diary entry, 13.06.12: HCP2 '*Some useful points but she gave more of her opinion of others' knowledge and attitude towards oxygen rather than her own. Does this move the data further away from interpretation – triple hermeneutics?*'

Some HCPs of course came with their own agenda and it soon became apparent if this was the case, as the interview schedule allowed them to talk freely from the outset. One example was a paramedic who was campaigning for nebuliser compressors on emergency vehicles to deliver nebulised drugs in order to avoid using high flow oxygen for the same purpose; it was difficult balancing allowing her to air her views, and hence gain trust, whilst eliciting the information that I needed. Others thought that I was testing them: HCP7 - '*I hope I don't show my ignorance*'.

For several (HCP17; HCP24; HCP26; HCP34) they felt the interview had exposed their own weaknesses; upon further discussion all felt that this developing insight was beneficial and would direct them to seek further information/education regarding oxygen therapy.

Concerning the data further, I suppose the second revelation for me, in terms of the unexpected, was the contradiction of oxygen. The majority of HCPs interviewed were knowledgeable and compliant with guidelines yet, despite this, when asked to consider oxygen in palliative care all would default to the position of giving it. Concurrent to reflecting on this serendipitous finding, my best friend of 25 years was in the terminal stage of breast cancer. A registered nurse herself, she was prescribed oxygen in the last 6-8 weeks of life and during my frequent visits I observed her relationship with oxygen develop. From an aid it became a life-line, a symbol to others of her severity – *'I'm on oxygen now'* – it helped her do basic tasks such as washing and eating, it eased her breathlessness and settled her anxiety; it became a focus, a crutch. Her oxygen saturations were around 90-92% without oxygen, so although borderline hypoxaemia, she did not meet criteria for oxygen apart from to palliate her distressing dyspnoea. During her terminal phase I spent nights with her, enabling her family to rest; when her oxygen cannula slipped during the night she became restless, although semi-comatose; when I re-positioned it she settled quickly. I don't know what the oxygen was doing for her physiologically or psychologically, but it was helping.

7.4 REFLECTION ON MY CURRENT THINKING ON COMPLETION OF THE STUDY

Reflecting on the finished structure of the thesis I find myself wondering could or should I have done things differently. Maybe the exploration of only emergency oxygen, or only palliative oxygen, would have been more appropriate, as the findings between the two are quite diverse. Perhaps I could have analysed the data pertaining to each category separately. Following full consideration of these issues I think the decisions that I made were appropriate; for most patients and HCPs, acute and palliative care, and therefore perceptions of acute and palliative oxygen, were entwined and inseparable.

Whether IPA was the correct methodological approach overall was a further consideration. IPA is concerned with microanalysis of the individual – I wonder whether I have preserved individual identities sufficiently. Smith et al. (2009) consider the use of IPA by novice researchers and acknowledges that recognising the work as ‘good enough’, as opposed to the excellence expected from experienced researchers (p184), can be one of the most difficult aspects. They also emphasise that IPA is a creative process and as such can be adapted to fit the needs of the study. Although concerned with individuals, this study regarded ‘oxygen’ as the homogenous feature, and the rationale for selecting a larger cohort was to recognise this singular feature as just one aspect of otherwise complex lives, attempting to look for convergences and divergences in order to identify commonalities.

I consider whether my perception of oxygen has changed during the compilation and development of the thesis. Exploration of perceptions has probably made me realise the extent to which psychosocial aspects of oxygen are important, and that the issue was not as unequivocal as physiological rationale would support.

them, either as a patient or a HCP, and revealing their positionality in relation to the phenomenon.

Finally, I have attempted to reflect on my ultimate personal position with regards to my own perceptions of oxygen therapy but these will be pronounced more robustly in the recommendations proffered in the final chapter.

phenomenon, it was decided that the broad context was necessary in order to position the research question. Yardley (2000) recommends that a fairly extensive grounding in intellectual history of the topic is desirable, since awareness of different perspectives and complex arguments that influence the subject matter enable the researcher to develop a sophisticated approach to interpreting data. By reviewing literature in such a broad manner, there is an endeavour to relate the thesis to not only the work of others, albeit not directly addressing the research question, but also to theories and concepts that were considered important. In this respect, the historical chapter (Chapter 2) served to illuminate potential sources of entrenched practice and demonstrate the longevity of such traditions, linking this to contemporary clinical issues.

Theory in the context of the literature was further used to influence interpretation, with theoretical predictions from the CIS (Chapter 3) used to inform and corroborate empirical findings. The underpinning theoretical context also ensured that unexpected findings, for example HCP dilemmas, were pursued. My understanding of the topic in this situation was crucial to ensure such findings were not merely noted but actively sought and examined (Yardley, 2000). Dialogue with relevant publications that were considered important in light of the findings, was additionally pursued and further enhances sensitivity to context (Smith et al., 2009).

Consideration of suitability of IPA as a methodology is important. It could be argued that, given the relatively large sample size, IPA was not the most appropriate methodological choice and that indeed the true ideographic nature of IPA has been lost. Smith et al. (2009) suggest that a fairly homogeneous group is necessary for the research question to be meaningful. The large sample is defended by the homogeneity of the focus of the study: the intention being to contemplate lived

experience specifically related to oxygen, rather than wider issues of living with a disease entity or, in the case of HCPs, the wider context of clinical practice. Once oxygen as the focus was established, purposive sampling to include a broader spectrum of diseases and professional groups in an attempt to capture a wider representation was possible, and directed the eventual sample size.

Sensitivity to the data itself is central and socio-cultural context is an important consideration (Yardley, 2000). In this study socio-economic status was not specifically considered for individuals, but the general geographical location in the North West of England has its own socioeconomic and cultural attributes – for both patients and HCPs. Within the two participant groups similarities in characteristics were also inherent: all patients had chronic respiratory disease and all HCPs had a professional cultural history common through their professional education, training, and work in the UK NHS (National Health Service). The findings therefore may suggest that perceptions of oxygen therapy are indeed culturally specific, but similarities in findings, from international literature and the participant who trained in Africa, demonstrated that, apart from external variables such as availability, oxygen is always perceived as useful in breathlessness (including acknowledged psychological benefit). The country of origin therefore appears to have little influence on perceptions and cultures which seem to transcend geography and, though limited to developed countries, findings could have international relevance.

The interactional nature of interviews, my experience and familiarity with participant group characteristics (both patients and HCPs), further enhance sensitivity to context. The emergent themes resulted from the use of IPA, focusing on hermeneutic, ideographic and contextual interpretation. The use of experience to inform and enable open participation in data analysis has been achieved through a

double hermeneutic. This could be considered an inherent bias as the researcher brings to the analysis pre-conceived ideas concerning the topic under examination. As reflection has revealed however, the process of IPA did in fact enable further development of insight into the phenomenon, and in doing so transcend the notion that personal pre-conceived ideas were fixed. The experience of the researcher can therefore be considered both as a strength and a limitation of this study.

The relationship between the researcher and the participant is crucial in qualitative research as an act of communication, rather than merely recording speech (Yardley, 2000), and is central to the quality of data. In this context my identity as a Respiratory Nurse Specialist, in addition to researcher, is important. This role identification was anticipated to invoke open and frank discussion with HCPs and trust from patients, and is supported by the notion that attempts to remain neutral during interviews are often futile (Yardley, 2000). But consideration of balance of power is necessary. Power in this sense from HCPs' perspective could be deemed as knowledge rather than status; this may have resulted in those with better knowledge being more candid, and those less knowledgeable feeling inferior and guarded in conversation. With patients I was the HCP that they were expressing '*faith in*', and reluctance to criticise may have been intrinsic. Yardley (2000) suggests that it is difficult to overcome this imbalance of power as the '*expert*', though attempts were made during interviews to allow participants to lead discussion. In addition, assurances were given to patients that information would not be relayed back to their care team, and for HCPs plans regarding strategies that would be adopted in the event of disclosed unsafe practice were discussed at consent stage. It was hoped that transparency of intentions in this way would serve to reassure individuals. Additionally, as discussed in the previous chapter, there was an issue of

APPENDICES

69	PsycINFO; 68	19 results	[Limit to: Human and (Age Groups 300 Adulthood age 18 yrs and older) and English Language];
70	MEDLINE; 30	207 results	[Limit to: Publication Year 2001-2006 and Humans and (Age Groups All Adult 19 plus years) and English Language];
71	EMBASE; 44	304 results	[Limit to: Publication Year 2001-2006 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language
72	EMBASE; 44 [266 results	Limit to: Publication Year 2002-2006 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language
73	MEDLINE; 30	170 results	[Limit to: Publication Year 2002-2006 and Humans and (Age Groups All Adult 19 plus years) and English Language
74	EMBASE,MEDLINE;	436 results	Duplicate filtered: [44 [Limit to: Publication Year 2002-2006 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language [30 [Limit to: Publication Year 2002-2006 and Humans and (Age Groups All Adult 19 plus years) and English Language]]];
75	MEDLINE; 30	177 results	[Limit to: Publication Year 1996-2001 and Humans and (Age Groups All Adult 19 plus years) and English Language];
76	EMBASE; 44	195 results	[Limit to: Publication Year 1996-2001 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language
77	MEDLINE,EMBASE;	372 results	Duplicate filtered: [30 [Limit to: Publication Year 1996-2001 and Humans and (Age Groups All Adult 19 plus years) and English Language]], [44 [Limit to: Publication Year 1996-2001 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language
78	EMBASE; 44	188 results	[Limit to: Publication Year 1985-1995 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English

			Language];
79	MEDLINE; 30		[Limit to: Publication Year 1985-1995 and Humans and (Age Groups All Adult 19 plus years) and English Language]; 160 results
80	EMBASE,MEDLINE;	348 results	Duplicate filtered: [44 [Limit to: Publication Year 1985-1995 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language]], [30 [Limit to: Publication Year 1985-1995 and Humans and (Age Groups All Adult 19 plus years) and English Language]];
82	MEDLINE; 30	102 results	[Limit to: Publication Year 1950-1984 and Humans and (Age Groups All Adult 19 plus years) and English Language];
83	EMBASE; 44	17 results	[Limit to: Publication Year 1960-1984 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language];
84	MEDLINE,EMBASE;	119 results	[44 [Limit to: Publication Year 1960-1984 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language]];
85	MEDLINE,EMBASE;	119 results	Duplicate filtered: [30 [Limit to: Publication Year 1950-1984 and Humans and (Age Groups All Adult 19 plus years) and English Language]], [44 [Limit to: Publication Year 1960-1984 and Human and (Human Age Groups Adult 18 to 64 years or Aged 65+ years) and English Language]];

APPENDIX B: Study Selection Proforma

Systematic Review Proforma

Review objective: *To identify research studies that have investigated, detailed, recorded in some manner respiratory patients and healthcare professionals perceptions of oxygen therapy.*

Reference Details :

.....

Date Reviewed:.....

<u>Inclusion Criteria</u>	
Empirical study with a clear, methodological stance, although actual method is unimportant.	
English language.	
Any recorded perceptions of receiving oxygen therapy by respiratory patients (any disease category – acute or chronic, any age range).	
Any recorded perceptions of prescribing and/or administering oxygen therapy by registered healthcare professional.	
Intervention – oxygen therapy delivered as part of medical management including acute oxygen therapy, domiciliary oxygen therapy and palliative oxygen therapy.	
<u>Exclusion Criteria</u>	
Editorials, discussion papers, narrative reviews.	
Any papers without an explicit stated methodology.	
Non-respiratory patients.	
Any papers detailing oxygen as a complimentary therapy.	
Paediatrics/Individuals under 18 years of age	

If excluded, specific reasons:.....

.....

Other comments:.....

.....

APPENDIX C: Quality Appraisal & Data Extraction

Author:					Title:
Year:					Journal:
Brief Summary of detail related to perception of oxygen:					
Key focus of the study:					
Method/design:					Country of Origin:
Quality appraisal:	Good	Fair	Poor	V Poor	Comment
1. Abstract & Title 2. Intro & Aims 3. Sampling 4. Data collection 5. Data analysis 6. Ethics 7. Strengths 8. Weaknesses 9. Findings/results 10. Transferability/ Generalisability 11. Implications & Usefulness to topic Q					
Overall comment:					

Data extraction:

Summary of aims of the study:

Participants:

Methodology

Data collection methods:

Data analysis:

Key results:

Relevance to 'Perceptions of Oxygen Therapy

APPENDIX F: Grid of Themes and Sub-Themes & Occurrences – Patients

Author	POSITIVE						NEGATIVE											IMPARTIALITY			
	Feeling Safe		Enabler		Comfort		Fear			Oxygen vs. self		Restriction			Embarrassment			Mixed blessings			
	'Faith in'	Keep Alive	Symptom relief	Mastery	Placebo	Benefit	Disease decline	Memories (of others)	Fear of dependency	Disappointment	Hopelessness & Existing	Social isolation	Frustration	Physical Complaints	Attitude of others	Changing body image	Shame	Guilt	Adaptation	Compromise Trade-off	Knowledge & understanding
Adams, 2008	X	X	X	X		X				X	X	X			X						
Berg, 1996			X	X	X	X		X													X
Booth et al, 1996					X	X															
Borak et al, , 1991									X						X						X
Bruera et al, 1993			X			X															
Bruera et al, 2003					X	X															
Cicutto et al, 2006	X		X	X																	
Clancy et al, 2009							X	X										X			
Cornford, 2000			X	X		X			X				X						X	X	
Crockett et al, 2006							X				X			X	X		X				
Cullen & Stiffler, 2009			X	X				X			X	X						X			
Currow et al, 2009			X		X	X				X											
Demirel et al, 2003			X							X			X								

Author	POSITIVE						NEGATIVE												IMPARTIALITY		
	Feeling Safe		Enabler		Comfort		Fear			Oxygen vs. self		Restriction			Embarrassment				Mixed blessings		
	'Faith in'	Keep Alive	Symptom relief	Mastery	Placebo	Benefit	Disease decline	Memories (of others)	Fear of dependency	Disappointment	Hopelessness & Existing	Social isolation	Frustration	Physical Complaints	Attitude of others	Changing body image	Shame	Guilt	Adaptation	Compromise Trade-off	Knowledge & understanding
Doi, 2003										X	X	X	X		X						
Earnest, 2002	X		X				X	X	X		X				X		X	X	X	X	
Eaton et al, 2001					X	X				X											X
Fraser et al, 2006			X	X																	
Gardiner et al, 2009							X														X
Gruffyd-Jones et al, 2007			X			X	X														X
Habraken et al, 2008	X		X		X																
Hasson et al, 2008		X	X				X														
Ingadottir and Josdottir, 2006															X		X		X	X	
Jaturapatporn et al, 2010	X	X	X	X								X	X	X						X	
Jones et al, 1978			X		X	X															
Kampelmacher et al, 1998			X					X		X		X	X				X				
Lai et al, 2007	X	X						X			X		X	X	X	X	X				

Author	POSITIVE						NEGATIVE											IMPARTIALITY				
	Feeling Safe		Enabler		Comfort		Fear			Oxygen vs. self		Restriction			Embarrassment			Mixed blessings				
	'Faith in'	Keep Alive	Symptom relief	Mastery	Placebo	Benefit	Disease decline	Memories (of others)	Fear of dependency	Disappointment	Hopelessness & Existing	Social isolation	Frustration	Physical Complaints	Attitude of others	Changing body image	Shame	Guilt	Adaptation	Compromise Trade-off	Knowledge & understanding	
Lewis et al, 2003					X	X				X												
Neri et al, 2006 *																	X					X
O'Neill et al, 2005			X																			
Peckham et al, 1998									X													X
Quantrill et al, 2007			X	X	X	X																
Reinke et al, 2008 *							X					X	X									
Ring & Danielson, 1997	X	X	X	X								X	X	X					X			
Ringbaek et al, 2001			X		X	X																
Roberts et al, 1993 *													X	X								
Robinson, 2005										X	X											
Uronis et al, 2008					X	X																
Williams 1993							X	X				X	X		X	X	X					

APPENDIX G: Grid of Themes and Sub-Themes & Occurrences - HCPs

Author	Year	Oxygen for symptom relief	Knowledge & understanding	Oxygen as a therapy for HCPs
Abernethy	2005	X		
Atis et al	2001	X	X	
Austin et al	2010			X
Barr et al	2005	X	X	
Breaden et al	2013	X	X	
Considine et al	2005		X	
Considine & Botti	2006		X	X
Glaab et al	2006		X	
Neri et al	2006	X		
Pepin et al	1996		X	
Reinke et al	2008			X
Roberts et al	1993	X		X
Stringer et al	2004	X		

APPENDIX H: Invitation Letter for Patients – Version 2

A Study Exploring Perceptions of Oxygen Therapy

Dear

I am inviting you to participate in a research study that I am undertaking to achieve a higher degree (PhD). I am a respiratory nurse specialist by background and am now a university lecturer, involved with education of healthcare professionals. The purpose of this study is to explore perceptions regarding oxygen therapy, in order to better understand what people think about oxygen and help to direct the necessary practice, education and future research in this fundamental area of health.

Before you decide to agree to participate, I would like you to understand, by reading the information leaflet provided, why the research is being done and what it would involve for you. This should take about 10 minutes. Further details regarding how you can ask questions, together with my contact details, are included. Participation in the study is voluntary. An option to withdraw from the study at any time without prejudice is offered. All data collected will be handled in a confidential manner with anonymity assured.

Thank you in anticipation for your co-operation.

Regards

Carol Kelly

Senior Lecturer Continuing Professional Development, Edge Hill University

APPENDIX I: Invitation Letter for Healthcare Professionals – Version 2

A Study Exploring Perceptions of Oxygen Therapy

Dear Healthcare Professional

I am inviting you to participate in a research study that I am undertaking to achieve a higher degree (PhD). I am a respiratory nurse specialist by background and am now a university lecturer, involved with education of healthcare professionals. The purpose of this study is to explore perceptions regarding oxygen therapy, in order to better understand what people think about oxygen and help to direct the necessary practice, education and future research in this fundamental area of health.

Before you decide to agree to participate, I would like you to understand, by reading the information leaflet provided (which should take about 10 minutes), why the research is being done and what it would involve for you. Further details regarding how you can ask questions, together with my contact details, are included. Participation in the study is voluntary. An option to withdraw from the study at any time without prejudice is offered. All data collected will be handled in a confidential manner with anonymity assured.

Thank you in anticipation for your co-operation.

Regards

Carol Kelly

Senior Lecturer Continuing Professional Development, Edge Hill University

APPENDIX J: Interview Schedule- Patients – Version 1 – First revision

A Study Exploring Perceptions of Oxygen Therapy

Before the Interview:

*Have you read the participant information leaflet?
Do you have any questions to ask about the study or what will happen?
Are you happy to sign the consent form? - Ask patient to sign form.*

This Interview will be taped – is that ok? - Explain that tapes will be stored securely and destroyed appropriately after the study completion.

We can stop the interview at any time, it doesn't matter – just let me know, it should last no longer than one hour. There are no right or wrong answers to the questions I am going to ask and it is really important that you talk to me honestly so that I can learn about your experiences of oxygen therapy. Do you want to ask any questions before we start?

Interview Questions/Prompts

Grand tour question: *'I am interested in your views about oxygen therapy; can you tell me your views?'*

Follow up on the themes raised by the respondent and then proceed to the following structured questions, omitting any aspects already covered - these questions can be adapted according to participant's responses.

Background/Demographics:

Tell me what you know about your chest condition.

Knowledge

Tell me what you understand about oxygen therapy.

Experiences

Can you tell me what experience you have of receiving oxygen therapy?

Have you any previous experience with oxygen?

*For instance: do you know anybody else who has oxygen?
Have you seen anything on TV/ read anything?*

What did you think about that?

Sensory

What happens when you receive oxygen therapy; what do you feel?

Where/when did you first encounter oxygen?

Feelings

How does receiving oxygen therapy make you feel?

Did you have any previous expectations?

Opinions or beliefs

Do you think receiving oxygen therapy helps you? How does it help you?

If you have oxygen at home when do you use it – for how long – why do you stop?

What do you see as the good things about receiving oxygen therapy?

Do you believe that oxygen therapy helps your lung condition?

Do you think there are any disadvantages to receiving oxygen therapy?

Do you think you have received enough information regarding oxygen therapy when you have been given it?

Do you worry about dependency?

What were your expectations of oxygen therapy?

Do you have any reservations about oxygen?

Do you think oxygen therapy has changed what you do and the activities that you perform?

Other

Do you have anything to add that you feel may be important?

Is there anything else that you would like to talk about that we haven't covered?

Is there anything that you would like me to ask?

Finish the interview

Do you have any questions?

Thank you for your time and considered answers.

If participant has indicated intent to be contacted in the future agree the means of contact and potential time frame.

Additional prompt questions:

How do you explain that?/ In what way?/ Can you explain that?/ How is that?

APPENDIX K: Interview Schedule- HCPs – Version 1

A Study Exploring Perceptions of Oxygen Therapy

Before the Interview:

Have you read the participant information leaflet?

Do you have any questions to ask about the study or what will happen?

Are you happy to sign the consent form? Ask participant to sign form.

This Interview will be taped – is that ok? Explain that tapes will be stored securely and destroyed appropriately after the study completion.

We can stop the interview at any time, it doesn't matter – just let me know, it should last no longer than one hour. There are no right or wrong answers to the questions I am going to ask and it is really important that you talk to me honestly so that I can learn about your experiences of oxygen therapy.

Do you want to ask any questions before we start?

Interview Questions/Prompts

Grand tour question: *'I am interested in your views about oxygen therapy; can you tell me your views?'*

Follow up on the themes raised by the respondent and then proceed to the following structured questions, omitting any aspects already covered - these questions can be adapted according to participant's responses.

Background/Demographics:

What is your professional background?

How long have you been qualified for?

Tell me about your involvement with oxygen therapy? What group of patients would you use oxygen therapy for? When and how are you involved with oxygen therapy?

Knowledge

Tell me what you understand about oxygen therapy?

What situations would you administer/prescribe oxygen therapy?

Are you familiar with any guidelines or protocols for oxygen therapy?

Have you had any training regarding oxygen therapy?

Experiences

What are your typical experiences of administering or prescribing oxygen therapy?

Can you recall any specific experiences you have of prescribing or administering oxygen therapy?

Feelings

How does it make you feel, or what do you think generally, when you prescribe or administer oxygen therapy for a patient?

Opinions or beliefs

How do you think oxygen therapy helps patients?

Do you think there are any dangers regarding oxygen therapy? Probe answers

Do you believe that oxygen therapy helps their lung condition/breathlessness?

Do you think you have received enough education/training regarding oxygen therapy?

Do you think oxygen therapy is beneficial for most medical emergencies?

Do you think oxygen therapy is helpful in palliative care settings?

Have you any suggestions for how oxygen therapy could be improved?

Some shops and gymnasiums have "oxygen bars" offering oxygen to inhale. What are your views regarding this?

Other

Do you have anything to add that you feel may be important?

Is there anything else that you would like to talk about that we haven't covered?

Is there anything that you would like me to ask?

Finish the interview

Do you have any questions?

Thank you for your time and considered answers.

If participant has indicated intent to be contacted in the future agree the means of contact and potential time frame.

APPENDIX L: Ethical Approval Letter – Edge Hill University



Edge Hill University
St Helens Road, Ormskirk,
Lancashire L39 4QP
Tel: 01695 575171
Fax: 01695 579997
www.edgehill.ac.uk

Thursday 10th March

Carol Kelly,
PhD Student
Graduate School/Faculty of Health

Carol Kelly – Ethical Approval – Mphil/PhD Project –
'How do Respiratory patients and healthcare professionals perceive oxygen
therapy? A mixed methods study to discover perceptions and possible
misconceptions of oxygen therapy.'

Dear Carol

Thanks for your submission of documentation and attendance at a University Research Ethics Committee Sub-Committee on Wednesday 2nd March to seek approval for your MPhil/PhD project.

I am happy to confirm that the Sub-Committee have granted ethical approval to your project with the following provisos:

- The project clearly requires NRAS approval and cannot substantively proceed with fieldwork preparation without it. University approval signifies support for your NRAS application and meets the requirements of the University with respect to postgraduate research student's research practice. NRAS approval and associated paperwork should be lodged with the Graduate School Office as soon as it is given.
- You should revise your information sheet to make clear what the research is and is not seeking to explore in respect of perceptions and misconceptions.
- You should provide an information sheet to provide avenues of referral for support subsequent to the fieldwork engagement, which will assist in supporting research participants and clarifying that the burden of a pastoral role does not sit with the researcher.



INVESTOR IN PEOPLE

Dr John Cater, Vice Chancellor

APPENDIX M: Ethical Approval Letter – NW NRES



National Research Ethics Service

NRES Committee North West - Cheshire

Research Ethics Office
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile:

13 June 2011

Ms Carol Ann Kelly
Senior Lecturer/PhD student
Edge Hill University
St Helens Rd
Ormskirk
Lancashire
L39 4QP

Dear Ms Kelly

Study title:	How do respiratory patients and healthcare professionals perceive oxygen therapy? A mixed methods study to discover perceptions and possible misconceptions of oxygen therapy.
REC reference:	11/NW/0167
Protocol number:	1

Thank you for your letter of 08 June 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centres"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		07 March 2011
Covering Letter		08 June 2011
Evidence of insurance or indemnity	AoN Risk Solutions - Edge Hill University	28 July 2010
Evidence of insurance or indemnity	Markel - Edge Hill University	14 September 2010
Interview Schedules/Topic Guides	Interview Schedule - Patients Version 1	11 February 2011
Interview Schedules/Topic Guides	Interview Schedule - HCPs - Version 1	11 February 2011
Investigator CV	Carol Kelly	
Investigator CV	Mary R O'Brien	
Investigator CV	Dr David Lynes	
Investigator CV	Nigel (Ben) Shaw	
Letter from Sponsor	Edge Hill University	22 February 2011
Letter of invitation to participant	2 - Patients	08 June 2011
Letter of invitation to participant	2 - Healthcare Professionals	08 June 2011
Participant Consent Form: Patients	2	08 June 2011
Participant Consent Form: Healthcare Professionals	2	08 June 2011
Participant Information Sheet: Patients	2	08 June 2011
Participant Information Sheet: Healthcare Professionals	2	08 June 2011
Protocol	1	11 February 2011
REC application	3.1	07 March 2011
Referees or other scientific critique report	Institutional Ethics Approval Letter	10 March 2011
Response to Request for Further Information		08 June 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

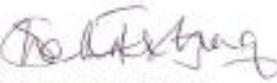
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/NW/0167

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Mr Jonathan Deans
Chair

Email: Shehnaz.ishaq@northwest.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written "*After ethical review – guidance for researchers*"

Copy to: Dr Mary O'Brien
Edge Hill University
St Helens Road
Ormskirk
Lancashire
L39 4QP

APPENDIX N: R&D Research Passport


NHS Foundation Trust

Our Ref : WHH11-010
29th July 2011

Ms Carol Kelly
Senior Lecturer
Edge Hill University
St Helens Road
Ormskirk
Lancashire L39 4QP

Tel: 01695 543434
Fax: 01695 543435

Dear Ms Kelly

REF: HOW DO RESPIRATORY PATIENTS AND HEALTHCARE PROFESSIONALS PERCEIVE OXYGEN THERAPY? A MIXED METHODS STUDY TO DISCOVER PERCEPTIONS AND POSSIBLE MISCONCEPTIONS OF OXYGEN THERAPY

NRES REF: 11/NW/0167

R&D REF: WHH11-010

PROTOCOL: VERSION 1 DATED 11th FEBRUARY 2011

PARTICIPANT INFORMATION SHEET: VERSION 2 DATED 8th JUNE 2011

PARTICIPANT CONSENT FORM: VERSION 2 DATED 8th JUNE 2011

PARTICIPANT INFORMATION SHEET FOR HEALTHCARE PROFESSIONALS: VERSION 2 DATED 8th JUNE 2011

HEALTHCARE PROFESSIONAL CONSENT FORM: VERSION 2 DATED 8th JUNE 2011

Members of the R&D Group considered the information supplied in relation to this research study. After due consideration by members of the committee, they would welcome the opportunity for this research to be conducted within the NHS Foundation Trust.

Please note that approval is granted subject to the following conditions:

- The research is conducted in line with the guidance given within the Research Governance Framework for Health and Social Care [2005] 2nd edition and where appropriate the Medicines for Human Use (Clinical Trial) Regulations 2004. You must also apply the principles of ICH Good Clinical Practice in conduct of your research.

- The research will be conducted in compliance with Trust Policies and carried out in accordance with the Data Protection Act (1998), Human Tissue Act 2004, Health & Safety at Work Act and the Caldicott principles and NHS Code of Confidentiality
- Any proposed changes or amendments to the protocol will be notified to the ethics committee, the research sponsor and R&D manager
- Each member of the research team is qualified by education, training and experience to perform his/her respective role in the study.
- Students and new researchers must have adequate supervision, support and training
- The Research Governance Framework published by the UK Health Department make clear that appropriate allocation of responsibility, and clear understanding of responsibility is fundamental to good overall governance of research. You must ensure that all researchers not employed by the Trust follow the standardised procedures for Issuing Honorary Research Contracts (HRC) or Letters of Access (LOAs) as laid down in the Research in the NS – HR Good Practice Resource Pack, version 2 dated February 2010
http://www.nhr.ac.uk/systems/pages/systems_research_passports.aspx
- Procedures are in place to ensure collection of high quality, accurate data and the integrity and confidentiality of data during processing and storage.
- All data and documentation associated with the research will be made available for audit at the request of the appropriate auditing authority
- Adverse Event and Serious Adverse Event reporting. – Hospitals NHS Foundation Trust acts as sponsor, reporting will be responsibility of the Chief Investigator and they must report this information to the MHRA and to ethics. A copy of all SAE's (including SUSAR's) and all annual safety reports must also be copied to the R&D Department. Where the Trust is not the sponsor of the trial, then all SUSAR's related to Trust patients MUST be copied to the R&D department when submitting to the sponsor
- Arrangements are to be made for the appropriate archiving of data when the research has finished
- On completion of the research you must complete and return a progress report to the R&D Manager at [redacted] .jst

✓

- If your project has been adopted by the National Institute for Health Research (NIHR) portfolio you will be required to provide monthly recruitment figures to the R&D Department and address any issues affecting recruitment

Yours sincerely

[Signature]
Subject

From: *[Redacted]* Division
Cc: *[Redacted]*
R&D File

Signed: *[Signature]* Principal Investigator Date: 2/8/11

APPENDIX O: Patient Information Sheet – Version 2

A Study Exploring Perceptions of Oxygen Therapy

I would like to invite you to take part in my research study. Before you decide I would like you to understand why the research is being done and what it would involve for you by reading this information sheet. This should take about 10 minutes. There will be opportunity for questions before finally agreeing to participate. Please take the time to read this information carefully and talk to others about the study if you wish. Take time to decide whether or not you wish to take part, there will be opportunity for questions before finally agreeing to participate.

Background

Oxygen therapy is one of the commonest treatments in modern day healthcare, especially for respiratory patients. Yet, despite the common usage we know little about how it is perceived by healthcare professionals, patients and the general public. Exploration of the perceptions of oxygen therapy, from both healthcare professionals' and patients' perspectives, may help us to understand the issues more clearly.

What is the purpose of this study?

The purpose of this study is to explore perceptions regarding oxygen therapy in order to better understand what people think about oxygen and help to direct the necessary practice, education and future research in this basic area of health.

I am a respiratory nurse specialist and university lecturer involved with education of healthcare professionals and I am undertaking this research as part of my study to obtain a higher degree (PhD).

Why have I been invited?

You have been asked to participate because you are known to the healthcare team, have a chronic respiratory illness and have used oxygen therapy in the past year; other respiratory patients (about 20 – 30) will be interviewed in the same way. I will also be conducting similar interviews with a number of healthcare professionals regarding their perceptions of oxygen therapy.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, I will discuss the study further and go through this information sheet with you. You can still decline at this stage, however if you do agree to participate then I will then ask you to sign a consent form. You are free to withdraw from the study at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part in this study I will come to your home, or other suitable convenient location, at a time and date that is convenient for you and conduct an

interview. Initially I will go through the information contained in this sheet again and answer any questions that you may have, this should take about 10 minutes. The interview itself will be conducted by me asking some simple questions about your experiences and thoughts about oxygen therapy. You are welcome to have a member of your family or a carer present during the interview if you wish.

Throughout the interview I will be asking some prepared questions, making notes and audio recording the procedure. The whole interview should take no more than one hour. At some point in the following weeks I may re-visit you, if you agree, and again at a time and date that is convenient for you, to ask you if you feel the written notes of the interview reflect what you said. This later visit should take no more than half an hour.

The data collected will then be combined with answers from the other participating patients to determine if any common themes appear. Specific reference to you at this stage will be confined to the use of a pseudonym (a false name) and you will remain anonymous at all times.

What are the possible disadvantages of taking part?

There should be no risks or disadvantages from taking part in the study. The data that will be collected will be kept in confidence and anonymity will be guaranteed; the interview data will not be disclosed to your usual care team.

What are the possible benefits of taking part?

There will be no direct benefit to you for taking part in this study. I cannot promise the study will help you either, but the information from this study may help improve the treatment of people receiving oxygen in the future.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, you may choose to let me continue to use collected data or to exclude it; all your identifiable information will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact me, Carol Kelly, in the first instance and I will do my best to answer your questions. You can contact me on: 01695 657090 or e-mail: kellyc@edgehill.ac.uk If you remain unhappy and wish to complain formally, you can do this The Independent Complaints Advocacy Service (ICAS) North West: 0300 456 8350.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Data will be stored and discarded securely. Anonymity and confidentiality will be assured through the use of a pseudonym. The second

appointment will be an opportunity to check accuracy of the data collected and serve as a further reassurance of anonymity and confidentiality.

What will happen to the results of the research study?

This study intends to explore perceptions regarding oxygen therapy from both the patients' and healthcare professionals' perspective. The results will aim to raise awareness of perceptions with a view to informing prescribing practices, source and format of patient information and education, education of healthcare professionals, future research agendas and clinical practice. The work will be published in healthcare journals to ensure dissemination of the work to appropriate healthcare professionals. I will also aim to disseminate the work to patients through the British Lung Foundation.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by The North West Research Ethics committee.

What do I do now?

I will contact you further to arrange a mutually convenient date, time and location for your interview. If at any point you change your mind regarding participation in the study you can inform me when I contact you or you may contact me on 01695 657090 and leave a message, alternatively you can e-mail me on kellyc@edgehill.ac.uk. At which point I will withdraw your details from the study.

Further information and contact details

If you would like any further information please contact me:

Carol Kelly
Senior Lecturer
Faculty of Health
Edge Hill University
St Helens Rd
Ormskirk, Lancashire, L39 4QP

Tel: Direct line. 01695 657090
Email: kellyc@edgehill.ac.uk

Thank you very much for your time in reading this information leaflet and for considering taking part in the study.

APPENDIX P: Participant Information Sheet for Healthcare Professionals

A Study Exploring Perceptions of Oxygen Therapy

I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the study is being done and what it will involve. Please take the time to read this information carefully; this should take about 10 minutes. There will be opportunity for questions before finally agreeing to participate.

Background

Oxygen therapy is one of the commonest treatments in modern day healthcare, especially for respiratory patients. Yet, despite the common usage we know little about how it is perceived by healthcare professionals, patients and the general public. Exploration of the perceptions of oxygen therapy, from both healthcare professionals' and patients' perspectives, may help us to understand the issues more clearly.

What is the purpose of this study?

The purpose of this study is to explore perceptions regarding oxygen therapy in order to better understand what people think about oxygen and help to direct the necessary practice, education and future research in this basic area of health.

I am a respiratory nurse specialist and university lecturer involved with education of healthcare professionals and I am undertaking this research as part of my study to obtain a higher degree (PhD).

Why have I been invited?

You have been asked to participate because you are part of the healthcare team who prescribes or administers oxygen therapy to patients; other healthcare professionals (about 30) will be interviewed in the same way. I will also be conducting similar interviews with a number of patients regarding their perceptions of oxygen therapy.

Do I have to take part?

It is up to you to decide to join the study. If you agree to take part, I will discuss the study further and go through this information sheet with you. You can still decline at this stage, however if you do agree to participate then I will then ask you to sign or agree verbal consent. You are free to withdraw from the study at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part in this study I will arrange an appointment with you, at a time and date that is convenient for you and conduct an interview. The interview will consist of me asking some simple questions about your experiences and thoughts regarding oxygen therapy.

The interview will be digitally recorded. The data collected will then be combined with answers from the other participating healthcare professionals to determine if any common themes appear. Specific reference to you at this stage will be confined to the use of a pseudonym and anonymity will be protected at all times.

What are the possible disadvantages of taking part?

There should be no risks or disadvantages from taking part in the study. The data that will be collected will be kept in confidence and anonymity will be guaranteed. If during the course of the interview any issues regarding your clinical practice are raised, advice and guidance regarding sources of further information and education may be given. In the event of any disclosure of unsafe practice it is necessary that you agree to accept advice and guidance as appropriate and you will be invited to consent to this prior to entering the study.

What are the possible benefits of taking part?

There will be no direct benefit to you for taking part in this study, but the information from this study may help to direct future practice, education and research in this important field in the future.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, you may choose to let me continue to use collected data or to exclude it; all your identifiable information will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact me (details below), in the first instance and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from: www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Data will be stored and discarded securely. Anonymity and confidentiality will be assured through the use of a pseudonym.

What will happen to the results of the research study?

This study intends to explore perceptions regarding oxygen therapy from both the patients' and healthcare professionals' perspective. The results will aim to raise awareness of perceptions with a view to informing prescribing practices, source and format of patient information and education, education of healthcare professionals, future research agendas and clinical practice. The work will be published in healthcare journals to ensure dissemination of the work to appropriate healthcare

professionals. I will also aim to disseminate the work to patients through the British Lung Foundation.

Who has reviewed the study?

This study has been reviewed and ethical approval granted by NW Ethics committee.

What do I do now?

If you wish to participate in the study please e-mail me at: kellyc@edgehill.ac.uk I will then contact you to arrange a mutually convenient date and time for an interview.

Further information and contact details

If you would any further information please contact me:

Carol Kelly, Senior Lecturer, Faculty of Health, Edge Hill University, St Helens Rd,
Ormskirk, Lancashire, L39 4QP
Tel: Direct line. 01695 657090
Email: kellyc@edgehill.ac.uk

Thank you very much for your time in reading this information leaflet and for considering taking part in the study.

APPENDIX Q: Patient CONSENT FORM – Version 2

A Study Exploring Perceptions of Oxygen Therapy

Researcher: Carol Kelly

1. I confirm that I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the interview will be audio-recorded and I agree for this to happen. I agree that some of the things I say may be quoted in publications and I understand that these will be anonymous.

4. I agree to identifiable contact details and limited medical information being accessed and kept by the researcher with the reassurance that confidentiality and anonymity will be assured.

5. I understand that relevant data collected during the study, may be looked at by individuals from Edge Hill University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission to these individuals to have access to this data.

6. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of person
taking consent

Date

Signature

If you be interested and willing to participate in future stages of this study please indicate here.

1 copy to be retained by the participant and 1 copy by the researcher.

APPENDIX R: Healthcare Professional CONSENT FORM – Version 2

A Study Exploring Perceptions of Oxygen Therapy

Researcher: Carol Kelly

1. I confirm that I have read and understand the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that the interview will be audio-recorded and I agree for this to happen. I agree that some of the things I say may be quoted in publications and I understand that these will be anonymous.

4. I agree to identifiable contact details and limited demographic information being kept by the researcher with the reassurance that confidentiality and anonymity will be assured.

5. I agree that in the event of any disclosure of unsafe practice I will accept advice and guidance regarding sources of information and education if necessary.

6. I understand that relevant data collected during the study, may be looked at by individuals from Edge Hill University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission to these individuals to have access to this data.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

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If you be interested and willing to participate in future stages of this study please indicate here.

1 copy to be retained by the participant and 1 copy by the researcher.
