

A Wolf in Sheep's Clothing? Patients' and Healthcare Professionals' Perceptions of Oxygen Therapy: An Interpretative Phenomenological Analysis

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ABSTRACT

Background: Despite emerging evidence and guidelines, poor prescribing and administration of oxygen therapy persists. This study aimed to explore healthcare professionals' (HCPs) and patients' perceptions of oxygen.

Design: Semi-structured interviews with 28 patients and 34 HCPs.

Findings: Three master themes uncovered: *oxygen as a panacea*, *the burden of oxygen*, and *antecedents to beliefs*. Patients used oxygen for breathlessness and as an enabler; they were grateful to oxygen and accepted it as part of the disease. HCPs used oxygen because it helps patients; it works; and it makes HCPs feel better. But oxygen is not benign and a burden is evident with potential antecedents to beliefs revealed.

Summary: The findings suggest that a set of fixed beliefs regarding oxygen exist, influenced by several impacting factors. The perception that oxygen is a universal remedy presides, but is, at times, contradictory. These findings will raise awareness of entrenched cultures, influence future educational and research strategies, and inform policy.

Keywords: oxygen; perceptions; COPD; healthcare professionals

INTRODUCTION

A Wolf in Sheep's Clothing - a person or thing that appears friendly or harmless but is really hostile and dangerous (Oxford Dictionary of English Idioms, 2010).

Oxygen has been traditionally given to patients to correct hypoxaemia, protect against potential hypoxaemia, or relieve dyspnoea.[1] Whilst there is no doubt that its use to correct hypoxaemia is essential, there is a growing body of evidence suggesting that when too much oxygen is given, this may lead to adverse events and even death.[1,2,3,4] Additionally, the use of oxygen to relieve dyspnoea is increasingly controversial, seemingly exacerbated by a lack of clear guidance and consensus.[5,6] The publication of the first UK (United Kingdom) Emergency Oxygen Guidelines[1] challenged established custom but, despite this initiative, audit suggests persistence of poor practices.[7,8,9] It is unclear why this is the case, and the problem potentially self-perpetuates as erroneous beliefs are conveyed to patients, carers and the general public.

There is a paucity of literature relating to this area of practice, however two systematic reviews have provided a synthetic analysis of data extracted from related studies [10,11]. The literature alludes to deep-seated beliefs that exist amongst HCPS [10] and there appears uncertainty among patients regarding the purpose and benefits of oxygen therapy, though an underlying faith in HCPs which seems to foster acceptance of a life-changing therapy[11]. Several studies featured in these reviews included perceptions of oxygen therapy, for example Arnold et al[12] aimed to obtain information regarding patients' perceptions and compliance. Although specific to ambulatory oxygen therapy, several themes were identified regarding patient perception. Patients overwhelmingly believed oxygen was for dyspnoea; felt

restricted and embarrassed by it but it also made them feel safe. Similarly, O'Driscoll et al[13] explored knowledge, attitudes, and beliefs of healthcare professionals, patients with COPD and the general public concerning oxygen therapy. This mixed methods study found low levels of factual knowledge and false beliefs amongst patients and the general public, and whilst HCPs had a higher level of knowledge, complex attitudes towards further research in this area were revealed.

In order to influence practice, potential beliefs, customs and cultures that may be fuelling discordance need to be exposed and challenged. The aim of this study was to investigate respiratory patients' and healthcare professionals' experiences and perceptions of oxygen therapy?

METHODS

The qualitative method of Interpretative Phenomenological Analysis (IPA),[14] was used. In IPA the researcher acts as co-participant; 'lived experiences' and how individuals make sense of a particular phenomenon are studied. CK, as an experienced respiratory nurse, with insight into issues regarding oxygen therapy, facilitated participant's reflections and perceptions of their experiences of oxygen. Participants were not known to the researchers prior to the study.

Participants

A purposive sample (consistent with a qualitative approach),[15] of 28 patients was recruited through a local UK respiratory service. Sampling was intentional, based on factors such as diagnosis and prescribed oxygen regime. Thirty-four Healthcare professionals (HCPs) were recruited via postgraduate programmes and a snowballing method. Again, an intentional sampling approach was used with consideration of participants' professional background, workplace,

and experience with patients receiving oxygen. See Tables 1 and 2 for demographic details and Appendix 1 (Table 3) for inclusion exclusion criteria.

Ethical Approval was granted through the NHS (National Health Service) research ethics committee (REC Reference: 11/NW0167), NHS Trust Research and Development department, and University Research Ethics Committee. All participation was voluntary with informed consent.

Data collection

In-depth, semi-structured interviews ranging between 20 and 60 minutes were undertaken by CK, face-to-face in the university or workplace, or by telephone between May 2013 and March 2014. Non-directive, open-ended interview questions, developed from the literature review and personal experience (Appendix 2) facilitated the dialogue which was digitally recorded, transcribed and analysed using IPA.[14].

Data analysis

IPA is concerned with the individual, and acknowledges the researcher's active role in interpretation.[14] CK analysed transcripts at the semantic level for individuals before commonalities were themed at group level. Data from patients and HCPs were initially analysed separately before making across group comparisons. The iterative and inductive stages suggested by Smith et al. (2009) were adopted (Figure 1). Yardley's [16] approach of four broad principles – *sensitivity to context; commitment and rigour, transparency and coherence; and impact and importance* were used to assess quality of findings; this included independent audit conducted by MO'B. Computer software (Nvivo®) was used to facilitate the development and

organisation of themes. Figures 2 and 3 detail definitions used and participant labelling formula.

FINDINGS

Twenty-eight patients were included together with 34 HCPs, including nurses, paramedics, pharmacists and general practitioners.

Three master themes were identified: *oxygen as a panacea*, *the burden of oxygen*, and *antecedents to beliefs*. Super-ordinate themes under these constants differed between HCPs and patients (Figures 4, 5 & 6). The following narrative aims to characterise participants' overall use, opinion of, and attitude towards oxygen. Extracts are used to illustrate themes, and demographics to preserve context of the respondent's record. Tables 2 and 3 provide further detail of individuals' overall perception of oxygen.

Oxygen as a Panacea – Patients

Patients overwhelmingly perceived oxygen to be for *breathlessness*, referring to the potential to make their breathing '*better*'. Some viewed relief from breathlessness as a broad concept, referring to oxygen as comforting, others referred to the mechanics of breathing:

'You know, to breathe deeper, to get breath in.' (P14-F-67-COPD-borderline hypoxaemia)

Related to relief of breathlessness patients' perceived *oxygen as an enabler*, fostering independence and helping them to do things previously denied:

'...I wouldn't be able to do it without the oxygen.' (P10-F-55-COPD-normoxaemia-ambulatory)

Unsurprisingly patients often reported that they were *grateful to oxygen*, referring to the fact that *'it works'*, *'it makes me feel better'*. Many of those reporting such merits had normal blood oxygen levels; oxygen clearly offering something over and above relief of hypoxia.

These nebulous statements were contrasted by patients reporting a more elementary gratitude to oxygen: *'It's keeping me alive.'* (P5-M-66-emphysema-borderline hypoxaemia-SBOT). For some this was related to mortality, for others longevity. Expanding on the perceived merits of oxygen is patients *wanting oxygen*. Overwhelmingly patients viewed oxygen in a positive manner; regarding it as a friend that they were extremely grateful to, and at times, reliant on.

The theme of *Oxygen as Part of the Disease* relates to *compromise*, *acceptance*, and *others' acceptance* in relation to the therapeutic nature of oxygen. Finally, *ambivalence*: this may be a stage in the adaptation process, or it may signify juxtaposition, when patients are aware of both advantages and disadvantages of oxygen. Patients referred to a need to *'put up with it'* (P14-F-67-COPD- borderline hypoxaemia-no oxygen), and, in relation to mortality, suggested that the sacrifice was worthwhile:

'because you have to put up with these things otherwise you'd be dead'
(P16-M-66-sleep apnoea-hypoxaemia-LTOT)

All but one patient interviewed regarded oxygen in a positive light, a finding seemingly unrelated to either modality (i.e. short burst or long term) or level of hypoxia.

Oxygen as a Panacea – HCPs

Oxygen was also considered as a panacea from HCPs' perspectives. *It works!* This major theme represented the voices of various HCPs as they attempt to articulate the utility and efficacy of oxygen. At times the responses were a rationale for using oxygen, alternatively, a defence for not adhering to guidelines. 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)

The majority of HCPs recalled how oxygen seems to have psychological benefits for patients, referring to it as *'a crutch'* (HCP12 Cardiac Nurse-F) and potential placebo effects. Overall, all HCP participants regarded beneficial effects as more than just correction of hypoxia. They described using oxygen to calm patients down, reduce dyspnoea, enable daily activities, or, non-specifically, just to help patients.

Existing myths and beliefs encompassed the idea that *'it's just oxygen'* and *'it doesn't do any harm'*. There appears to be a culture of *more is better* and *giving oxygen to everyone and anyone*; a deep-seated reflexive practice that was not dominant in any one profession. Fundamentally oxygen was often regarded as a *wonder drug* in the context that its benefits were multifaceted. HCPs reflected on complacency arising from the routine use, and prolific availability, of oxygen.

One of the most poignant findings was that *oxygen makes HCPs feel better*. The notion of oxygen as a therapy for HCPs 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:

'... health professionals feel something's being done, because patients expect something to be done, and when it's not done can feel very abandoned ...'
(HCP3-Palliative Care Nurse-F)

Expectation is referred to when considering the family and carers of patients.

Although often aware that they were treating the family rather than the patient, healthcare professionals regarded this as a justified approach.

The Burden of Oxygen – Patients

This positivity was balanced with a recognition that it was not, in itself, benign; the burden was important to both groups.

Oxygen *made the disease visible* and there were *associated costs*. 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). Another recalled: *'I didn't realise how ill I was before.'* (P5-M-66-emphysema- borderline hypoxaemia-SBOT). This patient, with normal blood oxygen levels, regarded the introduction of oxygen as a sign of worsening disease, a perception misplaced given his moderate severity. He was accepting of oxygen and willing to compromise his lifestyle for an essentially unnecessary intervention.

The idea of permanency 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). For many patients the oxygen concentrator, tubing, cylinders and interface were unwelcome outward signs of their disease, a source of embarrassment.

Patients expressed other *associated costs* to living with oxygen: feeling trapped, resentment and dependency. Resentment was also related to the physical intrusion of oxygen. One particular patient stated poignantly: *'...it's invading my privacy.'* (P4-M-62-COPD-hypoxaemia-LTOT).

The Burden of Oxygen – HCPs

Healthcare professionals are often aware of the burdens of oxygen, including *an awareness of the dangers* associated with it, in particular smoking and the risk of over-oxygenation. 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 big gas fire blazing, with an oxygen cylinder sat in front it, and a cigarette! ... and you just think ... you're going to end up killing yourself.' (HCP4-Student Paramedic-F)

A common concern was that patients adopt a dependant attitude towards oxygen and over-rely on it, both physically and psychologically. In terms of controversy and doubt, knowing what to do for the best is a *dilemma* faced on a regular basis, and individuals felt emotionally challenged when faced with decisions. There was an acknowledgement of potential deception of patients, almost collusion between HCPs, carers and the patient.

Antecedents to Beliefs – Patients

Patients referred to putting total trust in HCPs; on occasion this was a subservient approach: *'Because I've been told to do that.'* (P4-M-62-COPD-hypoxaemia-LTOT). At other times it was a way of handing decisions over.

Past experiences of oxygen were important, patients frequently reflected on their own and others' experiences, in addition to influences from social media, particularly television. Personal experiences centred on emergency services and oxygen was synonymous with emergency care:

'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)

Knowledge and understanding of oxygen was generally poor. Many understood that oxygen was needed in their blood, and though comprehension seldom went further. Others had totally misunderstood: '*It's strengthening me.*' (P21-F-66-COPD-hypoxaemia-LTOT)

Some patients thought that too much information was given; others simply saw no need:

'If you have this real need to breathe properly then I don't think you give it an awful lot of thought.' (P17-M-77-lung cancer-normoxaemia-no oxygen)

Antecedents to Beliefs – HCPs

The perception that *it's what always happens* was prevalent amongst HCPs interviewed. This was often directed towards the action of managing a clinical crisis, or automatically giving oxygen for breathlessness.

Expectations were an important influence on prescribing and administering oxygen, and appeared from several different facets: expectations of patients, family and carers, and self. HCPs recounted how patients developed fixed ideas regarding oxygen - a desire to have it and keep it: '*They just love oxygen!*' (HCP22-Respiratory Nurse-F). Often the pressure from patients is in collusion with families and carers ('*we do get a lot of pressure from family*' - HCP19- Community Matron-F). Faced with breathless distressed patients, HCPs found it extremely difficult to follow guidelines exactly.

Many reported a DIY (do-it-yourself) approach to education and ad hoc dissemination of guidelines:

'And then with the release of the new guidelines a few years ago, it suddenly changed ... people were told this is what you do now. There was no rationale, no reasoning as to why, and it was down to the individuals to go away and look into it.' (HCP6-Paramedic-M)

Discussion

This study explored why a divergence between what is known about oxygen, and how it is administered and prescribed in practice, exists.

Fundamentally, both patients and HCPs overwhelmingly regarded oxygen as beneficial and innocuous: a universal remedy. But oxygen is not benign and a burden is evident. This study has exposed potential antecedents to beliefs and common practices. Differences between groups were apparent: for patients an unquestioning faith in HCPs prevailed. For HCPs an entrenched culture was evident, influenced by expectations of patients, families and carers, and indeed themselves. A dearth of formal training and education was reported, leading to a DIY approach to education.

Oxygen as a Panacea – The Sheep

Oxygen as a positive therapy has been reported previously.[17,18,19] The current study uncovered patients' reverent approach to oxygen, feeling grateful, enamoured and indebted to its ability to control dyspnoea. Enablement seems corollary to relief of breathlessness which reinforced gratitude; with consequences that oxygen was accepted, wanted, and even embraced as part of their disease.

In relation to the relief of dyspnoea oxygen probably serves patients in several ways, including psychological support. Indeed, the ritual of putting oxygen on, may in itself constitute a placebo effect that results in subsidence of panic. This placebo effect has been acknowledged previously.[20]

The current study suggests that there isn't always a relationship between hypoxaemia and patients' overall acceptance or attitude to oxygen. This correlation has not been depicted in the literature before and therefore adds an important dimension.

Similarly, the majority of HCPs regarded oxygen as a universal remedy, a belief which stems experience that *it works!* Overuse and misunderstanding of oxygen by HCPs is common,[2,6,21] 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;[1,2,21] this is the first time that this culture, underpinned by beliefs, misconceptions and myths, has been captured and reported as empirical data.

It has been tentatively revealed previously that giving oxygen may also be therapeutic for HCPs.[10,22] This study, confirmed that this does indeed exist and that the tangible action of giving oxygen can be as rewarding for HCPs as for patients; a self-gratification distracting HCPs from more appropriate strategies for managing dyspnoea.

It seems oxygen comforts 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.

The Burden of Oxygen – The Wolf

In contrast, both patients and HCPs showed awareness of the burdens of oxygen. The related forfeit was not insignificant, with acknowledged alteration of lifestyle and body image; symbolic of illness severity and even death, as observed

elsewhere.[23,24,25] This association with death has been described as fatalism;[24] a philosophy evident in several patient interviews as they perceived their bleak futures.

Oxygen was symbolic, a medicalisation of the patient's circumstances: for some this was good as it made a silent illness visible, for others it impacted on lifestyle and quality of life; a reinforcement of the sick role [26].

It appears that patients and families often expect and welcome oxygen. Brearden et al.[27] highlighted a need to manage expectations, but as patients and carers often regard oxygen as synonymous with life, denial may be difficult to impose and defend. Issues such as collusion and deception were evident and at times caused HCPs to question their own professional integrity.

Likewise, dilemmas are presented to HCPs when administering oxygen in the emergency situation. Guidelines suggest that oxygen should now, contrary to traditional practice, be withheld in certain categories of patients.[1] Clearly for some individuals this seemed counter-intuitive.

Antecedents to Beliefs

Faith in HCPs and perceived need for oxygen has been related to a need to be rescued at times of acute dyspnoea.[28] Patients' knowledge and understanding is important and can influence compliance;[12,29,30] likewise lack of knowledge can add to patients' anxieties and fears.[30] The current study shows that patients' perceptions of oxygen are influenced by media and personal experience. It is likely that the most dramatic interactions are the most memorable.

Factors influencing HCPs included reflexive practice, [27] whereby oxygen is given automatically and instantaneously to critically ill patients. Analogies can be seen here with antibiotic therapy. Beliefs, expectations and incentives are cited as the main drivers of overuse of antibiotics,[31] resulting in norms which can govern the transactions that patients and HCPs expect to occur. Perception of benefit, even with normal blood oxygen levels, and fear of hypoxaemia, appear to drive common usage of high concentration of oxygen for all medical emergencies: *it's what always happens*.

It is evident that an entrenched culture exists and serves to influence how oxygen is perceived by HCPs. This culture does not appear as a set of fixed beliefs; 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.

Knowledge and understanding are important and the relationship with clinical practice is clear. Transfer of knowledge to patients is part of the therapeutic relationship, but its benefits can be contested if knowledge is not grounded in evidence. Findings here suggest that the faith patients have in HCP with regards oxygen, on occasion, may be poorly placed.

A key limitation of this study is the self-selecting volunteer participants. With regards to HCPs however, this may suggest that understanding and insight into issues surrounding oxygen may be even more naive in a non-specialist group. The culture uncovered here refers to the UK healthcare system, but the literature suggests, similar cultures and practices exist globally.

The final sample sizes of 28 patients and 34 HCPs is inconsistent with the traditional application of IPA and therefore may be considered a limitation. Smith et

al. (2009) however recognise 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). The authors therefore attempted to preserve individuality through the detail contained in Tables 1 and 2.

A further limitation may have been that HCPs felt unable to speak openly about concerns, however the data does not reflect this. In addition, the mode of interview may have influenced engagement; similarly, this did not seem to be the case as some telephone interviews were lengthier than, and data as rich as, those conducted face to face. Strengths are evident in the variety of participants included: for patients receiving different regimes of oxygen therapy; for HCPs the diversity of professional groups.

Overall, perceived benefits of oxygen seems to be driving poor evidence based practice, and a self-perpetuating cycle of perceived barriers to change and continued inappropriate use of oxygen are evident. To initiate change expectations of patients, carers and healthcare professionals may need to be challenged more confidently. There is a need to raise public awareness of potentially harmful effects of oxygen; the image of oxygen and challenge its image. Media, particularly TV, could play a central role in this. These findings will support strategies to raise awareness of entrenched cultures, influence future educational and research strategies, and inform policy.

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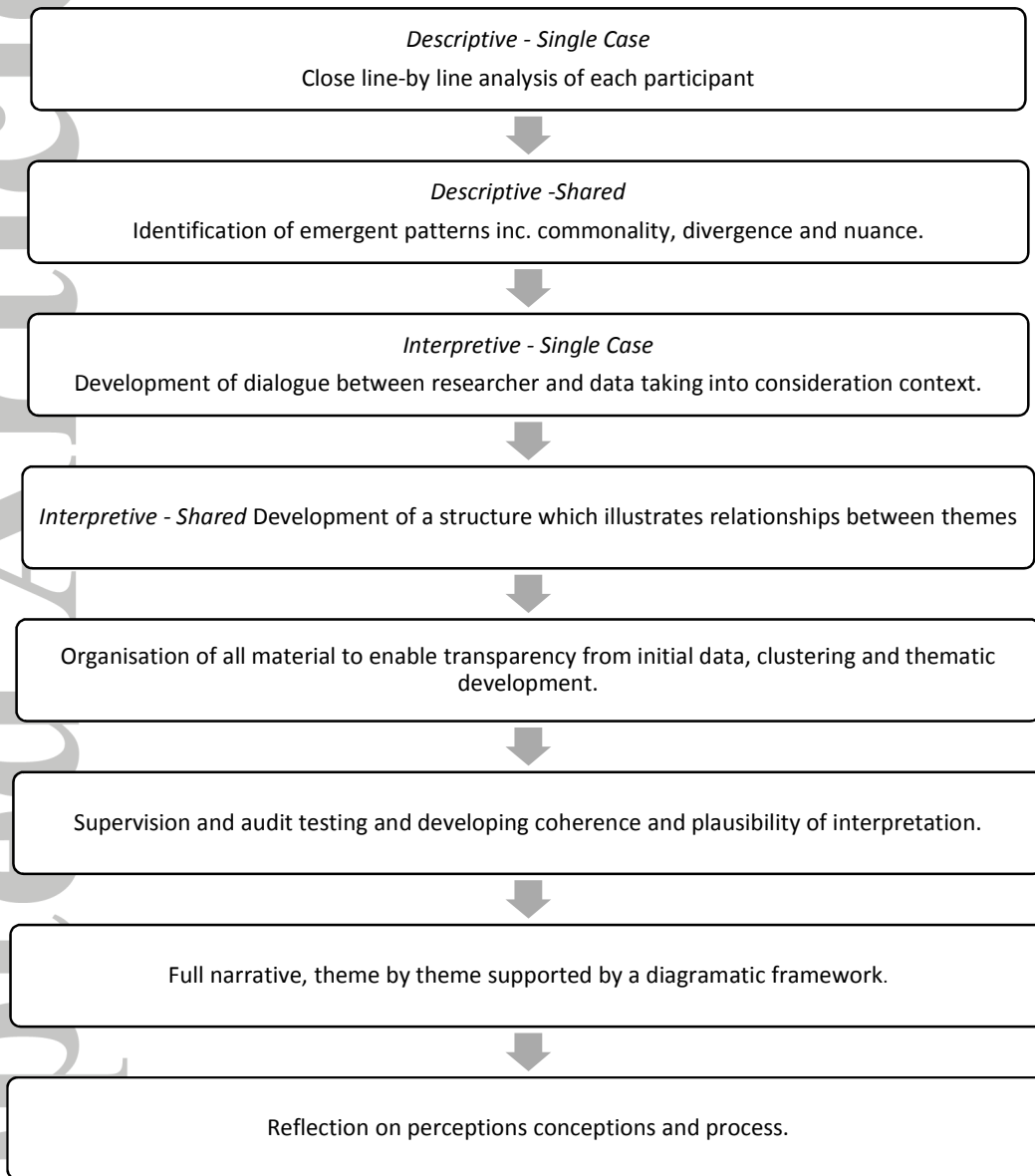
Figure 1: The Stages of IPA (adapted from Smith et al., 2009)

Fig.1: Definitions of blood oxygen levels used when reporting findings:

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

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

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

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Fig.2: Participant labelling formula:

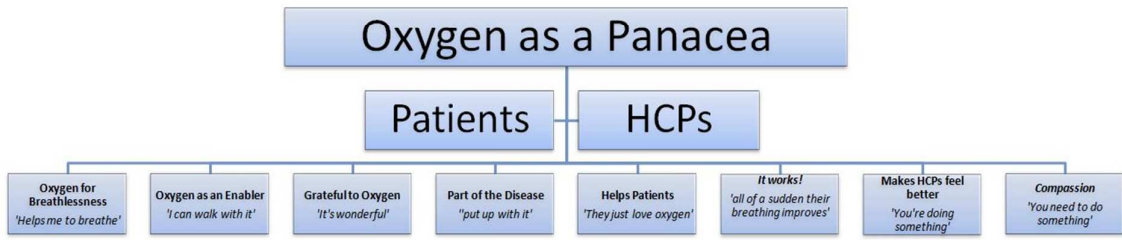
Patient participant number – sex (M=male; F= female) – age – principle respiratory diagnosis – blood oxygen level.

Example: (P14–F-67-COPD-borderline hypoxaemia)

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

Example: (HCP23- Pharmacist-F)

Figure 3: Emergent Themes: oxygen as a panacea



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Figure 4: Emergent Themes: *the burden of oxygen*

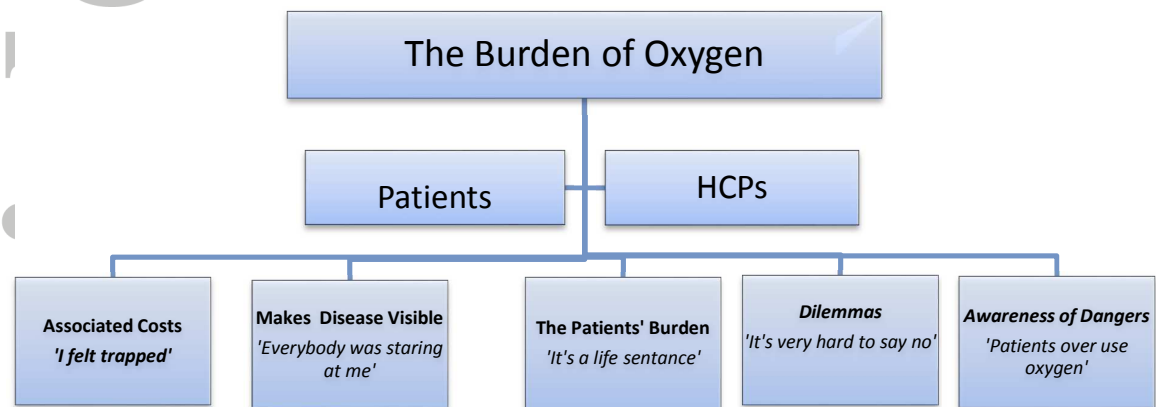
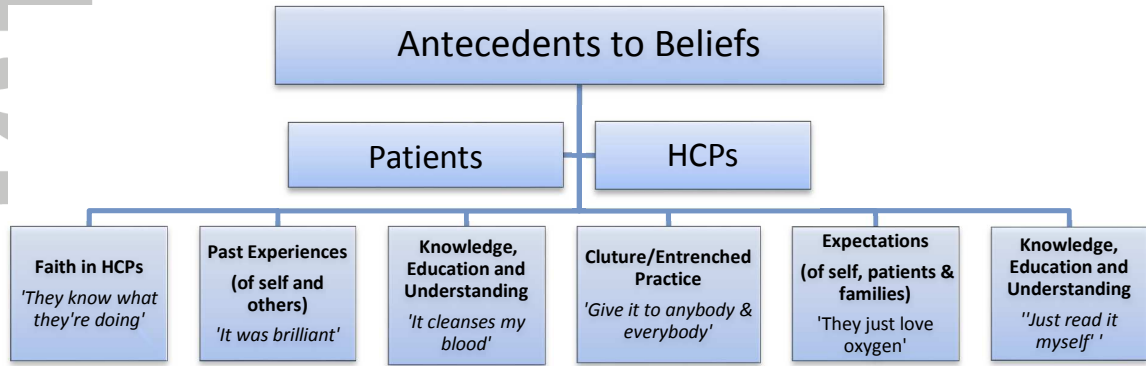


Figure 5: Emergent Themes: *antecedents to beliefs*



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Table 1: Patient Demographics and Overview of Oxygen

KEY: h.p.d - hours per day l.p.m. – litres per minute
 PaO₂ – Arterial blood oxygen SpO₂ – Pulse oximetry

PATIENT	SEX	AGE	Lives with	DIAGNOSIS	BLOOD OXYGEN STATUS	OXYGEN PRESCRIPTION	OVERALL ATTITUDE TO OXYGEN
P1	F	78	Alone	Hypoventilation Obesity Syndrome	Hypoxic – PaO ₂ 6.8kPa on air	Continuous 24 h.p.d 1 l.p.m.	“Loves” her oxygen thinks it’s “wonderful”. No real insight into diagnosis or reason for oxygen – doesn’t want to know.
P2	F	75	Sons	Emphysema	Hypoxic – PaO ₂ 6.0kPa now 7.2kPa on air	16 h.p.d 2 l.p.m. prescribed but now only 12 h.p.d as instructed	Grateful to oxygen for some respite from symptoms. Not much insight into disease or reason for oxygen – doesn’t feel she wants to know.
P3	F	71	Husband	COPD/asthma	Normoxic – SpO ₂ – 96% on air	Had LTOT for 6 months from hospital – now removed when sats ok	Very negative about oxygen - felt “life was over” with oxygen. “Ruined life completely; my life completely stopped; just couldn’t handle it”.
P4	M	62	Alone	COPD Type II Resp. Failure	Hypoxic PaO ₂ 7.09kPa PaCO ₂ 7.6kPa	LTOT 15 h.p.d. 2 l.p.m. plus ambulatory oxygen Uses average 15 hours	Takes oxygen for granted – part of everyday life. Quite accepting and compliant also pragmatic and fatalistic. Fair knowledge of oxygen but doesn’t wish to know finer details.
P5	M	66	Wife	Emphysema	PaO ₂ 8.1kPa on air – borderline hypoxia	Discharged from hospital on 15 h.p.d. now on SBOT 2 h.p.d	Very positive about oxygen. Thinks the oxygen has “worked” hence reduced. “So it’s obviously done me the world of good” Very accepting willing to compromise lifestyle to accommodate.
P6	M	73	Wife	“Out of Breath” – heavy smoker.	Hypoxic PaO ₂ 6.7kPa on air	On LTOT 1 year 1-2 l.p.m plus ambulatory 6 l.p.m	Appreciative– sees oxygen as an enabler. Some understanding of effects of oxygen on vital organs but also thinks it helps his lungs. Oxygen a part of everyday life: “a means to an end”.
P7	M	60	Partner	Idiopathic Pulmonary Fibrosis	Hypoxic PaO ₂ 7.2kPa on air.	Continuous 24 h.p.d 3 l.p.m. plus ambulatory	Very well informed about need for oxygen. Researched on internet. Intentional non-compliance – uses oxygen to suit his needs. “With my oxygen I can walk”
P8	F	75	Husband	COPD	Hypoxic PaO ₂ 7.4kPa on oxygen.	LTOT 15 h.p.d. ½ l.p.m. very sensitive to oxygen – CO ₂ rises.	No understanding of oxygen except that it “relieves breathlessness”. Grateful to oxygen but doesn’t know why “they keep you alive”. Reports poor quality of life & uncertain future.
P9	F	68	Alone	COPD	Mild - SpO ₂ 86% PaO ₂ 9.3kPa on 2 l.p.m. oxygen	LTOT – takes 24 hours per day – self prescribed regime.	Very high regard for oxygen. Feels it keeps her out of hospital. Limited understanding of disease & oxygen – “helps to breathe”. Pragmatic seems to accept oxygen as part of her illness.
P10	F	55	Husband	COPD	Normoxic SpO ₂ 92-94% on air	Ambulatory oxygen – 2 h.p.d. for activities	Limited understanding of oxygen therapy. Depends on oxygen for exercising – sees oxygen as an enabler. “it’s essential really isn’t it, so I feel safer with it.”
P11	F	80	Alone	Bronchiectasis	Borderline hypoxaemia -	LTOT prescribed 15 h.p.d. but uses 6 h.p.d.	Little understanding of disease and oxygen perceived oxygen to “open bronchioles and cleanses your blood” . Just seemed to accept oxygen for what it is and shouldn’t like to lose it.
P12	F	73	Alone	Emphysema & asthma	Normoxic - SpO ₂ 94% on air	On LTOT in past now removed and ambulatory only	Anxious lady. Oxygen seen as enabler “Well it helps me to breathe, you know, I mean, when I take it I do, I can feel myself breathing better, and it does help me”.

P13	M	89	Wife	Emphysema	Normoxic SpO2 93-95% on air	SBOT Twice daily x 10-15 mins and PRN	Very positive and grateful to oxygen– he'd been given it so presumed he needed it! If oxygen removed will require some re-adjustment. <i>'At the moment I feel I'd miss it very much.'</i>
P14	F	67	Alone	COPD	Normoxic	Not currently on oxygen but waiting assessment following referral.	Appeared to enjoy the 'sick' role. Had needed oxygen during recent admission hence referral. Didn't really know a lot about oxygen: <i>"Well if I am honest I don't know too much about it".</i>
P15	F	72	Son	Emphysema	Normoxic	Concentrator & ambulatory, 2 h.p.d – <i>"or more if a bad day"</i>	Ambivalent about oxygen. Accepted oxygen as part of her disease and it helps her <i>"to live"</i> . Associates oxygen with breathing and uses it to relieve breathlessness.
P16	M	66	Wife	Sleep apnoea Type II respiratory Failure	Type II RF but not aware of gases.	12 hours overnight – <i>"gases improved"</i> . Also on BiPAP.	Different perspective because on BiPAP. Generally felt a lack of information – angry at times. Appreciated he was better since starting oxygen. When asked thoughts on oxygen: <i>"Not a lot"</i> .
P17	M	77	Wife	Lobectomy for Lung Cancer	Normoxic SpO2 93% on air	Awaiting ambulatory oxygen assessment	Intractable dyspnoea. Wants oxygen, has helped in the past so feels <i>"needs"</i> for worsening breathlessness. Feels a need to <i>"fight the system"</i> to get it.
P18	M	68	Alone	<i>"Mark on his lung"</i> Congestive heart failure	Normoxic SpO2 97% on air	2 years ago on LTOT 14 h.p.d. now PRN – uses 15 mins. twice per day	Pragmatic and stoical man. Uses oxygen 15 mins. twice per day – his regime as nobody gave specific instructions. <i>"If it hadn't been for the oxygen then I wouldn't be here"</i>
P19	F	76	Alone	COPD	Borderline Normoxic SpO2 91% on air	LTOT 15 h.p.d. but does not use – just ambulatory oxygen now for 2-3 h.p.d.	Accepting of oxygen though not sure of reason for. Voiced disappointment with how much oxygen had helped – expected more. But if she needs it: <i>'I don't like having it, but if it helps.'</i>
P20	M	74	Wife	Sarcoidosis	Normoxic at rest SpO2 range 87-93%	LTOT 1 l.p.m x 10 h.p.d. plus 4 l.p.m. on exertion	Accepted oxygen as necessity – a means of coping with his disease/breathlessness: <i>"But we're very, what's the word, pragmatic, this isn't going to alter our lives, we'll work with it."</i>
P21	F	66	Husband	COPD	Hypoxic - SpO2 84%	LTOT 15 h.p.d x 18 months. recently restarted following chest infection.	Doesn't understand COPD – prefers to think it's <i>"avian"</i> despite smoking history. Feels the oxygen is principally for <i>"breathing better"</i> . Adjusted but worries she'll need more in the future.
P22	F	51	Husband	Interstitial lung disease	Normoxic at rest 79-90% self monitors.	Ambulatory 6 l.p.m for approx. 2 h.p.d.	Pragmatic lady but seemed quite concerned with others' opinions of her on oxygen. <i>"...people get shocked."</i> Grateful to oxygen as an assistant – likened it to a walking stick.
P23	F	62	Alone	COPD	Sats 89% at rest on air.	LTOT 15 h.p.d – takes 8-10 h.p.d	Accepting of oxygen and grateful. Feels she's become reliant on it and would like a <i>'back-up'</i> if withdrawn. Believes it is for breathlessness so only uses it in day, not night, hence 10 h.p.d
P24	M	69	Wife	Asbestos	Mild hypoxia –	LTOT 15 h.p.d. Manages	Reluctant at first but has learnt to adapt & adjust to life with

					ok last time	10-11 h.p.d	oxygen though refuses to go out wearing it – embarrassed. Talks about oxygen as something alien to his body – ‘not mine’.
P25	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	F	54	Daughter	COPD Hypoventilation Obesity Syndrome	Sats 91-93% on air in day.	O2 3lpm + BiPAP overnight 12 hours. Plus 3 lpm ambulatory O2.	Overall very complacent and accepting of oxygen. Just seems to accept it as necessary. Very grateful to the oxygen – feels it has helped. Alludes to info overload when first put on.
P27	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. Likes oxygen for breathlessness but won’t take overnight.
P28	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. Very pragmatic, grateful to oxygen for aiding recovery but also glad to be off it.

Table 2: HCP demographics and perceived overview of oxygen

INTERVIEWEE Profession	SEX	Exp. Yrs.	Place of Work	OVERALL ATTITUDE TO OXYGEN
HCP1: Paramedic	M	5-10	Pre-hospital setting	Alluded to a 'darker side' of oxygen. Differentiated between clinical & psychological breathlessness. Embraces guidelines but thinks oxygen doesn't harm.
HCP2: Senior Nurse	F	>20	Critical Care	Clearly knowledgeable. Critical of others' practice with regards to oxygen and frustrated by limited opportunities/time to teach.
HCP3 : Palliative Care Nurse	F	10-20	Intermediate care	Good grasp of the use of oxygen in palliative care. Aware of drawbacks for patients and family. Limited knowledge of oxygen in other settings.
HCP4: Student Paramedic	F	<5	Pre-hospital setting	Student in training but also has previous experience in Red Cross. Pragmatic regards oxygen. Works with guidelines but recounts occasions when deviates.
HCP5 : Respiratory Nurse Specialist	F	>20	Intermediate care	Good knowledge with regards respiratory patients but unaware of oxygen issues in other disease areas.
HCP6 : Senior Paramedic	M	5-10	Pre-hospital setting	Very knowledgeable. Talked about resistance to change and possible reasons why (lack of rationale/scepticism). Expressed concerns of a too cautious approach.
HCP7: Paramedic	F	5-10	Pre-hospital setting	Reports practice sometimes 'confusing' with multiple changes and mixed messages. Poor practice does persist and conflicts current guidelines at times. 'Old school resistance'. Oxygen as a placebo.
HCP8: Paramedic	F	<5	Pre-hospital setting	Aware of guidelines and dangers of O2 and keen to promote guideline usage. Patients demanding/expecting oxygen.
HCP9: Community Matron	F	10-20	Community	Discusses frustrations of patients' expectations also tension of mixed messages and 'doctor knows best'. Reflects on difficulty withdrawing oxygen and of difficulties denying to a dying patient or relatives.
HCP10: Clinic nurse – non-respiratory	F	>20	Hospital	Some useful insight into the 'lay' HCP thoughts on oxygen. Not aware of any guidelines and doesn't use/have pulse oximeter. Concerned by own lack of understanding of such a common therapy.
HCP11: Respiratory Nurse	F	5-10	Hospital	Difficulties changing practice: acceptance that oxygen is for breathlessness is the biggest challenge. Refers to patients' & HCPs' psychological benefit: "we are as dependent upon it as patients".
HCP12: CCU Nurse	F	5-10	Critical Care	Knowledgeable about oxygen. Difficulties advising medics and seniors who were either entrenched in existing practice or too junior. Barriers to change: time, fatigue and competing issues.
HCP13: Nurse Practitioner walk-in centre	F	>20	Community	Feels O ₂ given 'automatically' for breathlessness. Talked about mixed messages and difficulty keeping up with training. Angry & shocked about the lack of dissemination of guidelines.
HCP14: Ward nurse	F	10-20	Hospital	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	F	>20	Intermediate care	Little current experience with oxygen as specialises in asthma. Spoke of difficulties withdrawing and patients will 'DNA if they "get wind" of removal'. Pressure from families on occasion.
HCP16: Paramedic	M	5-10	Pre-hospital setting	Knowledgeable re oxygen. Articulate about changing practice and barriers faced: culture and 'old ways'. Oxygen used to make patients feel better. Expectations shaped by TV etc.
HCP17: Community Matron	F	>20	Community	Non-specialist. Feels oxygen restricts and fosters dependency. Helps HCPs & carers: "you feel like you're doing something productive and useful". Knowledge limited. Palliative oxygen always useful.
HCP18: Community Matron	F	5-10	Community	Patient dependency and difficulty withdrawing are features. Patients use oxygen for breathlessness, breathlessness can be synonymous with dying so educating patients is difficult.
HCP19: Community Matron	F	>20	Community	Oxygen synonymous with breathlessness. Also advocated using to reduce anxiety & keep patients at home. Reflected on patients and families resisting withdrawal of oxygen.
HCP20: Lung Cancer Nurse Specialist	F	10-20	Intermediate care	Reflected on patients want & expectation of oxygen. Contradictory practice: only ever prescribes for hypoxia unless circumstances such as breathlessness warrant. Oxygen reassures patients.
HCP21: Pharmacist	F	5-10	Hospital	Suggests many HCPs & doctors "don't really feel competent to prescribe & adjust". Variation in practice exists and fixed ideas. Challenges the pharmacy profession to participate more actively.
HCP22: COPD Nurse Specialist (Band 6)	F	5-10	Intermediate	Psychological benefits to patients: "they just love oxygen". Good knowledge guidelines but contradicts herself with palliative care: would always give "doesn't matter whether it works or not".
HCP23: Pharmacist	F	10-20	Primary care	Feels oxygen fundamentally associated with breathlessness. Culture of giving oxygen for emergencies feeds this – 'it's the thing to do!' Oxygen often a therapy for patients, carers, families and HCPs – doing something. Pressure from carers can be significant.
HCP24: Out of Hours Manager (ANP)	F	10-20	Primary care	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.
HCP25: Nurse Consultant	F	>20	Intermediate care	Patients and families want oxygen. Used to reduce anxiety &

				breathlessness; placebo effect. Mixed feelings re palliative care: 'you wouldn't want anybody to die not being able to breathe'.
HCP26: Third year student nurse	F	<5	Hospital and community	No formal training. Perception formed through personal experience: "...and if you give them oxygen, it calms them down". Too much oxygen is bad but unsure why. Not aware of any guidelines.
HCP27: Advanced Nurse Practitioner	F	>20	Intermediate care	No real views or insight. Administers oxygen according to 'BNF' guidelines. Reflected on personal experience of father with emphysema – used oxygen PRN for 'panic'. More training needed.
HCP28: GP	M	10-20	Primary care	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 self-directed.
HCP29: GP	M	10-20	Primary care	'Nobody really knows what they're doing' Acknowledges placebo effect. Reflects on entrenched practice: "anybody & everybody had an oxygen mask on, no matter what". Definitely not enough training.
HCP30: Pharmacist	M	>20	Intermediate care	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".
HCP31: Pharmacist (ILD Specialist)	M	5-10	Hospital	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 use of oxygen.
HCP32: Pharmacist Head of Medicines Management	M	>20	Intermediate care	Very insightful views. Generally feels both HCPs and patients overrate the 'value' of oxygen. Patients are let down by HCPs through lack of education and effective communication.
HCP33: GP	M	>20	Primary care	Feels 'phased' by oxygen acknowledging own lack of knowledge. 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.
HCP34: GP	F	10-20	Primary care	Limited knowledge. Feels it helps dyspnoea in acute and palliative situations. Acknowledges psychological benefit and that patients can become reliant on it. Has had no training and previously hadn't given it much thought 'it's just oxygen'.

Appendix 1

Table 3. Inclusion and exclusion criteria

Inclusion criteria for patients:

- established diagnosis of a chronic respiratory disease
- known to the healthcare team used oxygen in the preceding year (either on long term oxygen therapy or short term oxygen therapy)
- adults age 18 years or above

Exclusion criteria:

- Non-English speaking patients or patients with special communication needs.*
- No definitive diagnosis
- Children < 18 years
- No previous use of oxygen therapy
- Cognitive difficulties
- Unable to give informed consent

For healthcare professionals, Inclusion Criteria:

- Registered healthcare professional experience administering or prescribing oxygen therapy in the last year

Exclusion criteria:

- Non-English speaking healthcare professionals.*
- No previous experience administering or prescribing oxygen.

* Necessary owing to the nature of the data collection and analysis of the first phase.

Appendix 2 : Interview Questions/Prompts (Adjusted according to participant group, HCP or patient interview.

Grand tour question : *'I am interested in your views about oxygen therapy; can you tell me your views?'*

Knowledge

Tell me what you understand about oxygen therapy ?

Experiences

Can you tell me what experience you have of receiving (HCP : administering/prescribing) oxygen therapy?

Sensory

What happens when you receive (HCP : give) oxygen therapy; what do you feel?

Where/when did you first encounter oxygen?

Feelings

How does receiving (HCP : administering) oxygen therapy make you feel?

Opinions or beliefs

Do you think receiving oxygen therapy helps you (HCP : patients)? How does it help?

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 (HCP : administering) oxygen therapy?

Do you think you have received enough information regarding oxygen therapy ; when you have been given it?

What were your expectations of oxygen therapy?

Do you have any reservations about oxygen?

Do you think oxygen therapy has changed what you (HCP : patients) do and the activities that you (HCP : they) 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