

**Difficult decisions: An IPA (interpretative phenomenological analysis) study of Healthcare Professionals' Perceptions of Oxygen Therapy in Palliative Care.**

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# **Difficult decisions: An IPA (interpretative phenomenological analysis) study of Healthcare Professionals' Perceptions of Oxygen Therapy in Palliative Care.**

## **ABSTRACT**

**Background:** The role of oxygen therapy to palliate dyspnoea is controversial. Without a clear evidence base oxygen is commonly prescribed, sometimes to the detriment of patients. This use of oxygen appears to be an entrenched culture the roots of which remain obscure.

**Aim:** To explore Healthcare Professionals' (HCPs) perceptions of oxygen therapy in palliative care.

**Design:** IPA (interpretative phenomenological analysis) study utilising semi-structured interviews to explore beliefs and behaviours of HCPs regarding palliative oxygen therapy. Data were recorded, transcribed and analysed using IPA.

**Setting/Participants:** 34 HCPs, including doctors, nurses, pharmacists and paramedics in the UK who were involved in prescribing, or administering, oxygen therapy to palliate dyspnoea.

**Results:** Most HCPs in this study were well informed about oxygen therapy; all recognised the role of oxygen in palliative care setting as important. The overarching theme of *compassion* identified sub-themes of '*comfort*', '*do anything and everything*', and '*family benefit*'. The use of oxygen in the palliative care setting was not without its *dilemmas* however, as additional sub-themes of '*controversy*', '*doubt*' and '*dependency*' illustrated.

**Conclusion:** Findings suggest that oxygen therapy in palliative care poses an on-going dilemma for HCPs striving to provide optimum care. It seems patients and families often expect and welcome oxygen, but the perception of oxygen as a solution to dyspnoea can conflict with HCPs own doubt and experiences. There appears to be an emotional cost associated with this dilemma and the choices that need to be made.

## **Keywords**

Oxygen, palliative care, health personnel, perception

## **KEY STATEMENTS**

### **What is already known about the topic?**

- Oxygen is commonly prescribed in palliative care.
- Existing evidence does not support the use of oxygen except for hypoxaemia.
- Overuse of oxygen can be detrimental for patients.

### **What this paper adds?**

- Administration of oxygen enables HCPs to feel effective in caring.
- HCPs face deliberations in making decisions regarding oxygen therapy.
- An emotional cost to the HCP is evident.

### **Implications for practice, theory or policy?**

- Expectations of patients, carers and HCPs need to be challenged.
- Clear and definitive international guidelines are needed to facilitate difficult decisions regarding the use of oxygen therapy in palliative care.
- Alternative, evidence based strategies for relieving dyspnoea need to be promoted.

## Background

Dyspnoea is a common and distressing symptom in many terminal conditions, and one for which oxygen is commonly prescribed.[1,2] Symptom control is a central tenet of palliative care, yet the use of oxygen to palliate dyspnoea is an area of uncertainty, debate and controversy.[3] Principally this is because, despite widespread use of oxygen, a growing tide of evidence[4-8] suggests that, unless given to correct hypoxaemia (low blood oxygen), it offers little, or no, benefit to patients. Additionally, drawbacks are apparent, including physical, psychological, emotional and social discomfort.[9] In certain conditions, oxygen may cause deterioration in health status, and even death.[4-8,10] Moreover, the inappropriate use of oxygen places a financial burden on health services in times of austerity.

Guidelines and consensus statements add to ambiguity, often contributing no clear direction or definitive stance.[10-15] Oxygen is classed as a drug,[16] and there is unquestioned evidence regarding its use and efficacy in the presence of hypoxaemia.[10,11] However, 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 healthcare professionals (HCPs), who, faced with conflicting advice and information, strive to provide optimum care.

The origins of prescribing palliative oxygen are obscure, there seems to be a belief that oxygen alleviates breathlessness, although the use of air provides similar relief.[17,18] There is also general concurrence, based on landmark physiological studies, that the mechanisms for such relief are through facial cooling and airflow.[19-21] These theorems have been tested clinically; indeed a randomised

controlled crossover trial demonstrated that a handheld fan, directed to the face, reduced dyspnoea.[22]

It is undoubted that in addition to facial cooling there is a placebo effect from administering oxygen, this should not be underestimated,[23-25] and may even be advocated in practice. This is a divisive issue in palliative care, which possibly adds to ambiguity and erroneous beliefs regarding oxygen.

The mechanisms, assessment and treatment options for dyspnoea are covered in depth elsewhere.[3,14,15, 26-28] Fundamentally dyspnoea is difficult to manage: it is a complex physically and psychologically distressing and subjective experience. Dyspnoea treatment options are limited: the best result is alleviation rather than eradication of the symptom. That said, alternatives to oxygen therapy do exist, such as opiates, anxiolytics and fan therapy, each with a stronger evidence base and less potential side-effects than oxygen.[22,27-29]

Despite all these considerations, oxygen continues to be recommended for palliation of dyspnoea in patients with normal blood oxygen levels, not relieved by other treatments,[12,16] and remains a popular choice amongst both HCPs and patients alike.

There is literature considering healthcare professionals' perceptions of oxygen therapy. Most of what is published lacks rigour and utilises simple methods of investigation that offer little depth to this complex issue.

An e-mail survey of 214 physicians in Australia and New Zealand captured oxygen prescribing habits in palliative care. The findings showed that palliative care physicians were more likely to prescribe palliative oxygen than respiratory

physicians, (29% vs. 9%,  $p=0.009$ ), and that the most frequently (65%) cited reason for prescribing was 'intractable dyspnoea'.<sup>[1]</sup>

A similar Canadian telephone survey of physicians' prescribing habits for palliative oxygen, reported variability in practices, attributed to a lack of both evidence and clear guidelines.<sup>[2]</sup> Ultimately, uncertainty and inconsistency exists when deciding whether to prescribe palliative oxygen. This difficulty in management is reported to engender helplessness in patients, carers and HCPs.<sup>[2]</sup> The decision to use oxygen appears to be based on past experiences and biases, rather than sound pathophysiological rationale.

Another Canadian study exploring dyspnoea in the last year of life, from patients' and nurses' perspectives, provided some insight.<sup>[30]</sup> An inconsistent approach to managing dyspnoea was evident; some nurses reported that oxygen was helpful and should be ordered as soon as dyspnoea was apparent, others claimed that, although it wasn't '*clinically therapeutic*', it had a '*symbolic benefit*'. Several nurses were of the opinion that oxygen provided psychological comfort to both patients and their families.

Breaden et al <sup>[31]</sup> aimed to understand factors that guide Australian palliative care nurses initiating or recommending oxygen. One major theme concerned managing expectations of families, carers and other health professionals; linked to the prolific use of oxygen and initiation in order to "*treat the caregivers' anxiety*" (p270).

The idea of oxygen benefitting HCPs is probably the most ambiguous in the literature. A grounded theory study in the USA, highlighted a sense of frustration regarding dyspnoea management, and physicians considering oxygen as another

option.[32] This would seem a logical explanation for the common prescription of oxygen for normoxaemic patients. Roberts et al's study [30] of lung cancer draws on the idea further: participants speculated whether psychological benefit was as relevant to patients as it was to nurses.

The literature offers some insight into the inconsistencies of palliative oxygen prescription and administration, and a glimpse at a ritual obstructing HCPs practicing evidence-based care. The clues with regards to why this obstinate practice persists, however, lack tangibility and verification.

The findings reported here are from a larger study exploring both healthcare professionals' (HCPs) and patients' perspectives of oxygen therapy. From the data, HCPs perceptions regarding palliative oxygen was rich, and often contrary to their level of knowledge and understanding; this serendipitous finding seemed worthy of separate reporting.

## **Aim**

To explore healthcare professionals' (HCPs) perceptions of oxygen therapy in palliative care.

## **Methods**

Interpretative phenomenological analysis (IPA) is a qualitative research method that allows the study of how individuals make sense of a personal and significant phenomenon. IPA acknowledges the researcher's active role in the analysis; indeed the researcher's own conceptions are considered essential.[33]

### *Participant selection*

A convenient, purposive and intentional volunteer sample of 34 HCPs was recruited (Table 1), both via the host university (individuals undertaking various postgraduate professional study), and a snowballing method (through referral from participants). Further details of participants are included in Appendix B. Potential participants were initially approached via notification through the VLE (Virtual Learning Environment) or through distribution of leaflets in the classroom. Interested volunteers responded via e-mail to CK.

The target sample size of 30 was exceeded, despite data saturation, to ensure an adequate number of doctors were recruited. Whilst smaller sample sizes are usual in IPA, application to a larger corpus is recognised: analysis maintains individual cases whilst assessing key emergent themes for the whole group.[34] Thus, commitment to a detailed interpretative account remains, despite the large sample. This is justified by the study's relatively narrow focus: oxygen therapy. Identifying measurement of recurrence is deemed important for a large sample, and is reported (Table 2).

**Table 1: Demographics by profession**

<b>Healthcare Profession</b>	<b>Number of Participants</b>
Nurses	18
Paramedics	6
Doctors	4
Pharmacists	5
Other HCPs	1



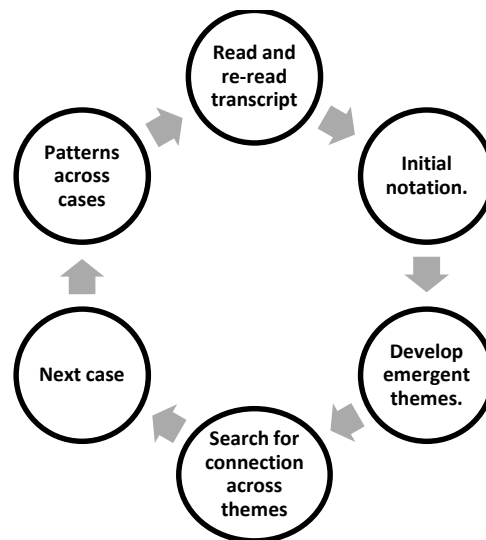
### *Data collection*

In-depth, face-to-face, semi-structured interviews ranging between 20 and 60 minutes were undertaken by CK, in the university or workplace, or by telephone, between May 2012 and March 2013. Open-ended and non-directive interview questions, originating from anecdotal experience and existing literature, facilitated dialogue (see Appendix A). Self-reported beliefs and behaviours were recorded, transcribed and analysed using IPA.[33]

### *Data Handling and Analysis*

IPA is ideographic (concerned with the individual), and acknowledges the researcher's active role in interpretation. [33] CK, with previous experience as a Respiratory Nurse Specialist, analysed transcripts at the semantic level. True to an idiographic mode of inquiry, cases were initially analysed as individuals, before common themes were constructed across the group. This involved an interpretative relationship with transcripts, obtaining meaning through a sustained engagement with the text,[33] and several, though not prescriptive, cyclical stages (Figure 1).

**Figure 1: Cyclical Process of Analysis** (adapted from Smith et al,[34])



Initial data analysis consisted of exploration of each individual's interview and identifying emergent themes across cases. Emergent themes were then grouped into two superordinate themes. NVivo software[35] was utilised to organise and store data.

Strategies for validating findings, based on broad principles for quality in qualitative research[36] were utilised to safeguard and maintain authenticity and credibility. This included independent audit by MO'B to ensure the account produced is credible.[34] Verbatim extracts provide grounding in examples [37] and use of a field journal aimed to enhance transparency of the IPA process.[34] Transcripts were returned to participants for verification: no comments were made.

### *Reflexivity*

The purpose of reflection in IPA is to emphasise appropriate reflections in the dynamic process of analysis. In IPA, although the researcher's experience is important to enhance the analysis, there is also potential to hinder.[38] A field journal served to record initial thoughts, reflections and ideas, both immediately following

interviews and during analysis: these then became an inherent part of the analysis. This supported an iterative process and facilitated identification of emergent themes and development of super-ordinate themes.

### *Ethics*

All participation was voluntary with full informed consent. NHS (National Health Service) research ethics (REC Reference: 11/NW0167), NHS Trust Research and Development approval and host university research ethics approval were obtained.

### **Findings**

The majority of HCPs in this study were well informed regarding oxygen therapy. Despite this, and without exception, all HCPs interviewed acknowledge the permissive use of oxygen in palliative situations. This paradox was true even of respondents who had generally aired caution and reserve when using oxygen for other patients.

Two overarching themes emerged from the data: *compassion* and *dilemma*, originating from sub-themes as outline in Table 2. Group level themes are illustrated with particular examples taken from individuals.

Table 2: Superordinate and ordinate themes

Superordinate Theme	Ordinate theme	No. of HCPs	No. of references
<b>Compassion</b>	Comfort	15	27
	Do Anything & Everything	12	14
	Family Benefit	7	10
<b>Dilemmas</b>	Controversy	8	13
	Doubt	9	11
	Dependency	10	16

### **Compassion**

The overarching theme of compassion contained sub-themes of ‘*comfort*’, ‘*do anything and everything*’, and ‘*family benefit*’.

*Comfort*: As may be predicted, most HCPs regarded the comfort of patients as prime importance. 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 were expressed:

*‘...if the patient was palliative and it eased their symptoms or they felt reassured, their anxiety dropped...’* (HCP12 – Generalist Nurse).

The notion of death was clearly central in the minds of HCPs, and often seemed synonymous with dyspnoea management:

*‘You wouldn’t want anybody to die not being able to breathe...it must be awful to die with a sense of breathlessness, must be so frightening...’* (HCP25 - Nurse Consultant).

Such remarks exemplified empathy and a reflective approach to practice: previous experience of death and breathlessness was regarded as the antipathy of a peaceful death.

When discussing the value of oxygen for normoxaemic patients, logic and reason were often in conflict with caution. 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 Specialist)

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

*'If it was my mum she would have all the oxygen'* (HCP10 – Generalist Nurse).

Resentment regarding the bureaucracy of ordering oxygen, however, was expressed, and policies were seen as a barrier to be circumnavigated in order to optimise care.

*'...without having to go through all the rigmarole of the form and the referral and this, that and the other'* (HCP29 - GP).

Often oxygen was regarded as a panacea with no drawbacks. Consideration that patients were at a stage when there is nothing to lose, allowed oxygen to be considered as a final attempt at palliation:

*'...in a way you've shot your last bolt'* (HCP33 – GP).

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'* (HCP05 – Respiratory Nurse Specialist).

*Family benefit:* The notion of expectation is referred to when considering the family and carers of palliative care patients. Often aware they were treating the family rather than the patient, HCPs regarded this as a justified approach.

*'...and sometimes of course with the oxygen, you're treating the relatives aren't you' (HCP23 – Pharmacist).*

The notion of actively treating the family in addition to the patient seems usual: this could be encompassed within the philosophy of palliative care. 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' (HCP22 – Respiratory Nurse Specialist).*

On occasion, respondents displayed an awareness of the potential drawbacks of this course of action:

*'Sometimes the family and the patient don't want to be seen using oxygen, they don't want to be remembered as a person with a mask' (HCP11-Respiratory Nurse).*

The use of oxygen was also seen to be a protective strategy against complaint or accusation. When considering the family, a Community Matron (HCP09) 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.'*

### **Dilemmas**

The use of oxygen in the palliative care setting was not without its dilemmas however, as additional sub-themes of *'controversy'*, *'doubt'* and *'dependency'* illustrated.

*Controversy:* The majority of HCPs interviewed seemed well versed with the controversy surrounding oxygen for palliative care, in terms of the lack of evidence and drawbacks to its use:

*'It's fraught with problems'* (HCP03 – Palliative Care Nurse Specialist).

Individual beliefs were evident, some of which appeared grounded,

*'We've had quite an ongoing sort of saga about trying to get information out of GPs, about when to prescribe oxygen and when not'* (HCP23 – Pharmacist);

Whereas others seemed to reflect possible erroneous beliefs:

*'It's probably going to prolong their life, maybe for a few hours, maybe a few days ...that's more cruel in a way. I suppose another person might say, "Well why are you doing that?"'* (HCP10 – Generalist Nurse).

An insight into dilemmas potentially experienced by carers and relatives was also apparent, and this brings about controversy in itself:

*'... to them they see that having the oxygen helps, has benefits or may well prolong things'* (HCP05 – Respiratory Nurse Specialist).

Likewise HCPs felt torn when making decisions regarding the provision of oxygen, it was difficult for personal emotions not to take priority:

*'We will say, "no you can't have oxygen, you're not hypoxic"' 'But if I was asked for oxygen by somebody that would be dying within a week, it would be very hard for me to say no.'* (HCP11 – Respiratory Nurse).

The notion of empathy, feeling for the needs of the patient, was expressed in relation to this controversy.

*'The same criteria [as for hypoxaemic patients] apply and it gets rejected but ... the heart is telling them this is what I need'* (HCP32 – Pharmacist).

*Doubt:* Participants revealed their personal doubts regarding efficacy and appropriateness of oxygen:

*'There's the expectation that it's going to make things better; totally better, but of course it doesn't'* (HCP33 – GP).

This doubt presented a real and overtly expressed dilemma for some participants;

*'But if you are dying of breathlessness, I actually don't know if it would help or not. So I just don't know'* (HCP25 – Nurse Consultant).

Participants were aware of the evidence base regarding the use of oxygen therapy which did have an impact on their views.

*'I've become more sceptical about oxygen because, there's been little evidence to actually demonstrate that it's effective'* (HCP03 – Palliative Care Nurse Specialist).

However, this knowledge and understanding appears to give little reassurance to some HCPs regarding their decision-making; indeed, it sometimes significantly compounded the issue:

*'It's quite hard actually because if somebody's breathless you think, like is it because of them dying, or is it because they're anxious. Because they know what's happening in the situation, it's quite hard to decide whether oxygen would be appropriate or not, and would I want to try it or not, you know what I mean - "I'm not going to give you the oxygen you're going to try the fan", it's quite hard really'* (HCP09 – Community Matron).

Further controversy was raised when discussing the ethics of giving oxygen to patients who were not hypoxic in order to make them *'feel better'*. Regarded by one participant: *'it just seems a little bit unethical'* (HCP28 – GP). This confession appeared to be referring to the deception of patients, almost a collusion between the healthcare professional, carers and patient, which does not reflect the truth of what the HCP believed. On the other hand, for some this was a justifiable way of using oxygen. Whatever the decision for individuals it is clear that an emotional cost is incurred by the healthcare professional.

*Dependency:* The dilemmas continue as HCPs express knowledge and understanding that receiving oxygen can foster dependency in some patients, and



perhaps psychological effects of oxygen are not always beneficial to patients. This takes the form of both physical and psychological dependency that can affect daily activities and ultimately quality of life:

*'... 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)

HCPs are aware that oxygen may bring about helplessness. The notion that the health carers themselves may be contributing to this dependency, is evident and gives rise to predicaments in practice, knowing what to do for the best is a quandary that they faced on a regular basis.

## **Discussion**

These findings suggest oxygen therapy in palliative care poses an on-going dilemma for HCPs. It seems patients and families often expect, and welcome, oxygen, but the perception of it as a solution to dyspnoea, can conflict with HCP's own doubt and experiences. There is an innate need for HCPs to help 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: 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 feel frustrated and do not know what else to do, resulting in an emotional cost to caring.

The findings add to existing literature supporting the prevalence of oxygen to relieve dyspnoea and provide comfort,[31] and the uncertainty that exists regarding appropriateness.[2] Roberts et al [30] suggested oxygen was often given to provide

psychological support, the current study supports this notion, and endorses the idea that HCPs may also prescribe oxygen to appease their own frustration and guilt.

Dyspnoea is a difficult symptom to manage, however knowledge and understanding of the phenomenon is developing[13,14,39] and it is now accepted that alternative approaches exist and should be promoted.[3, 40] It has been suggested that excellent communication is required to discuss difficult decisions[41]—addressing a patient’s fears of dyspnoea needs to be a key priority for HCPs, in addition to education regarding futility and dangers of oxygen.

The emotional cost of dilemmas faced, regarding oxygen use in this manner, has not, to the authors’ knowledge, been recorded previously in the literature. This is potentially an important finding. Awareness that occurrence of doubts and controversies is common, may enable HCPs to discuss these issues more openly, with both colleagues and patients, enabling resolution of conflicting opinions and expectations, and acting as a driver for change.

Breaden et al,[31] highlighted that specialist palliative care nurses’ felt an additional need to manage expectations of families, caregivers and other clinicians. It was reported that initiation of oxygen was to *‘treat the caregiver’s anxiety’* (p270). Given that patients and carers regard oxygen as synonymous with life, denial of oxygen may be hard to defend. When one of the overriding concerns regarding death for a respiratory patient is their fear of breathlessness and suffocation,[42] the situation is worsened.

Inconsistencies of oxygen prescription and administration in palliative care were evident, and has been reported elsewhere.[1,2] Additionally, frustrations of family physicians’ treating dyspnoea in the palliative care context have been

reported: “*weighs you down emotionally*”, [43] but the finding of propensity for clinical dilemmas and related emotional cost, in relation to the use of oxygen for dyspnoea, is unique.

One of the key limitations to this study is the self-selecting group of HCPs with an interest in oxygen. The majority were knowledgeable and experienced in both prescribing and administering oxygen, yet when it came to considering palliative care, they appeared to contradict themselves, on occasion opposing their own previously stated prudence regarding other clinical situations. This paradox implies the situation may be worse for less knowledgeable HCPs.

Expectation, from patients, carers and HCPs, appears to be a key feature and a logical strategy to reduce oxygen usage would be to alter anticipation. The myth that dyspnoea is synonymous with oxygen needs to be broken. This will require a shift in thinking amongst healthcare professions and the general public alike. Challenging culture will be the central driver in order to achieve this paradigm shift. Further research is needed to strengthen the existing evidence base for alternative interventions to manage dyspnoea; meanwhile alternatives, such as opioids and fan therapy, must be promoted. Education will be a central catalyst to this change, both to empower HCPs with knowledge and understanding, but also the confidence to educate each other, patients and carers. The study of patients and carers perceptions of oxygen therapy is warranted, and may add an important dimension.

## **Summary**

These findings suggest that most HCPs believe the use of oxygen therapy in palliative care is permissible, a practice endorsed by patients', families' and other HCPs' expectations. This is paradoxical to existing knowledge and understanding of

oxygen usage in other clinical situations. Most HCPs are aware of conflicting views and emerging evidence, and this poses an on-going dilemma as they strive to provide optimum care. In the absence of definitive guidelines there appears to be an emotional cost associated with the choices that need to be made in order to optimise care for patients with intractable dyspnoea.

3,035 excl abstract, figure and verbatim quotes (609) & references

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The authors declare that there is no conflict of interest.

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Access to additional data may be requested by contacting the first author at [kellyc@edgehill.ac.uk](mailto:kellyc@edgehill.ac.uk)

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