

Title: Stigma and the in(visible) Perspectives and expectations of home oxygen therapy among people with chronic breathlessness syndrome: a qualitative study.

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Abstract

Background

Chronic breathlessness syndrome in the context of advancing disease is distressing for all concerned. Oxygen is commonly prescribed in this setting, however, little is known about the perspectives of breathless people who either are on oxygen, or are yet to have it prescribed.

Aim

To understand and describe the perspectives and experiences of breathless people towards oxygen use at home.

Design

This qualitative study utilised an Interpretive Description approach using semi-structured interviews and thematic analysis.

Setting/participants

Nineteen people with chronic breathlessness syndrome living in South Australia participated in semi-structured interviews. Participants were divided into sub-groups according to whether they were chronically breathless and:

- 1) not using home oxygen ($n=6$);
- 2) using funded home oxygen for severe hypoxaemia ($n=7$); and
- 3) and using home oxygen for palliation outside of funding guidelines ($n=6$).

Results

Three main themes were identified;

1. Managing distress and living with chronic breathlessness syndrome, with or without oxygen, requires a range of self-management strategies.
2. Expectations of oxygen use: 'Not as good as I thought it would be', and;
3. The stigma of using oxygen: the visible and invisible.

Conclusion

People living with chronic breathlessness struggle daily with both the progression of the underlying disease and the distressing nature of the syndrome. While oxygen does provide benefit for some people, its use and the perceptions of its use are often associated with both the visible and invisible manifestations of stigma. Clinicians need to promote self-management

strategies and give careful thought to the prescribing of home oxygen, especially outside the current funding guidelines.

Key Words

Oxygen; palliative care; dyspnea; social stigma; chronic disease; shame

What is already known about the topic?

- Despite the existence of international oxygen prescribing guidelines, home oxygen is often ordered outside these recommendations.
- Oxygen therapy can be both helpful and unhelpful in people with chronic breathlessness.
- Research on the perspectives of people on oxygen therapy has found that they commonly experience a sense of isolation, feel a sense of embarrassment with its use and this feeling affects the way they feel about themselves.

What this paper adds?

- The experiences and perspectives of chronically breathless people towards oxygen therapy, from both the perspectives of those on oxygen, and those who have yet to be prescribed it.
- Oxygen therapy portrays people with chronic breathlessness as being different and, at times, is associated with a sense of stigma.

Implications for practice, theory and policy

- Careful thought needs to be given to the prescribing of home oxygen, especially outside the current prescribing guidelines.
- Prescribing clinicians need to have frank and honest discussions about the benefits and burdens of home oxygen.
- Clinicians should also acknowledge the expectations and fears of stigmatisation associated with oxygen therapy.

Background

Breathlessness is a common symptom, occurring in up to 50% of people receiving palliative care ¹ and increasing to approximately 65% as death approaches ². The optimal management of breathlessness is to treat the underlying cause(s) ³. When this aim is no longer feasible, chronic breathlessness may be lessened by non-pharmacological and pharmacological interventions ⁴. As recently agreed by an international consensus panel, the term ‘chronic breathlessness syndrome’ will be used throughout this article to describe breathlessness that remains after the underlying conditions have been optimally treated ⁵.

Oxygen is one of several strategies used to reduce breathlessness ⁶ and has been shown to increase the survival for people with Chronic Obstructive Pulmonary Disease (COPD) with severe hypoxaemia. However, oxygen’s benefits are less clear for people with different diseases and for those people who are not hypoxemic, or only mildly so, and in some situations, may be no better than medical air ^{7,8}. Nevertheless, clinicians commonly prescribe oxygen in the palliative setting and there is evidence that non-clinical factors can influence prescribing patterns. For example, clinicians often feel under pressure to prescribe oxygen because of high levels of caregiver distress ⁹⁻¹¹. Furthermore, while there is the potential for emotional and physical adverse effects associated with oxygen use ³, caregivers often overlook these, overestimating its’ benefits ¹⁰.

While previous systematic reviews and research studies have explored the experience of breathlessness ¹², there is a dearth of literature focused explicitly on experiences of the use of oxygen in the home ¹³⁻¹⁵. One example however is the study by Kelly and colleagues’ ¹⁶ who explored respiratory patients’ perceptions of oxygen therapy found that oxygen, whilst beneficial in many cases, created an increasing dependency and a sense of embarrassment and stigma for the person, thereby limiting many lifestyle choices and affecting a person’s body image. However, the voices of people living with chronic breathlessness from all causes, including those who are not receiving oxygen as well as those who are, have not been heard. Given that the use of oxygen is not without significant side effects ¹⁷ and safety concerns ³, its introduction into the home requires careful consideration. Therefore, the aim of this qualitative study is to explore the perspectives and experiences of people living with chronic breathlessness syndrome of oxygen use in the home.

Methods

The research design was general qualitative description and semi-structured interviews were used to collect the data. The qualitative approach of Interpretive Description¹⁸ was used to capture themes and patterns within the subjective understandings and perspectives of home oxygen therapy. Given the applied nature of the research and its potential to inform clinical understandings, Interpretive Description was an appropriate platform from which to explore the interplay between oxygen therapy and the illness experience of people living with chronic breathlessness syndrome. While Interpretive Description “does not position itself inside any particular epistemological orientation”^{18 p.75}, in this study, the disciplinary orientation is that of palliative care and its philosophical underpinnings are aligned to that of constructivism and naturalistic inquiry¹⁹.

Ethical approval for the study was obtained from the Southern Adelaide Clinical and Human Research ethics committee, (project number 395.15). People living with chronic breathlessness syndrome, who were over 18 years of age and able to converse in English, were recruited through the specialist palliative care clinical trials teams and respiratory services at two metropolitan hospitals in Adelaide, South Australia. Written information about the research project were disseminated through these hospital networks. Clinicians provided the names of patients agreeing to take part to the researchers, who then contacted the potential participants to arrange interviews after written consent had been obtained.

In order to maximise variations in emerging themes, theoretical sampling²⁰ was used to cover a range of people with chronic breathlessness syndrome. Participants were recruited purposively from the following groups to gain a range of perspectives of people with chronic breathlessness syndrome regarding oxygen: those not currently on home oxygen therapy; those people with severe hypoxaemia who qualified for home oxygen therapy; and finally those people who received palliative oxygen outside the current funding guidelines. Recruitment continued until data saturation had been reached, which was after the sixth interview²¹.

Categorisation into the aforementioned groups was based on the clinical information participants self-reported, as the researchers did not have access to oxygen saturation or arterial blood gas values to determine whether a participant did or did not qualify for funded home oxygen therapy under the National Guidelines²². We included these three groups to gain a broad perspective of the use of oxygen, including those who had not received it.

Data collection

Face-to-face, semi-structured interviews were conducted with eligible, consenting individuals by an experienced qualitative nurse researcher (KB) and research assistant (CL). The interviews took place in a location selected by the participant. Interviews were conducted between April 2016 and November 2016 and lasted between 10 and 45 minutes. The interviews were digitally recorded and transcribed verbatim. An interview guide (Appendix 1) was used to focus the discussion.

Data analysis

The researchers conducted thematic analysis following a six step process outlined by Braun and Clarke²³. The first step involved importing the transcribed interviews into the software programme QSR NVivo 11 (QSR International, Victoria, Australia, 2017). The subsequent steps involved the researchers (KB, AC, JP and CL) independently generating a list of codes from the transcripts using the interview questions as a guide in the first instance. These initial codes were then collated and collapsed into themes. The researchers then developed a 'thematic map' to explore the relationships between the themes and as a result of the discussions further refinements were made. Differences and inconsistencies in categorisation were reviewed by the team and themes with insufficient data to support them were discarded. The iterative nature of the analytic process allowed for clarification and justification (aim of the study reflected in the research question); procedural rigor (data collection techniques have been transparent); representativeness (a clear sampling strategy outlined); interpretive rigour (several researchers involved in the analytic process); reflexivity and evaluation rigor (researchers aware of the context in which this research has taken place and ethical guidelines have been followed); and consideration of the transferability of the data²⁴. Transcripts were not returned to the participants due to the frail nature of this population.

Results

Participants

Nineteen people (median age 77 years, range 45-91 years) with chronic breathlessness syndrome (male $n=10$; female $n=9$) and a variety of underlying diseases participated in the study (Table 1). Thirteen participants were recipients of home oxygen, and the remainder were not using oxygen at the time of the interviews ($n=6$). Of the thirteen participants on oxygen, seven qualified for home oxygen, and six received oxygen outside of the current funding guidelines, or at their own expense.

Table 1

Participant Characteristics

Characteristic		N (%)
Gender		
	Female	9 (47)
	Male	10 (53)
Age		
	40-49	2 (11)
	50-59	0
	60-69	3 (16)
	70-79	5 (26)
	80+	9 (47)
Diagnosis*		
	COPD only	9 (47)
	Respiratory failure ^a	2 (11)
	Chronic Obstructive Pulmonary Disease/Bronchiectasis	1 (5)
	Bronchiectasis	1 (5)

	Pulmonary Hypertension/Chronic Obstructive Pulmonary Disease	1 (5)
	Metastatic breast cancer with lung, liver, bone involvement	1 (5)
	Lung disease ^b	1 (5)
	Asbestosis	1 (5)
	Pulmonary fibrosis	1 (5)
	Declined to state	1 (5)
Receiving oxygen		
	Yes	13 (68)
	No	6 (32)
Oxygen prescription		
	Not applicable	6

* Participant reported measures

^a Limited information about the underlying condition provided

^b Detailed information on disease not provided

Key themes

The perspectives and experiences of home oxygen therapy for people living with chronic breathlessness were categorised into three main themes:

1. Managing distress and living with chronic breathlessness syndrome, with or without oxygen, requires a range of self-management strategies.
 - a. Managing home oxygen: securing a prescription, self-regulation and safety.
 - b. Integrating other self-management strategies, including the use of opioids.
2. Expectations of oxygen use: 'Not as good as I thought it would be', and;
3. The stigma of using oxygen: the visible and invisible.

Theme 1: Maintaining distress and living with chronic breathlessness syndrome, with or without oxygen, requires a range of self-management strategies

The experience of living with chronic breathlessness syndrome, with or without oxygen, was similar for every participant. The fear of drowning, feelings of terror, frustration and anger were omnipresent. Not surprisingly, being breathless all the time was distressing:

"It's a mongrel way to be. I'd rather be dead that's true. I've always been an active person right up until I got like this. I'd get out and do a bit of gardening and pruning and making little things ...now I can't do anything ... it's very frustrating." (P9, M, 84, Respiratory Failure, on oxygen)

In order to cope with the omnipresent nature of breathlessness, participants planned their days in careful detail, aspects of which relate the management of chronic breathlessness in general and not specifically to the issue of oxygen use and therefore will not be further elaborated upon here. Rather the focus of this theme is on the overall management of oxygen and the strategies used other than oxygen to manage the syndrome in the home care setting.

- a. Managing home oxygen: securing a prescription, self-regulation, self-regulation and safety*

Participants described the complexity associated with oxygen management, from the challenges of securing a prescription, self-regulation and titrating their oxygen usage, to managing its' safety at home. Obtaining an initial prescription in the home care setting was often difficult and many participants felt they needed it, having experienced its positive effects whilst

in hospital. They used this experience as the basis for initiating the home oxygen conversation with their treating physician:

"Yes, but I wanted oxygen [at home] and I kept saying to the doctor I wonder if it could help me because when I was in hospital I was on it 24 hours a day and then they'd (clinicians) try and wean me off it." (P3, ~~F, 65, Pulmonary Hypertension/Chronic Obstructive Pulmonary Disease~~, on oxygen)

For participants already on home oxygen, some would self-evaluate their prescription, as well advocating for the oxygen flow rate to be increased:

"I've been on the oxygen a long time ... See I can't even talk without getting breathless. It needs to go up [the flow rate] from 2, either to 2 and half or 2 and a quarter. They should tell me what is best. But it definitely needs to go up" (P18, ~~F, 91, Unknown medical condition~~, on oxygen)

This participant assumed that there was a direct relationship between the flow rate and the extent of her breathlessness. Other participants actively decided on when and how to use oxygen in order to provide relief, based on trial and error:

"Every time I tried to, I was just gasping for air - yeah. But the strangest thing is, by the second or third day I accidentally took it off just to see how I was going and I forgot – I left it off and I forgot. ... and I thought, hello what's going on? So I put it back on again straight away. Then the next day I took it off, left it off for three hours or four hours, and the next day I took it off and left it off." (P17, ~~M, 66, COPD~~, on oxygen)

As well as self-regulating their own use of oxygen, participants often tailored their own safety practices around its use. While the potential dangers of oxygen were usually recognised, some participants did not always fully appreciate them:

"I've been trying to look it up and search on the internet because they say you can blow yourself up, but I only found one case in like America where someone blew themselves up with oxygen but as I don't smoke in my home, ... I don't know whether I believe that it blows up. I mean I've seen people at the shops with oxygen and lighting a cigarette." (P16, F, 45, ~~Chronic Obstructive Pulmonary Disease~~, not on oxygen)

This participant, while acknowledging to some extent the potential danger of smoking and oxygen, continued to search the internet for evidence and weighed up the degree of risk for herself.

b. Integrating other evidence-based self-management strategies, including the use of opioids

All participants not only worked out what helped their symptoms and what did not, but also were largely proactive in seeking out and adopting complementary strategies to be used alongside oxygen:

"Now while I'm sitting here talking to you I'm quite happy, but if I got up and went to walk somewhere I'd have to be very, very careful or I'd fall over or something or other. So I've adopted the policy during this cold weather that I just won't go outside." (P11, M, 89, ~~Respiratory Failure~~, on oxygen)

This participant not only adopts his own safety practices for the prevention of falls, but also creates his own policy to avoid exacerbating symptoms by not going outside in winter. Some participants took advice from others on how to manage their breathlessness:

Patient: "We had a man at church that was very bad and he umm, I don't know what his was, but he said to me, "Margaret get a puffer" and when I sit down and if I have a few puffs of the fan it seems to just relieve me a bit."

Interviewer: "Is it a puffer or a little fan?"

Patient: "A fan." (P6, F, 83, ~~Pulmonary Fibrosis~~, on oxygen)

In this quote the participant describes how her social network was instrumental in the recommended use of a fan. However, self-strategies were sometimes not the result of recommendations, but rather were determined by trial and error, such as in the case of learned breathing techniques:

"You have to control it. If you get breathless and, say I was walking upstairs, so I would get breathless and I would feel a band around my chest, and then I know that what I shouldn't do is gasp for breath because that just won't work. And so then, I'll [breathing out] and then take a breath in. That way I'll sort of control it that way it's a matter of keeping in control." (P13, F, 63, COPD, not on oxygen)

It was not unusual for participants to describe that they adopted multiple, rather than single strategies to manage their breathlessness, oxygen use was seldom the only one:

"They all work. I mean I even do umm self-meditation. A lady comes to see me and we do meditation every afternoon ..." (P8, F, 49, Bronchiectasis, on oxygen)

Participants also used morphine, whether in tablet form, capsule or oral solution, to manage their chronic breathlessness:

"I take three puffers a day and umm they help manage it I guess [the breathlessness], it's the morphine that helps me more than anything." (P3, F, 65, Pulmonary Hypertension / COPD, on oxygen)

Many of the participants did not appear to fear morphine and, for the most part, it was well-accepted and provided good symptom relief. Yet, not all participants embraced its use:

"You know you have days when you struggle all day and I don't like taking the morph[ine] you know ... My husband says to me, "Take the morphine," and I know it helps me but I just don't like taking it." (P3, F, 65, Pulmonary Hypertension / COPD, on oxygen)

Theme 2: ‘Not as good as I thought it would be’; expectations of oxygen

Whilst most participants were grateful for home oxygen and the security it afforded, they also acknowledged the many disadvantages associated with its use, such as being tethered to the tubing at all times, the increased risk of tripping and needing to use portable oxygen cylinders when venturing outside the house. The next quote best exemplifies the advantages and disadvantages of oxygen use:

It [oxygen] was wonderful because I knew being in hospital that it helped me so much ... well it makes your life easier and you know, um, you get really pissed off with it trailing this around behind you, you trip over it and it’s a pain when you have to go out with your trolley and your bottle ... but at least I can get out ... it’s definitely an advantage having oxygen, a big advantage, yeah” (P3, ~~F, 65, Pulmonary Hypertension / Chronic Obstructive Pulmonary Disease~~, on oxygen)

Oxygen was therefore beneficial for the majority of the participants. However, a smaller number were more ambivalent about its value, and were reluctant to use it as often as had been prescribed. Participants expected oxygen to work better than it did and were disappointed when their expectations were not fulfilled:

“I don’t feel that it has any effect at all but I assume that it must ... I thought oxygen would work better ... I don’t feel like I need it ... but I just do what I’m told”
(P4, ~~M, 73, Chronic Obstructive Pulmonary Disease / Bronchiectasis~~, on oxygen)

Theme 3: The stigma of oxygen therapy: the visible and invisible.

For many participants, having oxygen or being seen with oxygen paraphernalia, was frequently associated with feelings of stigma, independent of whether the person was on oxygen or not. The hidden or invisible aspects of oxygen use related to feelings of embarrassment or shame²⁵. The visible aspects related to the seeing of the oxygen apparatus; being attached to oxygen tubing and carrying around a portable oxygen cylinder.

"I have seen people out with portable oxygen, but I suppose there’s stigma attached to it." (P13, ~~F, 63, Chronic Obstructive Pulmonary Disease~~, not on oxygen)

The participants' related how both the invisible and the visible aspects of oxygen use coexisted. Consequently, being breathless and needing oxygen in public spaces lead to feelings of shame and embarrassment. Moreover, it did not appear to matter whether the person was on oxygen at the time or not for these feelings to be experienced. Needing to use oxygen in public was seen as an obvious sign of serious illness, making participants feel vulnerable:

"I'm supposed to go out with a bottle when I go shopping ... but I don't take it out (with me) because I look at myself like I'm gonna be at target. If youngsters see me walking round with one of those (oxygen cylinder), they'll think, 'well there's an old guy, he is stuffed, we'll roll him (steal from him)...I don't want anybody to know I'm crook." (P17, ~~M, 66, COPD~~, on oxygen)

This participant felt particularly vulnerable when away from the safety of his own home. He saw the presence of a portable oxygen cylinder as a symbol of weakness, one that would mark him as an easy target for thieves. In addition, he could not hide from the gaze and judgement of others. He did not want anyone to know that he was ill and the presence of an oxygen cylinder immediately marked him as such. Similarly, the next participant hid the fact that she was ill from those around her:

"I come up with excuses as to why I can't walk upstairs, you know I'll tell people I've hurt my hip or my knee rather than admit the fact that I just couldn't breathe. It's more being sneaky about it, being ashamed of it and trying to not let other people know how much is an issue it is for me." (P13, ~~F, 63, Chronic Obstructive Pulmonary Disease~~, not on oxygen)

Whilst not on oxygen at the time of the interview, this participant expressed feeling ashamed of the condition that made her breathless and anticipated the stigma that her condition would attract in the eyes of others. Other non-oxygen users also echoed her sentiments:

"Well I've seen people walking around with cylinders at the shopping centres, but I don't really want it to come to that. I suppose if it did me some good I'd try it." (P15, ~~M, 82, Asbestosis~~, not on oxygen)

Therefore, being attached to an oxygen cylinder could be regarded as a public statement of being ill, however, participants often accepted oxygen if it was deemed necessary. This participant had a preconceived notion of what having a portable oxygen cylinder would be like based on what he had seen in public spaces; he anticipated that its use would be associated with stigma.

Discussion

This qualitative study confirms the distressing and debilitating nature of chronic breathlessness syndrome. It also highlights the importance of self-management strategies, including oxygen and opioids, which people living with chronic breathlessness are employing to stay as well and mobile as possible and remain at home. Oxygen, for many breathless people appears to be simultaneously helpful and unhelpful; an incongruence in their lives that they managed daily. They also had to come to terms with the discrepancy between what they expected oxygen would do, what it eventually delivered, and for some, this realisation led to disappointment. Oxygen use was also associated with stigma that manifested in the lives of the participants in both visible and invisible ways.

The distress that chronic breathlessness syndrome engenders is not a new finding^{9, 10, 13, 26-28}. Chronic breathlessness syndrome, with or without oxygen, limits the social and physical worlds of people who often experience this isolation and withdrawal from the world as stagnation, both physical and psychological²⁹. Clinicians frequently under-recognise and under-treat the syndrome, and this failure could be viewed as a ‘...breach of human rights’^{30 p. 394}. Therefore, it is imperative that clinicians view the syndrome as something that can be ameliorated, and prioritise its assessment and management accordingly.

The new perspective that this paper adds to the other research endeavours in the area is the focus on stigma, specifically in relation to oxygen use, and not just on breathlessness. Stigma can be defined as a ‘mark of disgrace’³¹, or an attribute that makes a person different from others and hence less desirable²⁵. The stigma involved in oxygen use may be similar in nature to the stigma experienced by people living with many chronic conditions. To date, the majority of the research on stigma has focused on conditions such as; tuberculosis³², HIV/AIDs,³³ mental illness³⁴, obesity³⁵ and various types of cancers³⁶. However, there has been some

research conducted on the stigma associated with being breathless. For example, Gysels and Higginson (2008) interviewed 18 people with mild to severe COPD to find out why they were not accessing services as their needs increased³⁷. They found that breathlessness in the context of COPD is often experienced as shame and the resulting stigma caused patients to hide their breathlessness from others, and hence they were not accessing services that could potentially assist them in the latter phases of the illness. The need to keep breathlessness hidden from others can be seen in some of the participant quotes mentioned previously in this paper.

In the research literature, stigma and the embarrassment associated with oxygen use has previously been reported, however mainly been in the context of COPD and smoking^{16, 38, 39}, where it is commonly viewed by society as being self-inflicted^{37, 40}. While oxygen use in this study was triggered by a variety of conditions, not just COPD, all people using this therapy were 'tainted with the same brush' so to speak; they were perceived as having a condition for which they were entirely responsible and as a result, felt ashamed³⁷.

Visibility is the state that makes a person or a thing 'seen', and the use of oxygen "ma[kes] the disease [very] visible"^{16p. 11}. Oxygen, and its associated paraphernalia, meant that participants could not hide their breathlessness from those who did not have an illness, and this aspect mattered to some who were cautious about its use. The visible 'illness' identity created by the wearing of oxygen apparatus has been studied more than the hidden aspects, and that is - the anticipation of stigma. People living with chronic breathlessness syndrome and not on oxygen, may anticipate that its' use will attract stigma; they did not have to experience actual stigma to suffer its' negative outcomes 'they merely had to believe that it may occur to them in the future'^{41 p. 85}. People with chronic breathless syndrome learn about the negative stereotypes associated with oxygen use before they actually use it on a permanent basis, and they take on a stigmatised identity that once adopted, is difficult to reverse or remove⁴².

Whether the stigma is actual or anticipated, visible or invisible, the universal outcome is generally one of shame, prejudice and discrimination²⁵. A person may withdraw from treatment, experience a reduced quality of life and have increased levels of stress⁴³. One way that clinicians may be able to overcome anticipated stigma in the area of chronic breathlessness syndrome could be to engage the community in education programs to 'enhance compassion

and reduce blame' ^{43 p. 284}. However, in order to empower clinicians to be able to disrupt perceptions of stigma, they may first need to be made aware of the potential for both visible and invisible stigmatisation that can occur in people who live with chronic breathlessness syndrome.

Strengths and limitations

The strength of this study lies in the privileging of the patient voice in the experience of chronic breathlessness syndrome, especially in relation to the anticipated nature of stigma for people not currently on oxygen. This aspect is a new research finding. While the sample size in each of the categories was small, this aspect is not unusual in qualitative research. In addition, although the results are not generalisable to other settings, they may be transferrable to other areas of chronic disease management. A further limitation of the study may have been that the majority of the participants may also have been part of a trial investigating opioids and breathlessness, and therefore their comfortableness with opioid use might be explained by this potential involvement and not necessarily reflect the broader breathlessness population.

Conclusion

In conclusion, this study provides insight into the experiences of people living with chronic breathlessness syndrome, both with and without home oxygen therapy. It has highlighted areas of unmet needs, the importance of clinicians, including palliative care clinicians, of privileging and promoting self-management strategies, and the need to become educated about the visible and invisible nature of stigmatisation in this population. In addition, considerations needs to be raised with patients prior to prescribing long-term oxygen use, especially outside of the recommended prescribing guidelines. Further research is needed to understand how palliative care clinicians can effectively integrate self-management and stigma awareness education into their usual clinical practice and thereby better respond to breathlessness patient's requests for oxygen therapy.

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Appendix 1

Semi-structured interview questions

1. Those with chronic breathlessness syndrome and not currently on oxygen

- Tell me about your breathlessness (frequency, intensity, exacerbating factors, relieving factors)
- What do you believe is happening to you when you are breathless?
- What strategies/therapies do you have to manage your breathlessness?
- Have you considered or asked if oxygen could help your breathlessness?
- What comes to mind when you think of oxygen therapy?
- From your perspective, what could be the advantages/disadvantages of using oxygen?
- How could you see oxygen fit with other therapies for breathlessness?
- If you were provided oxygen how/when, do you think you would use it?

2. Those with chronic breathlessness syndrome and who qualify for long term oxygen (severe hypoxaemia)

- Tell me about your breathlessness (frequency, intensity, exacerbating factors, relieving factors)
- What do you believe is happening to you when you are breathless?
- What strategies/therapies do you have to manage your breathlessness?
- How did your prescription for oxygen come about, was it a suggested therapy or did you or your carer request it?
- What were your feelings/thoughts/expectations of oxygen therapy when it was first proposed/requested?
- When you have this therapy, how does it make you feel, does it match your initial expectations?
- From your perspective, what the advantages/disadvantages about this therapy?
- How do you see oxygen fit with other therapies for breathlessness?
- How/when do you use your oxygen therapy?

3. Those with chronic breathlessness syndrome and who have palliative oxygen (outside the current funding guidelines)

- Tell me about your breathlessness (frequency, intensity, exacerbating factors, relieving factors)
- What do you believe is happening to you when you are breathless?
- What strategies/therapies do you have to manage your breathlessness?
- How did your prescription for oxygen come about, was it a suggested therapy or did you or your carer request it?
- What were your feelings/thoughts/expectations of oxygen therapy when it was first proposed/requested?
- When you have this therapy, how does it make you feel, does it match your initial expectations?

- From your perspective, what the advantages/disadvantages about this therapy?
- How do you see oxygen fit with other therapies for breathlessness?
- How/when do you use your oxygen therapy?

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