

Experiences of ambulatory oxygen for patients with fibrotic lung disease : a qualitative study

Dr Sharon Fleming

Ambulatory Oxygen in Fibrotic Lung Disease (AmbOx)

Clinicaltrials.gov: [NCT02286063](https://clinicaltrials.gov/ct2/show/study/NCT02286063)

- Royal Brompton Hospital ILD Unit –sponsor and main recruitment centre
- Respiratory Medicine Aintree Hospital
- North Bristol ILD Service

NHS
*National Institute for
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AmbOx team

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Background

Effectiveness of ambulatory oxygen

- ▶ Well accepted relationship with long term oxygen use and improved health outcomes for patients with COPD. Very few studies for patients with ILD.
- ▶ Oxygen used as a treatment empirically, but no studies on the effects of ambulatory oxygen on day-to-day life in patients with ILD.
- ▶ Some studies have assessed the effects of ambulatory oxygen on the ability to exercise, breathlessness and quality of life (Sharp et al. 2016) Three studies (N=98), all laboratory based. One study showed patients exercised longer, two studies showed no effect. No O2 titration, limited quality, None assessed QoL
- ▶ More recent review (Bell et al. 2017) aimed to study impact of oxygen therapy on dyspnoea, health-related quality of life (HRQoL), exercise capacity and mortality in interstitial lung disease (ILD). All oxygen therapy included. Short term and LTOT. Short term- No impact dyspnoea, some impact exercise performance (N low).
- ▶ More research needed (Rationale for AmbOx). No clinical guidelines on how ambulatory oxygen should be used.

Method of AmbOx trial

- ▶ Study design: Multicentre, randomized, cross-over controlled clinical trial (NCT02286063), evaluating quality of life during two weeks on ambulatory oxygen compared to two weeks off.
- ▶ Inclusion criteria: SaO₂ ≥ 94% at rest, dropping to ≤88% on a 6MWT, stable symptoms during a 2 week run-in period.
- ▶ Primary outcome: health status assessed by KBILD questionnaire.
- ▶ Analysis: general linear model with the difference in health status as the dependent variable and treatment sequence as fixed effect.
- ▶ Patients' experiences with portable oxygen were explored through interviews in a subgroup of 21 patients.

First Results: AmbOx trial

- ▶ Forty-one patients were randomised to ambulatory oxygen, 43 to no oxygen, crossing to the alternative arm after two weeks.
- ▶ Mean age 64.5 ± 1.1 yrs, 58 males, 53 ever smokers, FVC $73.3 \pm 19.1\%$, DLCO $38.7 \pm 12.8\%$. 43 patients had possible/definite IPF.
- ▶ 76 patients completed the trial. Serious adverse events, equally distributed across arms, were not related to ambulatory oxygen usage.
- ▶ Ambulatory oxygen, compared to no oxygen, was associated with improvements in total KBILD score (difference: 3.7; $p < 0.0001$), breathlessness and activity domain (difference: 8.7; $p < 0.0001$), chest symptoms domain (difference: 7.6; $p = 0.009$), but not psychological domain. Most patients reported symptom reduction on oxygen, although negative aspects were reported by some.
- ▶ Conclusions: the novel observation that ambulatory oxygen is associated with improved quality of life are expected to influence future ILD specific guidelines on ambulatory oxygen use.

Experiences of ambulatory oxygen for patients with fibrotic lung disease : a qualitative study

Background: Qualitative studies oxygen and AO

- ▶ Most studies report experiences of patients with COPD with LTOT. Limited studies include patients with fibrotic lung disease
- ▶ Review on patients' perception of oxygen (Kelly and Maden 2014) Patients with COPD and lung cancer. Mixed blessings.
- ▶ Study on why patients with COPD don't use oxygen (Arnold 2011). Some no benefit, embarrassed, heavy cylinder. Lack of information.
- ▶ Cullen and Stifler (2009) Metasynthesis. Long term Oxygen users with COPD face tremendous physical, psychological, and emotional challenges. Targeted support needed.
- ▶ Goldbardt et al. (2013) Benefits of LTOT for patients with COPD, including increased social activity, perceived improvements in health status and self-management in routine daily activities. Concerns were raised regarding stigma, dependency on LTOT and deterioration in health status.

Experiences of ambulatory oxygen for patients with fibrotic lung disease : a qualitative study

Background: Qualitative studies oxygen and AO

- ▶ Khor et al. 2017. Qualitative interviews (N=24) 12 O2 naïve and 12 O2 experienced patients with ILD. Oxygen use varied. Different expectations. Most less tired, felt better, prevented palpitations, improved cough and improved exercise tolerance. Some didn't like using it in public. Also practical challenges- carrying heavy cylinder, moving around, running out. O2 naïve saw it as a sign of worsening illness. Information provision to manage expectations is essential.
- ▶ Belkin et al (2015) 14 Carers of patients with IPF. Saw oxygen as negative, even those who had not been prescribed O2.
- ▶ Graney et al (2017) Longitudinal telephone interviews with 5 patients with IPF prescribed SO. Benefits but some challenges, some not expected by patients. Information on using O2 limited. Oxygen case managers needed.

Methods: Experiences of ambulatory oxygen for patients with fibrotic lung disease : a qualitative study

- ▶ Semi-structured interviews within 2 weeks of the end of treatment visit. Most interviews at the study site
- ▶ Interviews audio recorded
- ▶ Interviews transcribed verbatim
- ▶ Framework analysis using Nvivo. Stages of labelling data, sorting data by theme, summarising data, descriptive accounts, explanatory accounts (Ritchie and Spencer, 1994)
- ▶ 21 patients interviewed from Feb 2015 to January 2016 (13 males (age 49-82), 8 female (age 53-76))

Experiences of ambulatory oxygen for patients with fibrotic lung disease : a qualitative study

Results

Main themes:

Attitudes towards using ambulatory oxygen

Use of oxygen indoors

Use of oxygen outdoors

Benefits

Challenges

- Getting around
- Stigma
- Prognostic meaning of ambulatory oxygen
- Fears about dependency

Supply of oxygen and Information and support given

Attitudes toward using oxygen

- ▶ Feeling about using ambulatory oxygen varied. Most patients were apprehensive or even shocked about using O2 at first but many felt better when they experienced benefits in their exercise tolerance and quality of life:
 - ▶ *“Initially, it is going to be strange...a bit self-conscious with tubes hanging out of your nose and face and having to carry it around. At first it was, but I had got to the stage where in my job I was so incapacitated. I was beginning to think that I was going to have to leave my job and that would have broken my heart..... and when I got the oxygen all of a sudden it has all changed. I can do what I used to do. I can walk the full length of the building and talk to somebody when I get there. I can walk up the stairs and talk to somebody when I get to the top. I can even sit and sing now, I couldn’t sing for ages” (INV09)*
- ▶ A few patients were frightened or shocked at the thought of using oxygen and these feelings continued throughout the trial:
 - ▶ *“No I didn’t like the idea of it but I thought because I am getting more attention, better help if you like I will give it a go. I will give it a go but I didn’t want to. I must be honest. I didn’t want to but I thought if I can help....it frightened me.” (INV17)*

Use of ambulatory oxygen indoors

- ▶ Most patients found using oxygen indoors helpful with housework, getting upstairs and day to day activities:
 - ▶ *It was definitely helpful because you know when I am normally hoovering I have to take it steady or perhaps stop for a couple of minutes, do something on the computer and then I carry on and do it. With oxygen I could just do the whole lot” (INV18).*
- ▶ Others used it to go upstairs and found using oxygen made it easier. One participant found she could do more yoga at home with oxygen.
- ▶ A few patients used their oxygen indoors very little. One participant did not use it indoors at all:
 - ▶ *“It is sort of turning it on, putting it on, by the time you've got upstairs if you want to go to the loo and everything, by the time you've done all that you might as well just go up the stairs slowly as I did before.” (INV21)*

Use of ambulatory oxygen outdoors

- ▶ Most patients used AO outdoors to go for walks, to do gardening, to go shopping, to go on social outings, when walking at work and to get to and from public transport.
 - ▶ *“We were out shopping and normally every so often I would have to stop at a shop window for a few minutes to catch my breath. I didn't really do that when I was out shopping on the oxygen and where we shop there's a steady hill, I used to have to stop about 4/5 times up the hill, I didn't even have to stop.” (INV20)*
- ▶ However, the amount AO was used outdoors varied. Some patients used it most times they went out. Some used it rarely or not at all because of the challenges involved in using AO.
 - ▶ *“I didn't have a problem using the oxygen indoors. It is just the wife and I, it is when I am outside it is, I just feel people are looking at me and thinking what is up with him and then you have to go through why you have got this you know. You have always been alright. They cannot accept I have gone down so quickly. It is difficult but I will get through it. I know I will but it is just sometimes going in the gents changing room and use it but I have got to use it on the outside as well.” (INV06)*

Benefits of AO

- ▶ Nearly all of the patients felt benefits from using AO. They all said they could do more than before. Benefits ranged from being 'less breathless' when walking or doing daily activities, not having to stop as much when doing activity, less 'chest tightness, reduction of fatigue and having more energy, helping dizziness and giving a 'boost' when feeling low, reduction of cough and increased confidence to go out.
 - ▶ *"Freedom, being able to do things I haven't been able to do for such a long time, it made me feel less tired, it made me feel less breathless, my cough wasn't so bad, I could do things without having to stop."* She felt that she has her old life back from before she was ill. *"It taught me how much this disease has stopped me from doing things, it's not because I don't want to do them, I'd love to do them, and it's the fact that I physically, because of the breathlessness, can't do it"* (INV-022)
- ▶ Only one patient (INV 017) felt AO had not helped her at all.

Challenges of AO

- ▶ Getting around: Some found the cylinders heavy to carry, the tubing was awkward, cylinders also ran out if out for more than 2-3 hours
- ▶ Visibility: Half of the patients were not concerned about this:
 - ▶ *"I did feel like a twit using it for the first few times but now if they have a problem with it let them have a problem with it"(INV-0021). Another patient said: "It made me feels a bit strange at first you know but then after that I need it so I don't care" (INV-0014)*
 - ▶ Others worried about people looking at them and people thinking they were sicker than they were. For some this meant that they were reluctant to use AO outside of the house. However most did use AO outdoors despite these concerns.
 - ▶ *"I just felt embarrassed for having these tubes running up my nose and from a tank on my back, if it was a pill nobody notices it but with a cylinder on your back and a plastic tube up your nose it is much more visible" (INV-16)*
- ▶ Prognostic meaning of ambulatory oxygen: a few patients stated that having AO made them question if their illness was getting worse
 - ▶ *"End of the road, you get the oxygen and you think because the last 8 years I never had oxygen and I kept on walking and carry on but then all of a sudden you get the oxygen and you feel is it time? Is it time I am going to go? It is that feeling" (INV-03)*
- ▶ Fears about dependency: Five patients were initially worried about becoming dependent on oxygen but these fears decreased over time.

Supply of oxygen and information and support

- ▶ There were very little problems with the oxygen delivery and supply. However some patients were shocked when the first delivery of 8 cylinders arrived at home:
 - ▶ *“I was concerned about the practical aspects of the oxygen, where are you going to put it, where are you going to store it et cetera and how do you separate the used cylinders from the not used cylinders.”* (INV20)
- ▶ Patients reported they had good support and information about using AO.
 - ▶ *“It was good, they gave me leaflets. To explain everything and they explained as well. They explained everything. How to use it and if any problems call them, the explanation they gave to me was fine.”* (INV11)
- ▶ Patients were also telephoned by the Research Co-ordinator regularly throughout the RCT and they appreciated this support.

Discussion

- ▶ Little evidence available for effectiveness of AO for patients with ILD. Recent AmbOx trial shows evidence of improvements in breathlessness, activity levels and chest symptoms.
- ▶ Important to capture patients' experiences of ILD. Limited evidence available shows that there are many practical and psychosocial barriers to using AO.
- ▶ Some our study findings are congruent with previous evidence. Nearly all patients reported benefits and it seems more patients were more positive than other studies. Some patients had challenges with the visibility of AO and were reluctant to use it outside (but most overcame their embarrassment with time because of the benefits). Some found the cylinders heavy and awkward to carry (but not as many as some previous studies).

Discussion

- ▶ A difference in our findings from other studies was that patients felt supported while using AO and that there were very few problems with the delivery and supply. In fact staff were highly praised by many. This may be because of patients' participation in the RCT and the resultant support from the research Co-ordinator and oxygen supply staff.
- ▶ Highlights that patients prescribed AO face many challenges unique to their individual attitudes toward AO, their ability to cope with practical challenges such as managing technology and storing and carrying the cylinders, and how they cope with psychosocial challenges such as the visibility of the AO therapy.
- ▶ As suggested by Jeff Swigris's team (Graney et al. 2017) patients using AO need exceptional support and without this it may be that their outcomes from using AO may be less than optimal.
- ▶ Results will inform much needed guidelines for AO for patients with ILD. A subject which leads nicely into the presentation by Fiona.

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