Author's response to reviews

Title: Ambulatory oxygen: why do patients with COPD not use their portable systems as prescribed? A qualitative study

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Author's response to reviews: see over
Dear Natalie

Re: MS: 1591508727411480

Ambulatory oxygen: why do patients with COPD not use their portable systems as prescribed? A qualitative study

Elizabeth Arnold, Anne Bruton, Maggie Donovan-Hall, Angela Fenwick, Bridget Dibb and Elizabeth Walker

Thank you for giving us the opportunity to respond to the reviewers comments.

Firstly, we should like to argue the case for the importance of this study. In the UK ambulatory oxygen (AO) is regularly prescribed to patients with COPD, either with long term oxygen therapy (LTOT) (if patients have a low resting arterial blood oxygen level), or in isolation (if the patient has exercise desaturation). The British Thoracic Society (BTS) guidelines published in 2006 guide the prescription of AO to enable patients with prescribed oxygen to maintain activity, exercise and social contact outside the house. However, our research has demonstrated that the practical clinical reality of AO prescription and use in the UK is different to the theoretical guiding principles.

Despite the BTS guidelines, in some regions of the UK patients are still being prescribed AO (and LTOT) by their General Practitioner (GP) with little or no instructions for use. Patients with COPD are being prescribed LTOT and AO on hospital discharge and not being followed up (as they should be, according to the BTS guidelines) so have AO at home, again with no instructions apart from those they are getting from the local oxygen delivery man. Even the two participants who were prescribed AO through the local
general hospital respiratory assessment unit received few instructions beyond advice ‘to use it when I am out’. No other participants recalled receiving any information about ambulatory oxygen use (even though most had been prescribed AO within a few months of the interview). Only one participant in this study was able to carry and use AO as it was intended i.e. as an ambulatory system. Those with no carers did not use it at all, even though it had been prescribed.

AO is intended to enable oxygen patients to continue to remain socially and physically active, but previous research has demonstrated that many patients do not use their AO. There is little published evidence on why COPD patients choose to use their cylinders or not. Without this information it will be difficult to support patients who may have difficulty using AO, and ensure active patients receive the AO they need (one important point which emerged from seeing participants at home and talking in depth, was the different stories the participant chose to present to health care professionals compared to the reality of how their community AO use). This study helps to contribute to the debate, and may help to enable practitioners to make more informed decisions on oxygen prescription. It will also help them to ask more pertinent questions about individual AO usage when reviewing a patient with AO in the community.

We have addressed the reviewers’ individual points on the following pages. Appropriate changes have also been made in the revised manuscript as indicated.

**Reviewer 1**

We thank this reviewer for her comments and have addressed them here and in the text.

1. **Clinical status of the patient**

   This was a qualitative study and formal testing of COPD severity or clinical status was not undertaken as it was not relevant to the research question. This has been added in the Results section.

2. **Prescription of LTOT and AO per individual participants**

   As was already stated within the Results section AO was prescribed as an addition to LTOT in 25 of the 27 participants, 2 were prescribed AO as a result of exercise desaturation. However use of AO was no different from the other participants, both citing weight and embarrassment as negative factors in the use of AO.

3. **Use of sampling grids**
Sampling grids were not used as they are not appropriate to the methodology chosen. Grounded Theory (GT) is a qualitative approach which seeks initially to include as many participants as possible in the early phases of the study with different experiences of AO use (hence the wide entry criteria with no bar on age, occupation, severity, care circumstances). The participants in this study represented a wide variation of characteristics in terms of gender (and relevant size), living accommodation, presence of carers, prescriber of AO etc. Each transcript was analysed before the next interview. The researcher could then explore with the next patient specific issues which have arisen from previous interviews, and begin to focus on issues which are strongly represented in the cohort. The researcher can then recruit specific patients who may contribute experiences which support or (more importantly) negate any theory which may be emerging (i.e. participants with or without: carers, transport; recently prescribed or longer term users of AO). It was difficult to recruit participants purposively with differing opinions from the ones expressed in the findings, as often it was only during the in depth interview in their own homes (i.e. post recruitment) where the full picture of how participants were using AO, and the importance of the carers, became clear.

4. **Attendance at PR**

Six participants had attended pulmonary rehabilitation (PR), but this was not found to influence the participant’s view of AO and so was not described within the text. Four of the six did not receive their AO (in an LTOT package) until after PR and the remaining two did not take their AO with them to PR.

5. **Analysis details**

As described in the text a second experienced qualitative analyser checked the categories and codes produced by the researcher. There was no divergence in the two analyses as such, rather the second analyser would suggest additional areas of coding, emphasise supporting or conflicting data and areas needing more investigation during the interviews. This has now been added to the text under ‘Data Analysis’. Two practice interviews were held to help inform the semi-structured interview guide, these were incorporated in the full study.

6. **Semi-structured interview guide**

The initial questionnaire structure was devised by the researcher from her clinical experience. However as each transcript was analysed as soon as possible after each
interview and before the next interview, the researcher could target areas of interest with each new participant as it evolved from the previous participant interviews. In this way the participants shaped what were important issues to them and the views of the researcher were subsumed. The topic guide was therefore not a static document, but evolved during the research. This process has now been added to the text under ‘Interviews’

7. **Use of AO to fulfil 15 hours of LTOT**

Only 1 participant mentioned they were using ambulatory oxygen to enable them to reach 15 hours of prescribed long term oxygen. Of the other 26 participants; 5 had been prescribed 24 hour oxygen, but only 2 were rigorously keeping to their prescribed hours (whether it was 15 or 24 hours). Participants did not see this as a negative; they used their oxygen as they felt they needed it. This ‘adherence’ to long term oxygen therapy was not reported in this article, as the focus is use of ambulatory oxygen.

8. **Saturation of data**

In line with the chosen qualitative research methodology, saturation was reached when no new information was being reported by the participants. Some issues (such as ‘weight’) were saturated very quickly but other issues emerged around them which required further investigation and analysis. This has now been added under ‘Interviews’.

9. **Detachment**

Detachment was an aspect of the study which the researcher particularly sought to achieve. Grounded theory (GT) currently has several possible ‘approaches’ but the original form of GT methodology stressed that the researcher should be an objective collector of data from participants (although GT is now often undertaken by constructionist researchers). To conform with the original GT precepts, the researcher did not contribute to the interviews beyond encouraging the participant to talk and re-iterating or summarising their views. Their views were recorded verbatim and faithfully reproduced in transcripts. During analysis the researcher ensured that it was the views of the participants that shaped the emerging theory.

10. **Which issue is more important?**

It is not straightforward to say which issue was ‘more important’ (i.e. important to whom?). Those participants, who could not carry the cylinder (because of weight), asked a carer to carry it for them. Those for whom weight was a problem, but had no
carer, did not use it. However, even the participants who had a carer to carry the cylinder, still did not use it in public places because they felt embarrassed. The lack of information received by the participants could be deemed ‘more important’ as an issue, because participants were not able to make informed decisions about whether to use their AO or not, or helped to find alternative methods of carrying AO, or given ways to help them overcome their embarrassment at using the AO system in public.

We have altered our conclusion slightly to address this comment.

Reviewer 2

We thank this reviewer for his comments and have addressed them here and in the text. We have not agreed with some of these comments, because they seem to be more relevant to a quantitative piece of research, and some do not take into account the specifics of the UK situation, but we hope we have responded appropriately.

In response to the general comments on LTOT and AO:

In the UK, patients receiving long term oxygen therapy (LTOT) will also receive ambulatory oxygen (AO)(according to the BTS guidelines). The usual instruction given to patients using LTOT is to use it for 15 hours per day (not as many hours as possible regardless of subjective effort of exertion). AO is seen as an additional oxygen source to facilitate daily activities outside the house. Only six of the participants in this study were prescribed oxygen on a 24 hour prescription. Those participants who had received LTOT and AO as part of a hospital discharge package or from their GP were using the whole prescription as a reliever of breathlessness (short burst oxygen therapy), and were not achieving anything like 15 hours of supplementary oxygen per day. Only one participant reported that she was using AO to ensure she got 15 hours of oxygen per day as prescribed. Two participants were prescribed AO for desaturation during exercise. Neither received specific information beyond ‘use it when you are out’ and neither had been enrolled in any form of exercise therapy (e.g. PR). One could not carry the cylinder and the other was too embarrassed to be seen outside with a cylinder. It is possible that because LTOT was prescribed for 15 hours in the majority of these participants, this may have increased their confusion about how to use their AO. Participants suggested that as they already had achieved their 15 hours per day, why did they need to take supplementary oxygen when they were out? This was part of the general confusion expressed about use of AO and its advantages and disadvantages – presumably related to the lack of specific information provision.
One of the several important new findings from this research is the dissonance between what health professionals believe to be happening as a result of published guidelines, and what is actually happening on the ground.

1. **Recruitment flow**

Details of the patients’ recruitment flow have now been added to the text under ‘Recruitment and sampling’

2. **Knowing what instructions the participants received**

We would agree that the authors do not know what instructions the participant received, but more importantly not one participant could relay any received instructions (some participants had received their AO equipment just 3 months prior to this study being conducted). They had received information on their concentrator (if they had one), but for AO they were told nothing beyond ‘it will help you when you are out’. This lack of information directly influenced their view and use of AO. For many, the idea of using AO when you ‘were out’ meant taking it in the car.

3. **Lack of benefit and instructions received**

Again we would agree that the lack of information received by participants directly influenced their perception of ‘lack of benefit’. The majority of participants who expressed this view had received their AO as part of a discharge package from hospital or from their GP and had received no instructions at all on using AO. Hence the importance of highlighting this lack of information to health care professionals who may believe they are providing all the information a patient may need. We may have been too polite in suggesting the participant could not recall any instructions, so as not to offend our prescribing colleagues, when actually no participant could recall getting any specific instructions on AO at all. Not just instructions were lacking, none had received information on carrying bags (some participants were not given carrying bags when they received their AO) or trolleys to help them if they did not have a carer, or the carer could not carry the cylinder.

4. **Other oxygen equipment available**

In our region of the UK, when a patient is prescribed AO it is up to the oxygen supplier to decide if that is via cylinder oxygen or liquid oxygen. A conserver is prescribed if a box on the home oxygen order form (HOOF) form is left unchecked. This therefore means that when prescribers forget to check the box, or do not know
what a conserver is and have not tested a patient for AO with a conserver, the supply company will still attach a conserver to the cylinder supplied oxygen (liquid oxygen has an inbuilt conserver).

This region has an area of dense housing, so liquid oxygen mother tanks are not always possible, and therefore we have a large oxygen population using cylinder oxygen. There is a possibility of smaller (frail) cylinders but these are discouraged because of the costs involved. The majority of oxygen cylinders used by our patients locally weigh 3.4kgs. At the moment this is the only equipment available to the patients in this region of the UK. Portable oxygen concentrators will not be available here until 2011–2012 when the new UK contracts for the regional oxygen suppliers come into place.

5. Reference 26

The text in the paper referring to this citation has been altered to remove any perceived ambiguity. However, the cited paper (written by this reviewer) does contain the following: “The weight of the mobile unit was often stated as the most important factor in affecting usage. Therefore, development of more portable units is urgently required”

We hope we have addressed all the reviewers concerns and made the case for the importance of these new findings, which are only accessible through the use of qualitative methodologies. Please let us know if you require any further information.

Yours sincerely,

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