

Lay beliefs of patients using domiciliary oxygen: a qualitative study from general practice

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SUMMARY

Background. Oxygen, given for 15 hours a day to certain patients with chronic obstructive pulmonary disease, is known to reduce mortality and improve morbidity. There is, however, an apparent mismatch in provision — some patients who would potentially benefit are not receiving it and, conversely, other patients may be receiving it 'inappropriately'.

Aim. To investigate lay beliefs about oxygen therapy of patients receiving domiciliary treatment.

Method. Twenty-four patients receiving domiciliary oxygen therapy from three general practices in Middlesbrough were interviewed using qualitative, semi-structured interviews.

Results. There were two contradictory approaches to oxygen use. On the one hand, oxygen helped the individual maintain mastery and self-control over illness by relieving symptoms, thus enabling daily activities and roles to continue, and by the reassurance that it was available, even if not used. In addition, self-control over the illness was maintained by individual experimentation with the best ways to use oxygen, which increased personal involvement in treatment. On the other hand, there were concerns that oxygen should not master the individual through inducing dependency on its use.

Conclusions. These ambivalent ideas about oxygen should be considered when assessing patients for use of domiciliary oxygen and by general practitioners maintaining treatment. Some patients who according to medical criteria would benefit from domiciliary oxygen may wish to restrict its use because of worries about dependency and these worries may need addressing. Other patients using domiciliary oxygen who do not meet medical criteria for long-term use may nevertheless gain benefits, including improved self-control over their illnesses.

Keywords: pulmonary disease; oxygen therapy; qualitative research.

Introduction

DOMICILIARY oxygen, given for over 15 hours a day to patients with chronic obstructive pulmonary disease meeting certain criteria (forced expiratory volume in one second <1.5 litres and forced vital capacity <2.0 litres, and arterial oxygen tension <7.3 kPa and CO₂ >6 kPa over at least a three-week period),¹ reduces mortality² and may improve morbidity.³ There are, however, concerns that some patients who would benefit are not receiving long-term oxygen⁴ and that other patients are receiving oxygen inappropriately.⁵

Reasons for inadequate or inappropriate use of domiciliary

oxygen may lie partly in professional knowledge and behaviour. Improvements in oxygen treatment must, however, take into account how oxygen is used by patients in their daily lives. Patients with many chronic conditions face problems that extend beyond the medical features of the particular disease. They face, for instance, a restructuring of their daily lives.⁶ The onset of the disease usually causes severe disruption and threat, including a loss of self-identity and the taken-for-granted nature of health.⁷⁻¹⁰ Faced with these problems, maintaining self-integrity, self-esteem, and a feeling of independence is important. This can be accomplished through continuing in functional social roles,⁸ positively assessing one's life and illness,¹¹ and increasing self-control and mastery over the illness by involvement in treatment and self-care practices.¹¹⁻¹³

Qualitative methods are particularly appropriate to study how patients live with chronic diseases because they adopt an insider's perspective on how illness is experienced¹⁴ and therefore provide insights into how medical care may be planned and delivered more appropriately. The aim of this study was to examine how patients in general practice use domiciliary oxygen to cope with their daily lives and to investigate their understanding of the benefits and problems of oxygen.

Method

Patients receiving domiciliary oxygen therapy were interviewed in their homes using semi-structured interviews.

Recruitment

Patients from three practices were selected to minimise the effect of interviewing patients from one, possibly unrepresentative, practice. None of the practices was the author's. A computer-generated list of patients receiving oxygen on repeat prescriptions was produced. Patients with bronchial carcinomas and those unsuitable for interview because of excessive breathlessness, cognitive impairment, speech problems or deafness were excluded, as well as children. Letters of introduction explaining the study and asking whether they would agree to be interviewed were sent to all remaining patients in two of the practices and, because it was a larger practice with more patients consequently receiving oxygen, a random group from the third practice. Patients agreeing to be interviewed were contacted by telephone, if possible, or by letter and the study was continued until the emerging themes were clear. It was estimated that between 20 and 30 patients would be needed.

Interviews

Interviews were based on a schedule of open questions developed from previous literature and included daily restrictions, how patients coped with restrictions, the perceived benefits of oxygen, how and under what circumstances oxygen was used, and reservations about oxygen. The author, a general practitioner (GP), carried out the interviews from two practices and, partly because of time constraints but also to provide a different perspective, a nurse interviewed six patients from the remaining practice. The interviews lasted between one and two hours, were tape recorded, and were transcribed fully.

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Analysis

The computer software package QSR NUD*IST was used for analysis. The earlier transcripts were read and re-read to identify specific ideas expressed by the patients. The ideas were then grouped into broader concepts. Later interviews in particular (both 'in the field' as well as transcripts) were used to test out the broader concepts and refine them.

The local ethical committee gave approval.

Results

Study group characteristics

The number of patients using oxygen, identified from computer lists of repeat prescriptions from the three practices, was 63. Ten were excluded according to the criteria stated in the methods section. All remaining patients from two of the practices and a group of 14 from the third practice were invited to take part. The total number of invitations sent was 35. Of these, three were excluded (two had died and one was terminally ill), eight refused or did not reply, and 24 were interviewed. The average age of those interviewed was 69.7 years (range = 52 to 85 years) and 13 were female.

Restrictions and their mastery

The patients were asked what restrictions resulted from their conditions. All gave examples of problems, which commonly included difficulties with house work, gardening, and getting out for social activities and for shopping. For a few patients, simple activities, such as bathing, shaving or conversations with others caused problems. The oxygen itself was partly a restriction in that it was considered noisy, going out with larger cylinders was impossible, and even the smaller cylinders did not appear entirely satisfactory.

The patients were asked how they coped with their restrictions. Many coped by changing their activities and the ways in which they lived their lives. Therefore, they went out using cars, other people carried out jobs for them, they found various aids to help or used different methods and routines to help with activities such as shopping or housework.

'I go to, he takes me to the shops and as long as I've got a trolley, I'm all right. As long as I'm not there too long.' (Patient 19.)

Oxygen: a means to maintain mastery

Oxygen use was one way to master restrictions. Only occasionally did patients use oxygen almost continually — only seven claimed to use oxygen for more than 15 hours a day. Oxygen was usually used in response to situations where it was thought most beneficial; these situations included times when they felt breath-

- In keeping with people with other chronic diseases, patients on domiciliary oxygen adopt strategies to maintain control and mastery over their daily lives.
- On the one hand, oxygen is a way to maintain mastery by controlling symptoms of breathlessness and other more vague symptoms by the reassurance of its availability and through individual trial and error practices. On the other hand, however, it represents a potential threat to mastery because of worries about dependency.
- These lay beliefs therefore have implications for improving 'appropriate' and 'inappropriate' use of domiciliary oxygen.

Box 1. Keypoints.

less and there appeared no other choice. Oxygen was therefore used either before or after housework, gardening, decorating, and going out. The oxygen was also used to overcome more vague symptoms, such as feeling sluggish and tired, or to help sleep, build up resources or feel more relaxed. Oxygen use was timed to respond to these needs.

'When you wake up and you get out of bed on a morning, I feel as if I have to use it straightaway. I don't know, as if I've been asleep holding my breath sort of thing.' (Patient 5.)

Oxygen was therefore a way of mastering symptoms and continuing with activities, so that the considerable restrictions for many patients were not completely overwhelming.

Oxygen was used to maintain mastery in other, more subtle ways, however. Breathlessness was often frightening, involving a loss of control.

'The more panicking you do, the worse you get, and the worse you get the more panicking you do.' (Patient 6.)

This fear of breathlessness was thought to actually make the breathing worse. Oxygen helped to break the vicious circle: it not only relieved breathlessness but also relieved the associated fear, which was held to be at least partly responsible for the breathlessness. This not only applied to situations where oxygen was used; the knowledge that it was available to be used if necessary was often felt to be reassuring enough to prevent breathlessness developing. Some thought this would reduce the need to call the GP.

'If you know it's there you seem to relax but if you say to yourself, "I have no oxygen", then you'd start to panic I think and that's when the attacks come on.' (Patient 16.)

'Trial and error' practices were adopted. As discussed, oxygen was used around times when it was felt most beneficial. Some patients adapted the equipment to get the most benefit. Others worked out which times of the day were most beneficial, decided whether to break the period of oxygen use into shorter more frequent doses or decided whether to take it before, during or after activities known to cause breathlessness.

'I started to use it when I felt breathless, which wasn't the thing to do, I should have had so much before I went out and then sort of top up again when I came back.' (Patient 4.)

Oxygen: concerns about being mastered

Nevertheless, concerns about oxygen were voiced by many patients; in particular, worries that oxygen itself should not be allowed to master the individual. For instance, there was the view that it was important not to be reliant, addicted or dependent on oxygen.

'You have to use it in moderation. If you're going to use it all the time you're going to become dependent on it and that's something I don't want to do.' (Patient 14.)

There was also the related idea that the more oxygen was used, the more it would be required.

'You know I'm very conscious of it and I think, well, it might be a day when I'm very bad and it maybe wouldn't have the same effect, so I respect it and I don't use it that much.' (Patient 11.)

However, not all patients worried about becoming dependent. Some patients felt that, although they themselves would not become reliant, there was a danger for others. In addition, some (particularly, it seemed, those using oxygen for long periods)

realised that they could not cope without it and therefore felt there was no advantage in worrying about dependency.

Discussion

This study reveals two opposing views of oxygen use: oxygen is used to maintain feelings of independence but is also regarded as being capable of reducing independence. It was used to maintain feelings of independence through relief of breathlessness during daily activities, individual experimentation with the best ways to use it, and reassurance that it was available to be used if necessary. There are connections with a study of hyperbaric oxygen in multiple sclerosis and the evidence that lay ideas about the advantages of a treatment go beyond strict medical criteria.¹⁵ The way oxygen was used in an experimental way — such as working out methods and routines of use to gain the greatest personal benefit — is in keeping with evidence that involvement in treatment and self-care practices helps maintain mastery over chronic illness.¹¹⁻¹³ This also supports the view that patients adapt doctors' advice on medication to take it in ways that make sense for them personally.¹⁶

There was also the concern, however, that oxygen should not master the individual. This is in keeping with the powerful negative images many people have about medication.¹⁷ It is particularly in keeping with evidence that some patients with asthma fail to take prophylactic inhalers because of worries about dependency.¹⁸ Interestingly, other patients with asthma reluctantly accept prophylactic inhalers as a necessary part of their lives¹⁸ and this mirrors the views of those patients using oxygen who realised they could not cope without it and therefore felt no advantage in worrying about dependency.

Although a nurse carried out six interviews, the author undertook the remainder and was entirely responsible for devising the interview schedule and analysis of the data. It is difficult to know how much the author's particular (GP) background has influenced the results. More significantly, however, it is difficult to disentangle interpretation of what is said from expectations based on other research of how people cope with chronic illness. Although the results and the interpretation of the results were discussed with the nurse who carried out the six interviews, no attempt was made to do this formally or to use another experienced qualitative researcher to code the transcripts. Also, no attempt was made to use responder validation or to triangulate with other methods. These are not without acknowledged difficulties,¹⁹ though, which include, for responder validation, possible disinterest of subjects in further involvement and unfamiliarity of the subjects with the language of the researcher. And for triangulation, there are difficulties reconciling potentially different results from methods that are actually measuring different aspects of apparently the same study area. In this particular study, triangulation with a focus group might have been possible, although it would have been difficult practically, given the isolation of many of the patients caused by their respiratory conditions (and sometimes by the oxygen itself).

The study reveals lay beliefs that need to be taken into account in arranging or maintaining domiciliary oxygen treatment and, in particular, applying the evidence about which patients benefit or do not benefit from domiciliary oxygen. Therefore, GPs may feel justified to prescribe oxygen to a patient who does not meet the medical criteria¹ if, by doing so, the patient is helped to maintain self-control over their life in the ways described in this study. Oxygen use in this situation is 'inappropriate' only in narrow, biomedical terms. Conversely, it may be necessary to discuss patient beliefs about reliance and dependence to provide support and reassurance for those individuals who would benefit (accord-

ing to biomedical criteria) from taking oxygen for over 15 hours a day but who are reluctant to do so.

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