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REVIEW PAPER

Long-term oxygen therapy: review from the patients' perspective

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Chronic respiratory conditions are responsible for increasing numbers of patients in need of long-term oxygen therapy (LTOT). However, many patients do not use their oxygen as prescribed. Unless we can assist these patients in living with oxygen therapy, optimal clinical outcomes will not be achieved. We conducted a meta-synthesis of qualitative research studies. We included any qualitative study that focused on the psychosocial nature or experience of patients prescribed LTOT. Four research studies met the conditions of our search. We performed a rigorous methodological protocol for meta-synthesis as described by the Joanna Briggs Institute. A total of 12 findings formulated four themes. These themes included the following: adapting oxygen to life's circumstances, living in a restricted world, self-management is fostered by oxygen, and submission and dependency. From the four thematic categories established, meta-synthesis resulted in two major results: persons prescribed oxygen rationalize its use while negotiating lifestyle interference and physical restrictions and the drive to care for one's self is conflicted. This meta-synthesis showed that each oxygen user faces tremendous physical, psychological, and emotional challenges. They strive to adapt and maintain mastery but eventually oxygen dependency results. These challenges affect the patient's ability to adhere to their treatment guidelines. These barriers and challenges are seldom addressed and are under-treated. Clinicians involved in LTOT need to be aware and work with the patients to facilitate their use of oxygen. Inclusion of the patients' perspective can guide practice and assist with the development of new interventions and management strategies. *Chronic Respiratory Disease* 2009; **6**: 141–147

Key words: continuous oxygen therapy; domiciliary oxygen therapy; long-term oxygen therapy; meta-synthesis; patient perspective

Introduction

Receiving a prescription for long-term oxygen therapy (LTOT) is life altering for patients. Patients must admit the reality of their disease and acknowledge the restrictions that are now placed on their lives. Chronic respiratory conditions such as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, and cancer may be responsible for such symptoms as shortness of breath or decline in activities of daily living, and respiratory conditions are projected to be a major cause of death globally.[1] When chronic respiratory illness results in severe hypoxemia, a prescription for LTOT may be necessary. Utilization of LTOT for 15 h each day is required to achieve clinical outcomes.[2] Oxygen therapy is only efficacious if the patient follows instructions for use; however, many patients on LTOT do not follow their clinicians' instructions. Understanding the difficulties that patients experience on LTOT can aid health care providers to support these patients and improve their adherence. Patients should be followed, supported, and monitored to ascertain corrected hypoxemia.

Patients have reported difficulties with LTOT.[3] Patients struggle with LTOT, given the nature of administration; adherence to the prescribed time is problematic. Kampelmacher, *et al.*[4] studied 528 patients in the Netherlands and noted 108 patients were smokers and 15 of these smoked while using oxygen. Treatment issues, lack of breathlessness, or fear of oxygen addiction were noted by 20% of individuals as reasons for non-compliance. Only 33% stated the oxygen company assisted them with instruction prior to initiating administration. Complaints were related to restricted autonomy (50%), the delivery device (41%), oxygen source (38%),

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feeling ashamed (38%), and treatment duration (8%).[3] Doi[5] has examined the negative psychological effect LTOT creates for patients. Depression, reduced quality of life, low moral, dependency, and anxiety exist in this population. Robinson found that LTOT users were uncertain of oxygen's benefit: "I've been on oxygen 3 years and I still get progressively worse. I don't know if that is my fault or the illness (p. 41)."[6]

Little is known about the interventions that can reduce the psychosocial effect of LTOT on patients and even less on effective strategies that could influence LTOT adherence.[3] Qualitative research relevant to LTOT administration may elucidate and provide new evidence regarding emotional, psychological, physical, cultural, and social functions. An understanding of the patient's perspective may assist clinicians as they guide patients with issues surrounding LTOT.

The patient perspective can be gleaned from qualitative studies. When findings from multiple qualitative studies are combined, data patterns emerge then allowing meta-summary. Interpretative patterns and themes permit improved comprehension of the research as compared to any single study.[7] Research reviews of qualitative findings can be revealing as well as direct evidence-based practice. This can advance knowledge and potentially provide a new foundation from which interventions and management approaches can be tested.[8]

Given patient-centered health care, a clear foundation in biomedical science exists for patient management but is limited in scope because the patient perspective is absent. Synthesis of qualitative research allows for greater understanding of the phenomena under study and is interpretive or explanatory rather than deductive. Meta-synthesis is process driven in the same manner as meta-analysis but there are obvious important differences. Meta-synthesis is a meta-methodology that aggregates all forms of qualitative research and presents an interpretive conclusion.[8]

The objective of this article was to obtain qualitative research studies, then describe the findings, and synthesize patients' experiences surrounding the use of LTOT. The specific review question is "What are the experiences of persons using LTOT?"

Methods

Relevant studies for this review were identified via a traditional literature search. The search included English language published studies from 1980 to 2008 (inclusive). Search terms used were long term oxygen therapy or continuous oxygen therapy or oxygen delivery device or domiciliary oxygen therapy or oxygen therapy and qualitative or ethnography or grounded theory or action research or focus group or phenomenology or experience. The databases searched were Embase, CINAHL, Medline, and Psychinfo. The reference lists of articles obtained were reviewed for potential qualified studies based on inclusion criteria. Research abstracts meeting the inclusion criteria resulted in retrieval of the published study.

Inclusion criteria

Only qualitative articles relevant to the psychosocial nature or experiences of patients prescribed LTOT were qualified for inclusion. The participants were adults, 18 years and older, who were prescribed continuous oxygen therapy (>15 h/day). Participants were not limited to a specific chronic respiratory condition, although a majority of the patients in the identified articles had COPD, and many were receiving oxygen for related co-morbidities. In total, 20 articles were identified (Figure 1). Two were non-English and four were duplicates. In all, 10 did not meet the inclusion criteria and the four studies that met the inclusion criteria are overviewed in Table 1.

Exclusion criteria

Two articles regarding infants and children were excluded. Six studies were excluded in which the main focus was not the patient experience of LTOT but instead was focused on stroke, cystic fibrosis, ventilator therapy, pediatrics, or COPD. Two articles were quantitative and therefore excluded.

Types of studies

This review drew from qualitative studies that addressed the patient perspective of LTOT. Any qualitative study with a LTOT focus qualified including methods related to phenomenology, focus group, action research, grounded theory, or ethnography. Quantitative studies were not included.

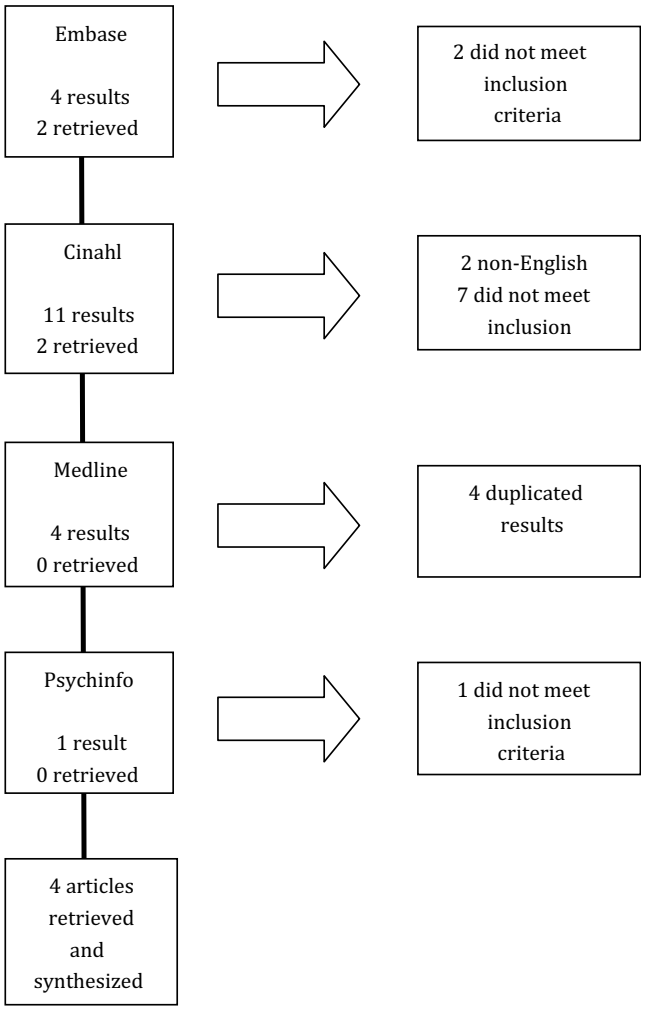

Figure 1 Inclusion criteria yield.

Types of interventions and outcome measures

Qualitative studies that examined oxygen interventions were considered. Outcome measures are not significant for qualitative studies because the findings emanate from the patients' experiences and are not predefined.

Data collection and analysis

A rigorous methodological protocol was used for this qualitative meta-synthesis as described by Pearson and the Joanna Briggs Institute (JBI).[9,10] Each qualitative research article was reviewed independently by the authors. Critical appraisal via the online software Qualitative Assessment and Review Instrument (QARI) developed by the JBI was carried out for each study. This permitted the authors to evaluate and engage with each article to determine its quality. After critical appraisal and assessment of each article's quality, the researchers ultimately determined whether the study should be included. Data extraction for the findings from each study followed and representative quotations from the participants were identified. These data permitted an illustration of the participants' voice. Credibility for each of the findings was determined by each reviewer using the credibility scale within the QARI program. All findings from the included studies were categorized via like themes identified by the authors. These themes were further evaluated and aggregated to represent an interpretative meta-synthesis.

The four qualitative articles included in this meta-synthesis described LTOT in terms of the patients' experiences (Table 1). In one study, 10 Swedish participants were interviewed in their homes.[11] Data were analyzed from the typed interviews and four categories emerged. After each of the five phases of data analysis, inter-subjective agreement of the researchers was accomplished. Quotations from the participants ascertained data credibility. In a study by Cornford, 24 participants were interviewed and conversations recorded and transcribed regarding the benefits and problems of LTOT.[12] Data analysis was accomplished via QSR-NUD*IST. Three themes emerged from the findings related to mastery and self-management. In a study by Berg, four major content areas were investigated including perceptions of quality of life, relationships with others, functional abilities in life activities, and changes in life due to the use of transtracheal oxygen.[13] Although the use of transtracheal oxygen has benefits of increased functional ability, less nasal irritation, greater privacy, along with more efficient oxygenation, this method is not used in routine practice. However, the patients who have used this modality for oxygen therapy have also perceived limitations on their lives. The themes that emerged from this study illustrated life dissatisfaction, loneliness, and reduced activities in daily living. A grounded theory study by Earnest focused on patterns of oxygen use via interviews with 27 individuals from Colorado and New Mexico.[14] Three major findings emerged from the transcripts. Coding and analysis occurred regularly until saturation of the data; trustworthiness of the findings was tested.

Table 1 Long-term oxygen therapy qualitative studies

Authors	*Orientation*	*Context*	*Participants*	*Focus of study*
Berg J. Quality of life in COPD patients using transtracheal oxygen. *Medsurg Nursing* 1996; 5(1):36–40.	Qualitative: two independent coders conducted thematic content analysis of transcribed guided interviews	USA	Four men and three women on transtracheal oxygen aged 54–76	Explore patients' perceptions of how transtracheal oxygen delivery has affected their quality of life
Ring L, Danielson E. Patients experiences of long-term oxygen therapy. *Journal of Advanced Nursing* 1997; 26(2):337–344.	Phenomenology: guided interviews were transcripted then analyzed over a five phase process	Sparsely populated north Sweden	Five men and five women with home oxygen aged 63–83	Patients' experiences in self-management of their dependence on oxygen and views of chronic issues
Cornford CS. Lay beliefs of patients using domiciliary oxygen: a qualitative study from general practice. *British Journal of General Practice* 2000; 50: 791–793.	Qualitative: semi-structured interviews with transcripts analyzed by QSR NUD*IST	Middlesbrough UK	11 men and 13 women on home oxygen aged 52–85	Investigate lay beliefs about oxygen therapy for patients receiving domiciliary treatment
Earnest MA. Explaining adherence to supplemental oxygen therapy: the patient perspective. *Journal of General Internal Medicine* 2002; 17(10): 749–755.	Grounded theory study with several iterations of coding and analysis. Saturation was identified	Communities in New Mexico and Colorado	13 men and 14 women with hypoxic COPD on LTOT aged 56–94	Investigate patterns of oxygen use benefits, circumstances, efficacy, and experiences

Findings and results

The synthesis was derived from four themes. A total of 12 findings formulated the four themes, which are described in Tables 2–5 along with representative quotations. Each finding was thematically categorized by the researchers and tested for representativeness. From the four thematic categories established, meta-synthesis resulted in two major results (Table 6).

In the first synthesized finding, we found that persons prescribed oxygen rationalize its use while negotiating lifestyle interference and physical restriction. The patient must become accustomed to 15 h/day of oxygen use and adopt the cannula as an extension of the body. A pattern of oxygen use is justified or reasoned and generally increases as the lung condition advances. Individual health beliefs also drive the rationale for oxygen use resulting in preferences for administration. Patients evolve a rhythm of use that works for their schedule – often after a period of trial and error. Lifestyle interference is brought about in part by the inconvenience and interference that result from a furniture size delivery system and the cannula. Portability is problematic and tubing can be confining. Moreover, living in a restricted world is resultant from reduced activity which is avoided. Activity may be anxiety provoking as it can worsen dyspnea leading to misery and isolation. Stigma and guilt further extend restriction.

Table 2 Adapting

Thematic category	*Adapting oxygen to life's circumstances*	
Findings	Living in one's own life rhythm	Patterns of oxygen use
Illustration in the patient's voice	I lie with the oxygen, get up around eight, use the oxygen until 11, then I'm free until 7p.m. Then I switch it on and in the evenings I mostly sit watching TV and that's ok.	I think about oxygen like I think about aspirin: If you have a headache, you take an aspirin. It's as simple as that.

The second synthesized finding discovered that the drive to care for one's self is conflicted, which is driven by self-mastery and eventual oxygen dependency. Oxygen is seen as an advantage for the body and can assist with greater self-autonomy. This may include activities of daily living and improved mobility. Mastery is desired and obtained under various physical or social conditions. This too can improve adherence, but fears of addiction or dependence compete against the desire for self-mastery. Eventually, dependence and submission are present as the patient is no longer in control. Apathy toward oxygen and circumstances

Table 3 Restriction

Thematic category	*Living in a restricted world*			
Study findings	Activity	Isolation	Restricted to time and room	Restrictions and their mastery
Illustration in the patient's voice	I don't do anything; I mean it's go from here into that chair. That's all.	I spend 90% of my time by myself.	It's hard when you can never walk where you want to and travel anywhere.	He takes me to the shops as long as I've got a trolley, I'm all right. As long as I'm not there too long.

as well as a sense of hopelessness is present. Given this scenario, negative emotions abound.

Discussion

Several quality-of-life studies corroborate the meta-synthesis results. Although these studies use quantitative methods, they importantly show corollary results. In the classic McSweeney, *et al.*[15] study of 203 COPD LTOT users, quality of life was lower and subjects exhibited mood disorders as compared with healthy subjects. Okubadejo[16] found that COPD LTOT users had a lower score on the Nottingham Extended Activities of Daily Living scale when compared with a similar COPD group without LTOT. In a recent quality-of-life study by Tsara, *et al.*,[17] Greek men with COPD receiving LTOT were evaluated and several outcomes showed difficulties. Activities of daily living (ADL) were scored in relation to the degree of assistance needed. LTOT users experienced greater incapacity when compared with the stable COPD non-LTOT patients for home management, eating, personal and self-care, and travel ($P < 0.001$). Moreover, there was no statistical difference between LTOT users and ADL in regards to whether the subject used a liquid or concentrator delivery device. Tsara reported LTOT subjects had high proportion of pathologic scores for the General Health Questionnaire indicating susceptibility toward anxiety, depression, anti-social behavior, and somatoform conditions.

Doi[5] surmised that a low ADL score for Japanese LTOT chronic respiratory failure subjects was due to dyspnea, mobility limitations due to the oxygen device, and stigma secondary to poor body image. Together these three factors showed reluctance for persons using LTOT to leave the home resulting in isolation. In additional analysis, LTOT users were divided into three subgroups related to their psychosomatic conditions (few, some, many problems). Activities of daily living, satisfaction related to pain, dyspnea and happiness, depression, and morale were all statistically significant when compared with the psychosomatic grouping. Those patients reporting high psychosomatic problems had lower life satisfaction, depression propensity, low morale, and a reduced function for ADL. These patterns appear before initiation of LTOT and worsen. Doi[5] found a negative psychosocial effect for LTOT and 41% depression in the 144 LTOT patients studied.

Lifestyle interference and physical restriction can be real obstacles as well as invisible barriers such as stigma and isolation. Patients may not use their oxygen and justify their actions for non-adherence. Kampelmacher[4] noted that stigma associated with oxygen use resulted in reduced compliance and non-use outside of the home. Restricted autonomy was noted by 50% of the LTOT users.

As the condition progresses, eventual submission to oxygen marks a new conflict as the patient desires to be in charge but becomes dependent on oxygen. One patient complained: "I am at the point where I have to live on the end of a piece of tubing 24 h a

Table 4 Self-management

Thematic category	*Self-management is fostered by oxygen*		
Study findings	Adopting a pattern of adherence: domains of self-management	Advantage for the body	Oxygen: a means to maintain mastery
Illustration in the patient's voice	I can't let this (oxygen) do all the work. I have to make my lungs work too. Like a back brace. You wear a back brace all the time and it's going to weaken your muscles.	Feel better otherwise I would not have accepted it. I have more strength. I recover more strength. It's an emergency help in order to survive.	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.

Table 5 Submission and dependency

Thematic category	*Submission and dependency*		
Study findings	Control (loss of)	Failure to name (delivery device)	Moving to full time use
Illustration in the patient's voice	I tell people I've lost my lungs, I've lost my legs.	The thing – you know	It does bother me to feel this way, because I wonder am I addicted to it. See, I started at 1 and I am up to 4 liters now.

day. I don't go out."[6] On the other hand, some LTOT users will go to any length to facilitate their desire to maintain mastery. For example, a patient remarked: "My personal system consists of three, 70 pound liquid oxygen tanks. Two are reserved for normal activity around the house, and share a common hose, which is switched between them as necessary. The third is used as a reservoir to fill portable LOX tanks for use in short-term travel, and to provide extra stretch for the few occasions when I must work in my yard or garage for a short while."

Initiation of LTOT is a tethering and restricting event, which may result in non-use. Patients work to adapt to this situation at various levels often without support. As patients wear their oxygen, they announce disability to world. Often this stigma and guilt make the situation worse because the condition is mostly self-inflicted. Thus, oxygen use becomes the external reflection of the internal conflicts and disease process – made worse if oxygen makes one feel better. Patients desire mastery over their situation but eventually submit, which may worsen the psycho-social aspects of the disease process.

This meta-synthesis provides valuable lessons for clinicians. To facilitate ADL, portable oxygen options should be discussed during the initiation of LTOT. Multi-disciplinary rehabilitation programs that emphasize lifestyle adaptation should be considered for the LTOT patient. Occupational therapists, rehabilitation nurses, and respiratory therapists can assist patients with adaptation of tasks to maximize independence and enhance functional abilities. Psychological and quality-of-life measures before and during administration of oxygen will permit on-going evaluation and monitoring for anxiety and depression. When psychological conditions are diagnosed, treatment should be considered. Interventions targeting negative emotions, stigma, and adherence within the context of chronic illness can also be considered. Patient education is an on-going important endeavor and is the responsibility of all healthcare professionals. Durable medical equipment suppliers have frequent patient contact and should consider a greater role regarding patient education. The feasibility of these recommendations is practical although some training of healthcare professionals may be necessary.

Table 6 Meta-synthesis

Synthesized findings	*Thematic categories*
Persons prescribed oxygen rationalize its use while negotiating lifestyle interference and physical restriction.	Adapting oxygen to life's circumstances Living in a restricted world
The drive to care for one's self is conflicted, which is driven by self-mastery and eventual oxygen dependency.	Self-management is fostered by oxygen Submission and dependency

Limitations

Evidence-based practice has, in part, driven the need for synthesis of qualitative research. Employment of qualitative meta-synthesis results will depend on acceptance into clinical medicine. Because acceptance may be slow, the synthesis process must be clear and transparent. There must be clinical utility in the findings and a context for modifying practice. Qualitative studies help to explain why people behave the way they do and how they are affected by the events that go on around them. Data for qualitative studies are collected through individual interviews, group interviews, or through direct observation. Because the data collection is so intensive and time consuming, it is necessary to keep samples small. Samples for qualitative studies are generally purposive to those who are experiencing the phenomena of interest (such as patients on LTOT) and are not random. Hence, findings are not generalizable, but the findings do help to understand the experiences of the people involved.[18]

Interpretation of phenomena under study in the natural setting is the focus of qualitative research. Although there are defined methods for combining qualitative studies, critique and suspicion exist. Meta-synthesis has been faulted for being a fad, superficial, and disappointing in its outcomes.[19] As meta-synthesis is a newer meta-methodology, it may

be limited in its process and scope. Our synthesis is limited by the four studies identified, and more original papers using high-quality qualitative research on patient perspectives is needed. There may be underdetermined findings yet to be discovered by qualitative researchers.

Conclusion

In conclusion, this meta-synthesis has shown that each oxygen user faces tremendous physical and psychosocial barriers and emotional challenges. Patients on LTOT strive to adapt and maintain mastery but eventual oxygen dependence results. Adherence is uncertain as patients determine under what circumstances they use their LTOT. These issues are seldom addressed and under-treated.

LTOT is administered primarily in COPD, which is a chronic and complex disease. Given the cost of LTOT treatment, there is a dearth of research related to appropriate interventions or management of LTOT. Knowledge is limited in key areas such as optimal timing and dosage, ambulation and supplemented oxygen, and methods for enhancing adherence given chronic COPD.[20] The patients' concerns represented in this meta-synthesis present a forum for discussion and may guide patient management, further guideline development, and assist in development of new interventions.

Conflict of interest

Dr. Deborah Cullen and Dr. Deborah Stiffler have no conflicts of interest.

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