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Looking ahead and behind at supplemental oxygen: A qualitative study of patients with pulmonary fibrosis

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ABSTRACT

Rationale: Supplemental oxygen is prescribed to patients with pulmonary fibrosis to normalize oxygen saturations, decrease symptoms and improve quality of life. Along with potential benefits, patients face challenges as they incorporate oxygen into their lives.
Objective: Our aim was to better understand the perceptions and experiences of patients with pulmonary fibrosis as they confronted the possibility and realities of using supplemental oxygen.
Methods: We performed a mixed-methods study in which we conducted a series of four structured telephone interviews with five patients with pulmonary fibrosis enrolled in a longitudinal observational study. Questionnaires were administered at the time of the interviews, which were conducted at enrollment in the longitudinal study, immediately prior to starting supplemental oxygen, one month and then 9–12 months after starting oxygen. We used conventional content analysis to analyze interview data for themes within and across the four time points.
Results: Prior to starting supplemental oxygen, participants uniformly expected it would improve their physical function and quality of life. They also expected practical and psychological limitations, which after starting oxygen, they found to be more pronounced than anticipated. Despite the challenges, participants attributed benefits in symptoms, confidence and mobility to oxygen and came to a reluctant acceptance of it. Their expectations for guidance and support were inadequately met.
Conclusions: For patients with pulmonary fibrosis, starting and using supplemental oxygen on an everyday basis confers benefits while also presenting a significant number of challenges. The process could be improved by providing them with clearer expectations and trustworthy educational resources. Oxygen case managers could help patients incorporate supplemental oxygen more seamlessly into their lives.

Introduction

Patients with pulmonary fibrosis (PF) face myriad challenges including progressive, debilitating shortness of breath, fatigue and poor quality of life (QOL). As fibrosis advances and gas exchange is increasingly impaired, patients become unable to maintain normal oxygen saturation, initially only while exerting and eventually at rest. As a result, supplemental oxygen (O_2) is prescribed in the hopes of ameliorating hypoxemia (and its secondary consequences), decreasing dyspnea and improving QOL. Although O_2 is ubiquitously prescribed for PF patients, little is known about how well these intended goals are met.

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In addition to normalizing oxygen saturations and alleviating symptoms, O_2 may improve physical functioning. In single-center studies of small samples of patients with PF, O_2 was shown to improve exercise capacity or distance covered during a timed walk test.[1,2] Despite this, it remains unclear whether such benefits translate to meaningful improvements in how PF patients feel and function in their daily lives. Adding a layer of complexity, O_2 creates challenges for patients and their caregivers.[3,4] Whether the desired and actual benefits of O_2 are outweighed by the challenges it creates has never been systematically evaluated. In this study, we sought to better understand how patients with PF view and experience O_2 – its benefits and challenges – at various stages of their illness. We conducted a thematic analysis of serial interviews with PF patients as they incorporated O_2 into their lives: from the time they anticipated it being prescribed to nearly one year after the initiation of O_2.

Methods

We conducted serial, structured telephone interviews with five participants enrolled in a longitudinal, observational study of the effects of O_2 whose methods were published previously.[5] Briefly, between August 2013 and October 2015, patients with PF of any etiology, greater than 18 years of age, not using O2 and able to speak and read English, were recruited to participate in a pre-/post-O_2 study aimed at determining whether and how O_2 affected symptoms, physical activity and quality of life in patients with PF. Diagnoses were confirmed by review of medical records and high-resolution chest computed tomography scans. Participants gave written, informed consent. The study was approved by the NJH Institutional Review Board (HS-2790), and the study is registered on ClinicalTrials.gov (NCT01961362).

For the longitudinal study, data were collected at four time points: 1) enrollment; 2) 7–10 days prior to initiation of O2 (participants informed us when O_2 was prescribed by their treating physicians, and data were conducted before use of O_2 began); 3) one month after initiation of O_2; and 4) 9–12 months after initiation of O_2. Since we did not know which participants would end up being prescribed O_2, we interviewed 40 participants at enrollment. Five of these 40 ended up being prescribed O_2 and were interviewed at the three other timepoints. In each case, the decision to prescribe O_2 was made solely by the participant's treating physician who was not a member of the research team.

We used REDCap (http://projectredcap.org/) to send and receive via email the response data from questionnaires: the University of California San Diego Shortness of Breath Questionnaire (UCSD); Version 1 of the Medical Outcomes Study Short-Form 36-item instrument (SF-36) and the Fatigue Severity Scale (FSS).

The UCSD is a 24-item questionnaire with 21 items asking respondents to rate dyspnea while performing physical activities across a range of energy demands and 3 additional items that assess the impact of dyspnea.[6] UCSD scores range from 0 to 120; higher scores indicate greater dyspnea. The UCSD has been shown to possess adequate reliability, validity and responsiveness in PF.[7]

The SF-36 is a generic health-related QOL (HRQL) questionnaire with eight domain and two component summary scores (physical and mental or PCS and MCS). Here, we report results for the component summaries. Each domain and component score was transformed to a scale in which respondents from the 1998 U.S. general population had a mean of 50 and a standard deviation of 10. Higher scores indicate greater HRQL.[8] The SF-36 has been shown to possess validity in patients with PF.[9]

The FSS is a 9-item questionnaire, scored from 9 to 63, with higher scores indicating more severe fatigue. There are no published data on the psychometric properties of the FSS in PF.

Interviews were designed to gain appreciation for patients' understanding of the process of when, why and how O_2 was prescribed, and to examine their changing views of the benefits and challenges of O_2 over time. Members of the research team conducted all interviews which were audio recorded. Audio files were transcribed verbatim. Atlas.ti7 (version 7.5.15; GmbH, Berlin) software was used for data management.

For the thematic analysis, interviews were initially grouped by time point and then read several times by the two analysts (B.A.G., J.J.S.) to become familiar with the data, achieve immersion and formulate initial impressions. Next, we developed a coding scheme which each investigator applied independently to the transcripts. During the course of the analysis, the investigators met weekly to confirm consensus around how the codes were applied and to discuss new codes as they were generated. We generated definitions for each code to ensure dependability of our analysis. Once all transcripts were coded, we focused on creating categories and ultimately themes to describe clusters of related codes. We developed a framework for describing how patients with pulmonary fibrosis look at O_2, either in anticipation ("looking ahead") or reflection ("looking behind"). To better understand whether and how perceptions changed—from looking ahead to looking behind—we carefully re-read transcripts ordered within participant and then ordered again by time points, conducting each reading against the back-drop of our codes, categories, themes and framework. This ensured they cover the data accurately and supports the trustworthiness of our findings.[10]

Results

At the time of enrollment and first interview, each participant had carried the diagnosis of PF for at least two years. Baseline characteristics of the participants are presented in Table 1. None of the participants were followed at our center. Table 2 shows O_2 use and questionnaire results at each of the four interview timepoints. At enrollment, SF-36 scores suggest impaired HRQL (scores ≤ 40) in physical health domains in all five participants and mental health domains in two. According to the UCSD, dyspnea with physical activity was mild to moderate in all participants (UCSD score > 25). According to the FSS, four participants had significant fatigue (score$>$36). The effects of O_2 on patient-reported outcomes varied: in some participants fatigue or dyspnea improved, but in some participants, the questionnaires failed to capture significant

Table 1
Clinical and demographic characteristics of the sample.

Variable	Result
Female/Male	3/2
Age (range) in years	64.6 ± 9.4 (53–76)
Smoking history	
Never	3
Past	2
PF diagnosis	
IPF	4
cHP	1
Comorbid conditions	
None	2
PH + OSA	1
HTN + OSA	1
CAD + HTN + DM2	1
Years of PF, median (range)	2 (2–15)
FVC%	52.2 ± 14.8 (40–77)

Footnote: Values = mean ± standard deviation or counts unless noted otherwise; PF = pulmonary fibrosis; IPF = idiopathic pulmonary fibrosis; cHP = chronic hypersensitivity pneumonitis; PH = pulmonary hypertension; OSA = obstructive sleep apnea; CAD = coronary artery disease; HTN = systemic hypertension; DM2 = type 2 diabetes; FVC% = percent predicted forced vital capacity.