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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.

Table 2
O_2 flow rate and questionnaire scores at interview time points.

Participant	Time point	O_2 use	SF-36 PCS/MCS (higher = better)	UCSD (higher = worse)	FSS (higher = worse)
Female, 57 years old, IPF	Enrollment	N/A	28.4/40.1	45	47
	Just prior to O_2	N/A	27.6/38.7	43	59
	1 month later	2 L/min exertion	20.3/61.0	18	42
	9–12 mos later	2 L/min exertion	25.0/59.2	44	40
Male, 67 years old, IPF	Enrollment	N/A	28.1/50.0	37	63
	Just prior to O_2	N/A	27.1/64.0	36	27
	1 month later	3 L/min exertion	30.6/62.7	34	32
	9–12 mos later	3 L/min exertion	34.2/40.4	.	38
Male, 70 years old, IPF	Enrollment	N/A	34.4/49.2	29	42
	Just prior to O_2	N/A	34.9/58.6	37	50
	1 month later	2 L/min exertion	27.8/63.5	44	46
	9–12 mos later	3 L/min exertion	29.7/45.0	74	54
Female, 53 years old, cHP	Enrollment	N/A	43.2/39.3	39	47
	Just prior to O_2	N/A	43.2/52.4	31	42
	1 month later	2 L/min exertion	44.1/54.1	37	23
	9–12 mos later	2 L/min exertion	29.9/63.3	44	36
Female, 76 years old, IPF	Enrollment	N/A	40.4/59.5	29	22
	Just prior to O_2	N/A	28.3/64.2	70	35
	1 month later	3 L/min exertion	26.4/64.3	74	9
	9–12 mos later	3 L/min exertion	./.	69	42

L/min = liters of O_2 per minute; O_2 = supplemental oxygen; IPF = idiopathic pulmonary fibrosis; cHP = chronic hypersensitivity pneumonitis; SF-36 = Medical Outcomes Study Short-Form 36-item Instrument; UCSD=University of California San Diego Shortness of Breath Questionnaire; FSS=Fatigue Severity Scale;. = missing.

objective improvements. The four major themes we identified are highlighted in Table 3.

Looking ahead

At enrollment

Participants recognized O_2 would possibly be prescribed to them in the future. They had cursory working knowledge of O_2 that was acquired mainly via the internet, predominantly on websites and interactive forums focused on PF. If O_2 were prescribed at some point in the future, participants anticipated being able to find helpful resources easily and expected guidance from their prescribing providers, O_2 suppliers, in-person support groups and internet resources.

Participants had varying opinions about the need for O_2 in the future. One female participant with IPF was "actually looking forward to it," while another female participant with chronic hypersensitivity pneumonitis (cHP) recognized that O_2 "does denote a progression … in my disease that I wouldn't be happy about and … feels like maybe it would be a setback." All participants had formulated expectations about the benefits of oxygen (Table 4) but also anticipated hardships. Participants expected O_2 to be "cumbersome," were concerned about the "logistics of—of carrying around supplement [sic] oxygen," and believed they would be "limited to the amount of oxygen you can carry around … you are going to be limited because it depends on how much oxygen your tanks hold." One participant mentioned expecting their electric bill to increase, because the concentrator would be running all the time. Two participants voiced concern over how they would be perceived by others while using O_2:

> *Female with IPF: "Just the stigma of it … I don't know. People that I see on oxygen … now I wonder the reasoning. And I know a lot of people assume that they put themselves in that position, by smoking or COPD or smoking-related, and I don't want people to think that of me, because that's not why I have it."*
>
> *Female with cHP: "I know the attention it draws, and it is not attention that I want."*

Table 3
Anticipating O_2 use and Reality of O_2 use.

	Benefits of O_2	Practical Limitations	Psychosocial Impact	Resources and Education
Looking Ahead: Anticipating O_2	• Improve physical function and endurance • Increase amount of physical activity • Lessen symptoms including cough, fatigue, dyspnea • Improve quality of life • Prevent secondary consequences of hypoxemia	• Limited by amount of oxygen able to be carried • Physically difficult to carry delivery system • Challenging to increase activity when using O_2 • Tripping hazard of the tubing	• Fear of the progression of disease that O_2 signifies • Draws unwanted attention from others • Afraid to be seen in public with O_2	• Expectation of physician guidance • Education from oxygen supply company • Plan to utilize online resources and support groups
Looking Behind: Reality of O_2	• Increased participation in activities in and out of the home • Increased energy • Improvement in cough with O_2 • No significant impact on dyspnea	• Cumbersome to move with equipment • Tripping over tubing around the home • Significant planning required for any activity outside the home • Travel limitations due to O_2	• Improved confidence and independence • Psychological comfort of having O_2 available • Self-conscious when seen with O_2 • Feeling constantly tethered to a machine • Being perceived by others as sick	• Significant education from pulmonary rehabilitation • Received little to no guidance from prescribing physician • Oxygen supply companies provide variable information • Ongoing use of online resources

Table 4
Hopes/expectations and reality of benefits of using O_2 during the daytime.

Participant	Enrollment	Just prior to O_2	1 month later	9-12 mos later
Female, 57 years old, IPF	Now, I have to … just, walking across the house … I have to stop and rest. I'm just hoping that I can actually do something. Just now the doctor's concerned of what damage it has done to my heart, because I have gone down so far. So, that has me concerned. So, I'm hoping that eliminates that problem. My mobility mainly … better … I don't know. I'm at a point where I'm hoping I can exercise more and just feel healthier, I guess.	Not having to stop every time when you're out of breath … that's the hardest thing for me, the fact that I have to slow down and like let other people do things for me. I don't like that. So, I'm hoping that will be a benefit for me. My mobility. My freedom … just mainly my mobility, because I'm not doing very much now. Go back to water aerobics. I'm planning on having my tank right beside me.	I feel better, I get a cough often, and when I start coughing, it's better to have the oxygen. I have more energy. I can actually walk across the house. Before, I actually wasn't doing much, not going anywhere, not even grocery shopping. I got my freedom back. It just gave me that feeling that I can accomplish something still.	I do my housework now. I did pulmonary rehab this last fall, and now it's got me knowing what I can do. And so I still will walk—I just finished with it, but now I have a club, and I've been walking every day on the treadmill. And before, I wouldn't even have dreamed of doing that. I wouldn't even have tried to do it.
Male, 67 years old, IPF	I feel like it would expand my ability to do more of the things that I want to do.	… using oxygen, I hope, um, to, to be more physically active, um, able to do things that, um, as I look back, I've, um, um stopped doing or done considerably less, or, and were hesitant about … um, so I think it's going to bring a fullness, a richness, um, that has been declining, um for a period of time.	I'm able to do more things out by the house. You know, I'm able to, to, to exercise now, which is something that I, I wasn't able to do before … I feel like I'm, um, getting stronger and, um, uh, more stamina.	Well, it certainly has expanded my ability to do the things I want to do. [I am] more comfortable pushing what might be the limits of my breathing ability … um, and knowing that there is, um, some relief available other than just trying to huff your way through it.
Male, 70 years old, IPF	It would probably help my coughing. Oh, I would hope to gain a better quality of life. More … more mobility … to be able to do more things, you know, that I can't do right now.	I'll be able to, uh, do more of the things that I want to do and probably feel less tired … I'll have a quality of life that is not there right now, so I'm confident oxygen will increase my quality of life. … do [things] without getting tired and, you know, having everybody look at me and say why is this guy panting?	I've been able to do things that normally would have been really tiring for me and exhausting, so it's improved my quality of life from what it was a couple months ago. It makes you feel refreshed. Uh, without oxygen, I was coughing a lot and, uh, now, I don't have that added stress of coughing all the time like I was before.	Well, I can do more, but not as much as I used to before. But I can get along on my day to day routine.
Female, 53 years old, cHP	… my assumptions are that if I was on oxygen, I would be able to do those things (e.g., walking outof a play) and not need to stop and rest. … on a daily basis, there would be things that I would—would be easier for me to do. Um, you know, things around the house, um yard work, things like that I tend not to do because I know it—it is too difficult for me.	Well, I would hope that it makes things easier to do … and not get tired so quickly. … the biggest benefit, I think, for me, is that it would increase my um, uh, stamina and energy level. Hopefully, it will help extend my life.	… it provides more oxygen to my body, so I know that … but from a actual benefit for me personally, like, do I feel like I want to go run a—a marathon or you know, go for a hike? I don't. I don't notice any, um, any differences … any benefits.	Um, honestly, I think one of the benefits is it's made me more sympathetic to other people who might have medical conditions.
Female, 76 years old, IPF	If it gets to the point where I need oxygen, that will help me to go ahead and do some of the chores I do around here, you know. Making the bed, doing the laundry … Well, hopefully, it would, you know, maintain at least the level of exercise that I have now, maintain, you know, my independence being able to go out.	Well, hopefully, I will continue to live a little longer … I hope to—to live a little longer by using supplemental oxygen.	I don't think honestly I'll be doing a lot more. It just maintains my daily activities really. I probably don't get as tired if I'm using the oxygen, you know, like for shopping. I used to get—wear myself down and get weak if I'm not using the oxygen and I'm walking too far.	Well, there are things that I would be unable to do did I not have that option [of using oxygen].

O_2 = supplemental oxygen; IPF = idiopathic pulmonary fibrosis; cHP = chronic hypersensitivity pneumonitis; FVC% = percent predicted forced vital capacity.

Just prior to starting O_2

Each of the five participants was prescribed O_2 in response to peripheral oxygen desaturation that occurred during an office walk test. Hopes and expectations for benefits at this time point are detailed in Table 4. Anticipated hardships centered on the "hassle of having to carry it [O_2] around," the difficulty of leaving the home with O_2 and the physical challenges of concentrators, tanks and oxygen tubing. Being perceived negatively by others remained a concern:

> *One male participant with IPF: "I'm not particularly pleased about being, um, treated or perceived to be treated like an old invalid … simply because people see the oxygen."*

Another man with IPF: "I am trading from one stigma for another, because, you know, I've heard people say, 'Well he's on oxygen because he was a smoker.'"

A male participant with IPF likened his impending link to an O_2 delivery device to his grandchildren being constantly "tied" to their cell phones:

"Every time you see them, you know … they come in the house; the first thing they have to do is plug that damned cell phone in … you know? And it's the same tethering process."

Looking behind

One month on O_2

Overall, participants found they had not been well-informed about many facets of O_2. Only one participant recalled his O_2 prescriber explicitly stating what he could expect from using O_2:

"Yeah, he said it would improve my quality of — of life, but we didn't go into detail about the trials and tribulations of using, uh, you know, supplemental oxygen."

Participants struggled with choosing a delivery system that would meet their O_2 and lifestyle needs, and they had little guidance in making this decision. By one month, all participants had purchased a finger pulse oximeter, either on their own or at the suggestion of their O_2 prescriber, or more commonly, pulmonary rehabilitation staff. However, participants were given little to no direction on when or how to use them.

Only one participant was explicitly instructed to adjust O_2 flow when exerting; two others decided on their own to use symptoms to determine whether their flow of O_2 was adequate. The remaining two participants never adjusted their flow and were never instructed to do so. The over-arching theme from interviews at this time point was that the entire process of starting O_2 — prescribers stating and managing expectations for what patients could expect from oxygen suppliers, choosing an oxygen delivery system, instructions on whether to purchase and how to use a pulse oximeter, changing O_2 flow, where and how to gather more information about O_2 — could be improved.

One female participant summed up her experience: "You know, that was my biggest disappointment, is I was told that I needed it, but from then on, it was like OK, what do I do now? I didn't have any help in choosing what I wanted to do and what I had to use. It was very frustrating to get started. Mainly, the supplier says, 'This is all you can get.' But then the nurse at the doctor's office says, 'Oh, no, you can get a portable concentrator.' But nobody explains to me what's best, what's best for me? I don't want the insurance company to dictate everything that I need. What is best for me? Nobody could tell me that. I was strictly on my own on that part."

Although not necessarily corroborated by questionnaire data, as highlighted in Table 4, all but one participant felt like their expectations for the benefits of O_2 were met. However, despite the benefits, there were hardships, as one man with IPF stated:

"You're lugging this thing around. You're tethered to it. Um, those are the adjustments that you have to make off the trade. The tradeoff is well worth it, but it's, you know, it is an adjustment. Um, so, yeah—life is full of tradeoffs."

Participants mentioned enduring the same hardships they had anticipated in the prior round of interviews ("cumbersome," "tethered to a machine" and feeling "self-conscious" in public), but there were also new difficulties mentioned. One female participant was "annoyed" when using O_2 with exertion:

"… like when I'm out working in the yard, um, the tank itself is supposed to remain upright, and when I bend over, or you know it—it gets at a certain angle, it starts to sputter and make noise … and, so, it's kind of, um—it's kind of a, um, hassle. It's just one more thing I have to worry about when I'm out doing stuff."

Others began to realize using O_2 required a great deal of planning before leaving home:

One man with IPF said: "I mean, you, you have to adapt to, to planning to take the charger and the machine and the cannula and, you know, the cleaning supplies that go with, you know, that, all that stuff."

Another man with IPF noted: "… you really have to preplan things and make sure you got—you got the right, uh, spares with you and, uh, uh, also the hose, you know?"

All five participants used the internet extensively to get information on how to live with O_2, primarily in the form of online support groups. However, participants found the quality of internet sites to be highly variable and frequently commented on the degree of misinformation they contained. Oxygen suppliers were reasonably helpful in providing practical information to some participants but not to others.

9-12 months on O_2

For most participants, perceived benefits remained after several months on O_2 (Table 4); as did the hardships.

A female participant with cHP said: "I've always been an independent person, and I, um, don't like that it makes me less independent."

One female with IPF summed it up: "Um, just the traveling with it and going out of the house with it. Just the inconvenience of it all and the stupid line all over the house, and I trip on, because it's always — my leash, as my husband calls it."

Participants continued to use the internet as the primary resource to gather disease- and O_2-specific information. Besides educational resources, participants identified other key areas that could improve patients' experiences as they navigate the initiation and use of O_2. They thought prescribers should establish reasonable expectations for O_2. Lighter, more convenient delivery devices with remote control capability to adjust O_2 flow rates (two participants mentioned) would make O_2 use better. One male participant thought an "oxygen buddy" would be a valuable resource:

"… somebody that I could ask questions of; somebody who has been down that path, that, um, you know, that they would, would be available to, and willing, to talk about how do you do this or how do you do that."

Discussion

In this study, we sought to better understand PF patients' expectations and experiences during the life-altering process of starting and using O_2. We identified four major themes woven through the interviews over time: 1) benefits of O_2; 2) practical and physical limitations imposed by O_2; 3) psychosocial impact; and 4) a general lack of education and resources. To our knowledge, this is the first study to collect qualitative data from the same PF patients before and after the initiation of O_2.

Before being prescribed O_2, participants uniformly anticipated that O_2 would increase overall physical activity, and for most, this was true. While most participants reported improvements in mobility, others also noted increased confidence in their ability to

perform physical tasks, knowing they had O_2 to support their oxygen saturations. There was also the perception by some participants that O_2 improved cough, energy level, independence and overall quality of life.

Quantitative data on the benefits of O_2 in patients with chronic pulmonary disease are sparse. O_2 improves survival in patients with chronic obstructive pulmonary disease (COPD) and resting hypoxemia or right heart failure,[11,12] but it has no benefits in COPD patients with mild-to-moderate resting or exercise-induced hypoxemia.[13] Such studies in patients with PF are long overdue: pathophysiological differences in gas exchange abnormalities between PF and COPD suggest results from COPD studies may not be generalizable to patients with PF.

O_2 increases distance traveled during a 6-min walk test in patients with various patterns of interstitial lung disease.[2] The effect of O_2 on dyspnea, assessed immediately after PF patients perform a timed walk test is variable.[14] It remains unclear whether the beneficial effects of O_2 observed during lab-based walk tests translate to durable improvements in how patients feel and function on a day-to-day basis. The questionnaire data from the current study confirm that some patients feel and function better after O_2 is initiated. However, some patients perceive beneficial effects of O_2 that were not captured by questionnaires (e.g., independence). Research is needed to clarify this apparent paradox.

At baseline, many patients with PF have significantly impaired physical functional capacity[15] and in all PF patients, physical functioning is inextricably tied to exertional dyspnea. As PF progresses, dyspnea worsens, and physical function declines. In fact, this is one of the main pathways to impaired QOL in patients with PF.[16] To improve dyspnea is one reason O_2 is prescribed in PF; the hope is that physical functional capacity and QOL follow, and this appears to occur in some patients. They adapt well to life with O_2. They figure out how to minimize the challenges and frustrations and maximize the benefits of O_2. But, for some patients with PF, the addition of O_2 paradoxically worsens their situation. These patients may be unable or unwilling to adapt to life with O_2. They may find that the practical limitations (e.g., inability to travel or leave home without additional planning) are overwhelmingly frustrating or that the physical limitations (e.g., tanks are large, heavy, and unwieldy, making them difficult to carry or use when active; tubing in the home creating a tripping risk) prevent them from participating in activities they had previously found enjoyable.

In fact, on average, patients with idiopathic PF prescribed O_2 have worse QOL than those who do not require O_2.[17,18] In qualitative studies, O_2 was found to have a negative impact on the QOL of PF patients and their caregivers.[3,19] Although much of the difference in QOL between PF patients who need and those who do not need O_2 may be explained by disease severity (PF patients prescribed O_2 have more severe disease than PF patients not prescribed O_2), the hardships of O_2 confer an additional negative impact on overall QOL. In some studies of patients with COPD, O_2 use has been shown to be associated with slightly more impaired QOL[20]; however, in the recently completed LOTT study of O_2 in COPD patients with resting (mild) or exercise-induced peripheral oxygen desaturation, O_2 was not associated with worse (or better) QOL.[13]

Adding to the practical and physical challenges it creates, O_2 represents a tangible sign of disease for patients with PF. Once patients start using O_2, many feel that they become defined by it. O_2 visibly designates them as "sick," marring their otherwise normal outward appearance. In chronic respiratory diseases, this is closely tied to the concept of "invisible disability,[21] which refers to disease-related physical and emotional impairments that go unnoticed, because they cannot be seen by others. Invisible disability works both ways for PF patients: without O_2, no one can tell a PF patient is sick — they can hide their lung disease from the outside world. Meanwhile, there is no visible explanation for why they cannot keep up or need to stop and rest. But, with O_2, they are viewed — or at least perceive to be viewed — as sick. Moreover, O_2 may compound PF patients' internal unrest, because O_2 can be a distressing reminder they have reached an unwanted milestone of progression and are living with a terminal illness.

Identifying predictors of which patients will adapt well to O_2 and which will not would facilitate improved patient/provider communication around O_2 at the time it is prescribed and could help identify problem areas to target to improve adaptation and acceptance. Sadly, there are patients in whom PF progression outpaces the ability of O_2 to offer any significant benefits. Hopefully, the discovery of more effective drugs for PF will someday eliminate this issue.

Prior to the initiation of O_2, participants anticipated they would find ample help, education and support from a variety of sources, but they were all disappointed about certain aspects of guidance they received once O_2 was prescribed. In many cases, websites were found to contain bad information. This observation corroborates findings from a recently-published study in which investigators systematically reviewed the top-ranked websites identified from a web search for "idiopathic pulmonary fibrosis." They found that the majority of websites contained inaccurate and outdated information, and they voiced concern over the lack of any reliable method for patients to discriminate between high- and low-quality websites.[22]

In another survey-based study, nearly two-thirds of patients diagnosed with PF reported not having information and resources they needed when they were diagnosed, and only 39.0% of PF patients felt they were generally well-informed about O_2 specifically,[23] again demonstrating a great need for additional education on both the disease and available therapeutic options. Directing patients and their families to trustworthy PF-specific sites that provide up-to-date, patient-friendly information and have an interactive forum may be beneficial.[24]

Referral to pulmonary rehabilitation is another option. Besides educating patients about disease management and the use of O_2 (how to use pulse oximeters and adjusting flow with exertion),[25] pulmonary rehabilitation has been shown to lessen symptoms, increase physical functional capacity and improve QOL among PF patients.[26,27] We believe there are extremely few PF patients who should not be referred to pulmonary rehabilitation.

We also believe providers should explicitly encourage active self-management for PF patients on O_2. In other chronic disease states, self-management strategies improve symptoms and overall health status.[28] For PF patients on O_2, prescription and use of a portable pulse oximeter, whose cost is covered in the same way other durable medical equipment is covered, should be standard of care to promote self-management. When starting O_2, patients should be taught how to both interpret and respond to the data by adjusting their oxygen flow to meet prespecified goals. At institutions that care for PF patients, consideration should be given to establishing an oxygen case manager who can assist patients and caregivers with issues like finding the right delivery device to meet their needs, discerning what insurance will and will not cover, choosing a supply company, and navigating how to travel with oxygen.

Our study has limitations. We included only five participants, which may limit the generalizability of our findings; however, as with all qualitative research, the strength of this study is in the depth rather than the breadth of findings. This type of study has not been performed previously; thus, the findings are novel. We believe our systematic approach to the question and analysis, the prolonged engagement with the data, and triangulation methods we employed (drawing on extensive clinical experience and prior

research, having multiple investigators involved in the study, including patients as investigators to comment on and corroborate findings) support the credibility of the study. We interviewed 40 participants at enrollment in the longitudinal study, but because only five of the 40 were prescribed O_2 during follow-up, we could interview only five participants over time. Still, we conducted a total of 20 interviews, and we believe the novelty of the study design and timeliness and importance of the findings reflect the study's value. The interviews were structured, with a series of scripted questions asked to each participant. This may have limited the scope of responses and shaped the themes that arose; however, the richness of these data provide unique insight to patients' perceptions as they transitioned onto O_2 and incorporated it into their lives.

Conclusion

For patients with PF, O_2 is viewed as offering certain benefits but also presenting several emotional and physical hardships. For many, the hardships, once borne out, are outweighed by the benefits; nonetheless, patients must resign themselves to reluctant acceptance of O_2. The transition from not needing O_2 to requiring and depending on it, can be a frustrating and anxiety-provoking process for many patients with PF. The experience could be improved by better managing expectations for O_2, improving disease-related and O_2-specific resources, and partnering with patients as they adopt self-management strategies.

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