Heart & Lung 48 (2019) 245–249

Contents lists available at ScienceDirect

Heart & Lung

journal homepage: www.heartandlung.com

Care of Adults With Pulmonary Disorders

Equipment, access and worry about running short of oxygen: Key concerns in the ATS patient supplemental oxygen survey

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ARTICLE INFO

Article history:
Received 14 May 2018
Received in revised form 3 December 2018
Accepted 16 December 2018
Available online 28 December 2018

Introduction

"The fundamental importance of oxygen to life on this planet ensures its place in the care of patients with respiratory disorders".[1] In the 1980′s, use of supplemental oxygen therapy increased after the NOTT (Nocturnal Oxygen Therapy Trial) and the MRC (Medical Research Council) trials demonstrated survival benefits of providing long-term oxygen therapy to patients with resting arterial partial pressure consistently less than 55 mm Hg.[2,3] Today, more than one million people in the United States use long term oxygen therapy, the majority with chronic obstructive lung disease (COPD).[4] Supplemental oxygen has allowed patients who otherwise would be homebound to be more mobile, to work, to exercise or attend pulmonary rehabilitation, travel, care for family members, and also to experience improvement in their symptoms, including dyspnea, ultimately improving their quality of life.[5,6]

In the United States, oxygen is commonly provided as a benefit of the Center for Medicare and Medicaid Services (CMS) for patients who use the national health insurance product. The Competitive Bidding Program (CBP) began in July 2013 and is a federal program that determines reimbursement for durable medical equipment (DME) including oxygen. CBP is a program mandated by the US Congress to reduce costs of oxygen, ensure beneficiary access to quality services and reduce beneficiary out-of-pocket expenses. CMS reviews submitted bids from DME companies and awards contracts to those that meet quality and financial standards and offer the best price for oxygen. Contracted DME suppliers must agree to accept assignment on claims and accept a single payment amount from CMS. Results of this bidding process determine what services and equipment are available at each DME and are not uniform across DME providers.[7] It is important to note that not all patients live in a competitive bidding area. Patients and clinicians anecdotally report with increasing frequency the significant and varied barriers in achieving home oxygen services that match their needs. In response, the American Thoracic Society (ATS) Nursing Assembly Oxygen Working Group surveyed oxygen users to better understand problems that patients experience. The findings of that survey were recently published.[7] This was the first study to elicit patient-reported experiences in a cohort of 1926 supplemental oxygen users and revealed that more than one-half of respondents noted numerous and wide-ranging oxygen problems. Experiencing problems with oxygen was associated with greater use of health care resources that could, potentially, be lessened with education.

In 2017, Dobson and DaVanzo, commissioned by the American Association for Homecare,[8] conducted a survey of beneficiaries, case managers and suppliers of durable medical equipment (DME). Beneficiaries reported that their access to durable medical equipment (DME) services and supplies was hampered which adversely

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https://doi.org/10.1016/j.hrtlng.2018.12.006

impacted case managers' ability to coordinate DME for their patients, and placed additional strain on suppliers to deliver quality products without delay. This survey assessed change in services since the implementation of competitive bidding in 2013 and found that patients, case managers, and suppliers all reported worsening problems since that time. A followup report in 2018 noted that patients may be put at risk because of insufficient oxygen equipment that doesn't meet their requirements.[9]

Patients have unique needs related to their oxygen, diverse experiences obtaining oxygen, and wide-ranging consequences if oxygen delivery is disrupted. The purpose of this study was to supplement the quantitative data provided in the ATS Nursing Assembly Oxygen Working Group *Patient Supplemental Oxygen Survey*[7] with qualitative data from 2 select survey items to obtain more detailed information from the respondents' perspective.

Design

The study design was thematic analysis of focus group content obtained from interviews with patients from the "*Patient Supplemental Oxygen Survey*."[7]

Methods

The "Patient Supplemental Oxygen Survey consisted of a 60-item online developed by members of the ATS Nursing Assembly Oxygen Working Group.[7] The survey included four sections (Information about the patient), (Information about the oxygen equipment you use), (Information about the quality of service from your oxygen supplier), and (Is there some issue, other than those mentioned above, that you are having related to your supplemental oxygen) reported in the published manuscript. After Institutional Review Board approval was obtained, the survey was posted on lung disease-related websites of patient and professional organizations in the United States, and was also distributed within the ATS Public Advisory Roundtable (PAR). Respondents were a convenience sample of adults in the United States prescribed oxygen as a consequence of lung disease. Survey responses were obtained using Survey Monkey® and were exported into SPSS.

The focus of the qualitative analysis for this study was on the following 2 questions:

- What is the biggest problem that you would say you have with your oxygen?
- Is there some issue, other than those mentioned above, that you are having related to your oxygen?

We chose these 2 questions because of their focus on the respondent's identified biggest problem. In analysis of the "*Patient Supplemental Oxygen Survey*", we detected rich data provided by the patients that was not published in the quantitative results[7] that deserved additional qualitative analysis. In addition to the option to select a response, these 2 questions provided the option for Other where the respondent could fill in the blank. The focus of this analysis was on the "Other" free text.

Analysis

Responses to these 2 open-ended questions were analyzed using content analysis. An inductive approach was use to explore the key aspects in the oxygen user responses. This analysis included immersion in the data, multiple readings, writing down as many headings as possibile to describe all areas of the content, reviewing this list of headings and finally, grouping together similar categories and removing repetitious or overlapping headings.[10] To assure rigor and trustworthiness, data were reviewed by 3 of the authors (KOL, LAC, SJJ) then systematically coded and categorized into themes.[11] Once the categories and themes were identified, descriptive terms were also quantified.[12]

Results

Clinical and demographic characteristics

The final survey respondents ($n = 1926$) were 64 ± 11 years of age, primarily female, from suburban areas, and represented every state (Figure E4). Almost one-half (44%) reported living in a Competitive Bidding Program (CBP) area, 45% were unsure, and 11% lived in non-CPB areas. COPD (39%) and interstitial lung disease (ILD) (27%) were the most common diagnoses. The majority were retired (47%) or disabled (41%), with only 23% working outside the home.

Themes

The first question analyzed was "What is the biggest problem that you would say you have with your oxygen?" and our analysis included the 128 survey responses to the free text option "Other" in this question. This question also had 14 choices to select, in addition to "Other". (Table 1). For this question, 47 respondents experienced related problems, another 47 experienced access issues, 17 respondents wrote no problems for their response, 9 reported angst/concernt/worry about quality of life, and 8 reported problems across all 3 areas. The other question included in the qualitative analysis was "Is there some issue, other than those mentioned above, that you are having related to your oxygen?" This question was the last of 60 questions and 745 respondents replied. While the number of respondents differed between the two questions, responses were transcribed for both and the content analysis revealed similar themes in responses to both questions. Three themes emerged: (1) equipment related issues, (2) access related issues, and (3) emotionally related issues.

Equipment-related

In this category, comments focused on lack of portability, reduced availability of liquid oxygen, and the desire for portable oxygen concentrators (POC) that delivered high flow oxygen. These equipment issues all affect patient mobility. Of those replying, 25% specifically addressed the need for access to a POC that met their oxygen demands, especially high flow oxygen, and 17% specifically addressed the desire to keep liquid oxygen or acquire a liquid oxygen system. Please see Table 2 for detailed respondent comments.

Table 1
Q. What is the biggest problem that you would say you have with your oxygen (choose only one)?

1. Equipment not working correctly.
2. Incorrect or delayed oxygen orders from my healthcare providers.
3. Delayed or unreliable delivery of oxygen equipment by my oxygen supplier.
4. Not being provided enough tanks for my activity needs outside of the house.
5. Lack of portable systems that I can carry/pull/physically manage.
6. Lack of portable systems that provide high enough continuous liter flow
7. Not getting or having problems getting oxygen for my travel needs.
8. Getting enough portable oxygen so that I can continue to work.
9. I used to use liquid oxygen but my supplier no longer offers it.
10. I need liquid oxygen because it offers high flow and portability but it is not available to me.
11. The medical equipment company does not respond to my calls and / or needs.
12. I received oxygen bills that were more than the amount explained to me.
13. Not being able to mix systems, for example tanks and POC, or small and large tanks.
14. Not being able to change oxygen companies.
15. Other: (please specify).

One respondent reported: "*I need 2 portables to be able to have it on continuous flow which I need, instead I have to use demand pulse flow to conserve oxygen, but then my oxygen levels drop.*"

Another respondent reported "*Largest problem lies with heaviness of tanks and I need my caregiver to manage them.*"

Access related

This category included comments about insurance coverage and experiences where DME companies provided equipment/information/service that did not meet their needs. Respondents described delays in oxygen set-up, both from the hospital and at home. Some reported frustration in not being able to change companies or obtain equipment so they could return to work or travel. Financial issues were described including paying for extra equipment to allow greater mobility outside the home, basic billing problems with their provider, or receiving unexpected equipment charges. Please see Table 3 for detailed respondent comments.

One respondent reported "*Failure to get instruction. I have found out what I know in bits and pieces, never up front and nothing written*"

Emotionally related

The strain on quality of life experienced was reflected in respondents' descriptions of the constant worrying and planning needed due to the unknown of when their oxygen would run out, when they would receive deliveries, and if they would be able to get out of the house. The burden and worry included terms describing the resulting social isolation due to not getting out of the house. Please see Table 4 for detailed respondent comments.

Table 2
Equipment issues (Respondent comments) ($N = 47$)

Largest problem lies with heaviness of tanks and my inability to manage them. I need my caregiver to manage them. Also, I no longer travel due to this problem.
We can fit a computer in our palm, but my portable oxygen weighs $\sim$7 pounds. I weigh 100 pounds and am sick. Can't we make a small concentrator?
Would like to see someone invent a remote control. I need to be able to turn O2 up but I have to get up to walk across the room to my machine and am out of breath by then.
It is my understanding that liquid oxygen is being phased out. This is a great disservice to oxygen patients! Liquid oxygen has the most flexibility for patients and honestly leaves me feeling the least disabled. When I travel it is becoming more and more difficult to locate liquid oxygen at my destinations. Please fight for its continued availability.
There are no continuous flow portable oxygen concentrators over 3LPM and my oxygen requirement is much higher. Need a James Bond oxygen system light weight, long duration.
Would like to have a high continuous flow portable concentrator but can't have one in addition to the one that I have one that plugs in.
Heavy portable tanks cause fatigue and back pain.
Need 2 portables to be able to have it on continuous flow which I need, instead have to use demand pulse flow to conserve oxygen, but then my oxygen levels drop.
POC rentals for travel are too expensive. Also, liquid systems too "delicate" and awkward. I reverted to Green O2 tank system.
When I first received my portable oxygen I received 16 M9 tanks that only lasted 4 hours. The driver told me they only delivered every 3 months, but I could bring empty tanks back to be exchanged. I used 3 tanks every workday so I was exchanging tanks every week. On the last time before the first month was over they told me that I couldn't exchange all of the tanks because I had reached the monthly maximum of 36 tanks. This caused a huge problem because I was going to run out of the portable tanks before I could get more. After going round and round with my supplier and pulmonologist office, they replaced my small tanks with a homefill system and 2 D tanks. This limits some of the things that I should be able to do. I can't go camping because I only have about 20 hours of oxygen if I can't fill the tanks. When I take trips that I can drive to I have to take my concentrator with me so I can fill my tanks. The homefill tanks are not as easy to deal with. I am still able to get around pretty good, but they could be an issue with someone who has difficulty with tasks.

Table 3
Access issues (Respondent comments) ($N = 47$)

The initial set up caused a 9 h discharge delay from hospital.
It's frustrating that I have to wait 5 years to change oxygen supplier if I want to. Not being able to change oxygen suppliers, not being able to get a POC with the company I have, having all sorts of problems with the supplier for the past 2 years and being stuck with them. My life is just existence at home right now, with no hope of change for at least 3 yrs. and I hate it.
At first, the company was real bad. I called and said, the machine was SOOO noisy, i couldn't sleep, They said, GET USE TO IT!! Even after my dr called them. I then called and requested extra tubing, so i could put it in a room further away. They said, I was not eligible for more. A pH friend sent me her extra. But eventually, they swapped out the machine, it is a little quieter, but it is in the far room. They send me whatever i need. I worry though, if i need a portable one, they won't give me a small enough one. I am barely 98 pounds, and severe scoliosis.
While we were trying to find a way for me to return to work, we kept calling (DME) to explain what we needed. They told me I would need to carry two 1 h cylinders with me daily, which each took 10 h to fill, along with another two or three 4 h cylinders. Then I would need to stop by their office EACH day to refill the cylinders. Impossible with a full time job.
Incorrect bill tracking by oxygen company. They insist they've never received a proper prescription since I was discharged from hospital over a year ago. They are threatening to make me pay $900/month!
Patient Advocacy Protection System not in place: everything is set in place for patient and physicians to meet guideline criteria to obtain and retain equipment (recert), but there is nothing in place making sure the Oxygen Supplier is meeting standards after making the deal and patient have no recourse. Suppliers should be required to supply the patient Medicare rights and what to know before they commit to a supplier (if they are on Medicare, even if they are not there should be guidelines for patient awareness that is not provided by the supplier). The patient agrees/signs a contract. They should have a copy of contract. I am being billed for 2 pieces of equipment. I chose the company because one piece of equipment fullfilled my needs. I was told they supply extra equipment free of charge. A year later I notice they were charging for both. Nothing is in writing for patient protection.
My oxygen supplier refuses to accomodate me with a POC, even though my pulmonary physician requested one and my insurance approved it.
Extreme jump in electric bill and being told I could not buy my own.
DME provider said I would no longer get emergency tanks when electricity went out because they said they are not paid for.
Failure to get instruction. I have found out what I know in bits and pieces, never up front and nothing written.
When I travel it is becoming more and more difficult to locate liquid oxygen at my destinations. It is my understanding that liquid oxygen is being phased out. This is a great disservice to oxygen patients! Liquid oxygen has the most flexibility for patients and honestly leaves me feeling the least disabled. Please fight for its continued availability.

One respondent reported: *Because of the limits of my current oxygen, I am mostly homebound. The oxygen available to me is too heavy to carry or too bulky to wheel, so an outing is more trouble than it's worth.*

Discussion

The key concerns that this cohort of respondents experienced reflected their decreased mobility related to malfunctioning equipment, lack of portable systems to allow for time away from home, and poor service by DME companies, all causing emotional distress of angst, worry, concern and a decrease in quality of life.

This oxygen survey studied patients with several lung diseases including COPD, ILD, pulmonary hypertension, Alpha-1 antitrypsin deficiency, and Lymphyangioleiomyomatosis (LAM). Previous oxygen studies have been disease-focused, most frequently in COPD,[13–16] with a recent growing interest in ILD.[17–20] Du Plessis, et al reported exertional hypoxemia to be more severe for patients with fibrotic lung disease than those patients with COPD. Their group compared results of a 6-minute walk test (6MW) performed on room air in 134 patients with ILD and 247 patients with chronic COPD. Diffusing capacity (DLco) was the strongest predictor of desaturation in both cohorts with ILD patients experiencing greater oxygen desaturation during the 6MW compared to patients with COPD.[21] Higher flow

Table 4
Angst/Concern/Worry (Respondent comments) ($N = 9$)

Constant concern about running out of O_2
They have never sent anyone to check the concentrator. I often wonder if it is putting out the right amount of oxygen.
Well I have a wedding comming up and a rehearsal dinner and I would like to have a shoulder one to use first time seeing people family etc… not feeling good about going with a pull tank! at all . I am the stepmother of the Groom! thanks so much for your time… also as well the doc has ordered the shoulder tank 2 time and no word from them I asked the provirder and they asked me to have the doc fax them a prescription and I have done everything they have asked and still no word and now I am freaking out about going to the wedding again. Thanks for your time.
To have a consistent knowledgeable person to ask about things that come up. For example I have been on 6 liters continuous for 4 months and was just made aware that I should have high flow cannulas or a mask, neither of which have been offered to me. When I asked for high flow cannula, I was told they were out…it has since been two weeks. I have asked for bigger tanks in order to leave the house but there are no bigger tanks that fit my home fill and they say they don't deliver tanks. I have asked for more tanks but they say I am only allowed to have three. When I went from four liters to 6?liters they had to purchase a larger POC that went to 10 liters. It took three weeks to get it, although I don't think that was their fault . I am currently listed for transplant and I am trying to stay healthy but I can't leave home for long or I will run out. I have excellent insurance but the oxygen supplier has to be approved by care Centrix which is a national company and my provider is the only one in the immediate area. I will not be eligible for Medicare for several more months as I have been disabled a little less than two years.
The tanks are too heavy for me to carry around, so I don't go anywhere, or sit in the car and have others get my things for me. I wish my insurance would cover a POC.
Electrical failures. Weight of the tanks. Always having to make sure I have enough to last for whatever activity I am doing.
Because of the limits of my current oxygen, I am mostly homebound. The oxygen available to me is too heavy to carry or too bulky to wheel, so an outing is more trouble than it's worth.
When traveling with 4 batteries and a POC, I always run out on the plane, which is traumatizing.
Electrical failures. Weight of the tanks. Always having to make sure I have enough to last for whatever activity I am doing.
Very soon, my portable oxygen concentrator (max setting 6 pulse) will be insufficient and I will need LOX. It is most unlikely that Inogen can or will arrange supply. There is no incentive for another supplier to take my account, now in its third year.

needs due to the greater desaturation noted in ILD patients may result in higher reported levels of stress and anxiety for this group.

Many of the respondents' comments reflect that oxygen is not a one size fits all model, and that disease-specific guidelines are needed to match systems to patients based on their activity outside the home and their oxygen flow rate needs.[18] Portable systems can deliver continuous flow (CF) and intermittent flow (IF) and, while IF devices are safe and generally effective in correcting hypoxemia, there is variability in delivery and patient response and therefore patients need to be tested on these devices.[6] Patients with obstructive lung diseases often can adequately saturate with pulsed delivery systems in comparison to patients with restrictive lung disease who may not require oxygen at rest, but require notably high doses with exertion. It is recommended that each patient be tested during rest and exertion using the specific IF devices.[6] IF devices are traditionally not recommended for sleep because of poor synchronization between triggering and inspiration and inability to maintain adequate oxygen saturation with sleep.[22] Newer models may be up to 10x more sensitive to nighttime breathing and be able to trigger to maintain adequate saturation.[23] It is imperative that patients be tested on devices before they are prescribed.

Symptom burden is common in patients with lung disease, including dyspnea, and reduced quality of life. Most patients indicated that they were worried about their dyspnea and quality of life. Introduction of long term oxygen therapy for patients with severe COPD was associated with early, significant improvements in health-related quality of life and sustained response at 6 months.[14] Schaeffer, et al reported that hyperoxia significantly improved exertional dyspnoea and exercise tolerance in patients with fibrotic ILD.[17]

Another consideration is that more than half of individuals with one chronic condition, such as lung disease, also have multiple other chronic conditions adding to the complexity and burden of managing their health.[24] Chronic conditions require a life-long care perspective and the role of the caregiver is crucial. While this survey did not assess caregivers, the impact on their families clearly is a cause for additional stress among these respondents. Other researchers have looked at the impact of supplemental oxygen on the caregiver, and found that the need for supplemental oxygen often creates angst amongst patients as well as caregivers and prevents them from living "normal lives".[25] In another study of informal caregivers' (ICs) experiences with supplemental oxygen, Graney reported ICs realized that oxygen introduced new roles and responsibilities for them, significantly impacting their relationships with their patient-loved one.[26] In another study, Graney found that patients did not find that they had been well-informed about the many facets of oxygen.[27]

As many oxygen users report their key concerns about their oxygen use, providers and researchers are also expressing their concerns and difficulties with supplemental oxygen. One provider endorses "a detailed discussion that includes an educational overview of oxygen, recommendations for how to use it (correctly), and disclosure of what hardships and benefits the patient (and their caregiver) might expect from oxygen". He also advocates for use of a pulse oximeter to allow patients to adjust their oxygen flow to maintain saturations $> 89\%$ at all times.[28] Another provider suggests that the process can be improved by providing patients with clearer expectations and trustworthy educational resources. Utilization of oxygen case managers could help patients incorporate supplemental oxygen more seamlessly into their lives.[27] Each patient should be tested on the specific oxygen device they receive to make sure that it delivers the correct prescription and have appropriate monitoring and reassessment of oxygen needs because of variability in delivery and patient response.[6] Further research is advocated regarding the role of clinically meaningful outcomes for supplemental oxygen in patients with ILD.[29]

Conclusions

Patients report their inability to obtain equipment that meets their needs and the subsequent forced isolation due to inability to obtain user-friendly oxygen delivery systems and/or identify suppliers who can meet their needs. Results provide insight into the patient experience and its marked impact on angst and worry in their daily lives. This mismatch in unmet perceived oxygen needs can result in social isolation, ultimately affecting quality of life. Future research studies should focus on oxygen systems that support mobility in specific lung diseases, symptom and quality of life assessment for oxygen users and their caregivers, guidelines that address disease-specific studies, and incorporation of educational tools.

Acknowledgments

The American Thoracic Society provided survey assistance.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.hrtlng.2018.12.006.

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