ORIGINAL RESEARCH

Burden and Unmet Needs with Portable Oxygen in Patients on Long-Term Oxygen Therapy

Jessica Dakkak[1]*, Wilson Tang[1]*, Jonathan T. Smith[1], Aparna Balasubramanian[2], Moriah Mattson[1], Ana Ainechi[1], Brice Dudley[1], Martha N. Hill[3], Stephen C. Mathai[2], Meredith C. McCormack[2], Soumyadipta Acharya[1], and Sonye K. Danoff[2]

[1]Center for Bioengineering Innovation and Design, Department of Biomedical Engineering, Whiting School of Engineering, [2]Division of Pulmonary and Critical Care Medicine, Department of Medicine, Johns Hopkins School of Medicine, and [3]School of Nursing, Johns Hopkins School of Nursing, Johns Hopkins University, Baltimore, Maryland

Abstract

Rationale: Over 1.5 million Americans receive long-term oxygen therapy (LTOT) for the treatment of chronic hypoxemia to optimize functional status and quality of life. However, current portable oxygen equipment, including portable gas tanks (GTs), portable liquid tanks (LTs), and portable oxygen concentrators (POCs), each have limitations that can hinder patient mobility and daily activities.

Objectives: To examine patient experiences with portable oxygen to guide equipment innovation and thereby improve patient care on oxygen therapy.

Methods: The burden and unmet needs with portable oxygen equipment were assessed in 836 LTOT patients with chronic lung disease (chronic obstructive pulmonary disease [COPD], interstitial lung disease, and pulmonary hypertension) through an online survey. The survey included a combination of multiple-choice, Likert-scale, short-answer, and open-ended questions. Distribution was achieved through patient support organizations, including the U.S. COPD Coalition, the Pulmonary Fibrosis Foundation, and the Pulmonary Hypertension Association.

Results: Improvements in portability were ranked as the highest priority by patients across all equipment types, followed by increases in the duration of oxygen supply for GTs, accessibility for LTs, and flow capabilities for POCs. All device types were found to be burdensome, with the greatest burden among GT users, 51% of whom characterized GT use as "strenuous" or "extremely strenuous" (high burden). POCs ranked as the most common (61%) and least burdensome devices; however, 29% of POC users still reported a high associated burden. Forty-seven percent of POC respondents described using a POC despite it not meeting their oxygen needs to benefit from advantages over alternative equipment. Among non-POC users, limited oxygen flow rate capabilities and cost were the top reasons preventing POC use.

Conclusions: Although improvements have been made to portable oxygen equipment, this study highlights the burden that remains and reveals a clear need for advances in technology to improve the functional status and quality of life of portable LTOT users.

Keywords: lung disease; hypoxia; durable medical equipment; equipment design; quality of life

(Received in original form May 16, 2020; accepted in final form February 9, 2021)

*Co–first authors for this paper.

Supported by the Johns Hopkins Discovery Award.

Author Contributions: J.D., W.T., J.T.S., S.C.M., M.C.M., and S.K.D. made substantial contributions to the design, acquisition, analysis, and interpretation of the data and made substantial contributions to drafting and revising the manuscript. A.B. made substantial contributions to the analysis and interpretation of the data and made substantial contributions to drafting and revising the manuscript. M.M., A.A., and B.D. made substantial contributions to the design and acquisition of the data and made substantial contributions to drafting the manuscript. M.N.H. made substantial contributions to the design and acquisition of the data and made substantial contributions to drafting and revising the manuscript. S.A. made substantial contributions to the design, acquisition, analysis, and interpretation of the data and made substantial contributions to revising the manuscript.

Correspondence and requests for reprints should be addressed to Jessica Dakkak, M.S.E., Department of Biomedical Engineering, Johns Hopkins University, Clark Hall, Suite 208, 3400 N. Charles Street, Baltimore, MD 21218. E-mail: jessica.dakkak@gmail.com.

This article has a related editorial.

This article has an online supplement, which is accessible from this issue's table of contents at www.atsjournals.org.

Ann Am Thorac Soc Vol 18, No 9, pp 1498–1505, Sep 2021

DOI: 10.1513/AnnalsATS.202005-487OC
Internet address: www.atsjournals.org

Long-term oxygen therapy (LTOT) is a standard of care for chronic hypoxemia from respiratory diseases, including chronic obstructive pulmonary disease (COPD), interstitial lung disease (ILD), and pulmonary hypertension (PH). Over 1.5 million individuals in the United States are prescribed LTOT (1), contributing to national healthcare expenditures of over $49 billion U.S. dollars (2). Although LTOT is a necessary therapy to prevent end-organ damage related to hypoxemia (indicated for an arterial partial pressure of oxygen <55 mm HG or oxygen saturation as measured by pulse oximetry <88% on room air [3]), there is mounting evidence that available portable oxygen equipment restricts patient mobility, daily activities, and independence (4–7).

Portable LTOT equipment, including portable gas tanks (GTs), portable liquid tanks (LTs), and portable oxygen concentrators (POCs), is often prescribed to enable an active lifestyle outside of the home (*see* Figure E1 in the online supplement) (8). As highlighted by the Official American Thoracic Society practice guidelines, GTs, LTs, and POCs have varying characteristics, including weight, size, filling mechanisms, flow capacity, supply duration, cost, and travel compliance, that should be optimized to meet patient goals (9). In practice, GTs are the equipment of choice by Medicare providers (10), although the large, heavy tanks can impose ergonomic challenges for patients. LTs are uncommon because Medicare reimbursement policy disincentivizes liquid oxygen provision due to high provider costs (7, 11, 12), often constraining high-flow oxygen patients to more cumbersome equipment. POCs have redefined portability, providing lightweight, rechargeable equipment; however, limitations in accessibility, battery life, and oxygen output still remain (4, 7).

The inadequacy of current portable LTOT devices in meeting mobility needs is a serious concern. Lack of physical activity can contribute to increases in chronic lung disease exacerbations and morbidity, including poor mental health and quality of life (13–16). Previous research has highlighted issues with oxygen equipment (1, 4, 6–8, 11, 17) as well as the need for evidence-based guidelines surrounding effective delivery of LTOT (9); however, the burden imposed by portable oxygen equipment, its adequacy in meeting lifestyle needs, and accessibility to equipment are still poorly understood. This study investigates the challenges unmasked by the Patient Supplemental Oxygen Survey (7) and further defines patient experiences with portable oxygen by quantifying the burden and ascertaining unmet needs to drive innovation in portable LTOT equipment and improve patient care.

Methods

Study Design and Population

This cross-sectional survey of adults with COPD, ILD, or PH on LTOT was approved by the Johns Hopkins University Institutional Review Board and administered online from February 6, 2019, to October 13, 2019. Distribution was achieved through patient advocacy organizations, including the U.S. COPD Coalition, the Pulmonary Fibrosis Foundation, and the Pulmonary Hypertension Association. Inclusion criteria were oxygen supplementation for more than 1 month, age over 18 years, English-speaking ability, and ability to provide informed consent. Exclusion criteria were no portable oxygen use and a diagnosis aside from COPD (including alpha-1 antitrypsin deficiency), ILD (including sarcoidosis and lymphangioleiomyomatosis), or PH. Of the 908 responses collected, 836 met the inclusion criteria for final analysis (Figure E2).

Survey Development

The survey content was developed through input from clinical experts in COPD, ILD, and PH, including pulmonologists, a nurse practitioner, and a respiratory therapist. The survey was piloted by 13 participants and refined with input from participating advocacy organizations. The online survey included 45 questions with multiple-choice, Likert-scale, short-answer, and open-ended responses, a subset of which was used in the analysis of portable oxygen (Table E1). The first page of the survey included the purpose of the study, length of the survey, and the voluntary nature of completing the survey. No incentives were offered to respondents for completion of the survey.

Survey Data

Demographic data included sex, age, pulmonary diagnosis, duration of oxygen therapy, insurance status, and flow requirements (pulse flow settings by patient report were excluded from calculations, whereas purely numerical entries were assumed to be continuous flow rates). Information regarding mobility limitations, the weight of oxygen equipment, the output of oxygen equipment, and methods of oxygen transportation were also obtained. Free-response questions regarding the challenges and impact of equipment on mobility and independence (labeled positive, negative, or neutral) were categorized and labeled by two independent study team members, with only labels in agreement used for analysis. Respondents were further asked, "Which challenge with your oxygen equipment if resolved, would make the biggest impact to you and how?" The perceived burden with GTs, LTs, and POCs was measured on a Likert scale for each device type. Finally, participants were asked if they had a POC and if not, the reasons for not having the device. On interim review of the survey responses, sex had been omitted in 500 participants. In addition, the burden was identified as a critical issue, and a question was added. A follow-up within 4 months of the initial response was sent for these questions, with a response rate of 40% (n = 199).

Statistical Analysis

All statistical analyses were conducted using Python 3.6.8 (Python Software Foundation) and Stata 16 (StataCorp). P values <0.05 were considered to indicate statistical significance. Summary statistics for participant characteristics were described using means with standard deviations or medians with interquartile ranges (IQRs) for continuous variables as appropriate. Categorical variables were described with percentages. The distributional differences across device groups were assessed using the chi-square test for categorical variables and using the Kruskal-Wallis test for continuous variables.

Burden was dichotomized into high burden (including "strenuous" and "extremely strenuous" Likert-scale responses) or low burden (including "no burden," "minimally inconvenient," or "inconvenient" responses). A perceived higher burden was compared from one device to another: *1*) GTs to POCs (reference device), *2*) LTs to POCs (reference device), *3*) GTs to LTs (reference device). A dichotomous outcome of a higher burden, defined as an individual reporting a greater burden for a given device than for the reference device, versus an equal or lower burden than the reference device was used. Burden proportions were assessed using a two-sided proportion difference z test at a 0.1 significance.

Table 1. Participant demographics and characteristics

Characteristic	All Respondents	Portable GT Users*	Portable LT Users*	POC Users*
Total	836	474 (57%)	89 (11%)	507 (61%)
Sex				
Female	417 (50%)	235 (50%)	42 (47%)	269 (53%)
Male	112 (14%)	62 (13%)	11 (12%)	74 (15%)
Nonrespondents	307 (37%)	177 (37)	36 (40%)	164 (32%)
Age, mean ± SD	62 ± 11	62 ± 11	63 ± 11	64 ± 11
Disease state*				
COPD	304 (36%)	184 (39%)	36 (40%)	170 (33%)
ILD	363 (43%)	212 (45%)	35 (39%)	224 (44%)
PH	357 (43%)	195 (41%)	39 (44%)	219 (43%)
Years on LTOT				
[redacted]	90 (11%)	53 (11%)	8 (9%)	50 (10%)
1–3 yr	236 (28%)	134 (28%)	8 (9%)	150 (30%)
3+ yr	490 (59%)	279 (59%)	72 (81%)	293 (58%)
Nonrespondents	20 (2%)	8 (2%)	1 (1%)	14 (3%)
Insurance*				
Medicare	532 (64%)	299 (63%)	65 (73%)	316 (62%)
Medicaid	81 (10%)	62 (13%)	8 (9%)	26 (5%)
Private	487 (59%)	260 (55%)	48 (54%)	325 (64%)
Other	22 (3%)	14 (3%)	5 (6%)	11 (2%)
None	22 (3%)	12 (3%)	2 (2%)	10 (2%)
Flow rate, median (IQR)†				
At rest	3.0 (2.0–4.0)	3.0 (2.0–4.0)	3.5 (2.0–5.0)	2.0 (2.0–3.0)
With activity	4.0 (3.0–6.0)	5.0 (3.0–6.0)	6.0 (4.0–9.0)	4.0 (3.0–5.0)
Mobility limitation due to O_2‡	266 (45%)	159 (47%)	32 (50%)	147 (43%)

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; GT = gas tank; ILD = interstitial lung disease; IQR = interquartile range; LT = liquid tank; LTOT = long-term oxygen therapy; PH = pulmonary hypertension; POC = portable oxygen concentrator; SD = standard deviation.

*Participants report more than a single entry.

†Flow rates are reported in continuous flows. Pulse settings were excluded from analysis, and any numerical responses were assumed to be continuous.

‡Data are show as *n* (%) of respondents who reported experiencing limitations with mobility out of the total number of respondents who answered the question regarding mobility.

Results

Participant Characteristics

The study population consisted of 836 respondents with COPD, PH, or ILD using portable LTOT. The average age of respondents ($n = 755$) was 62 years old; of those who responded to the question regarding sex ($n = 529$), 79% were women (Table 1). Three percent of respondents reported no insurance, with 64% having Medicare. The prevalence of pulmonary diagnoses was 36% COPD, 43% ILD, and 43% PH (Table 1), with a minority of individuals having multiple diagnoses. The median duration of LTOT use was 4 years among GT and POC users and nearly 9 years among LT users (Table 1). Fifty percent of participants reported using >3 L/min of oxygen at rest, whereas 40% reported using >5 L/min with activity.

Equipment Challenges: Weight, Portability, and Oxygen Duration

More than one portable device was used by 27% of participants, with the most common combination being a GT and POC (22% of participants) (Figure E3). On average, respondents reported 1.8 (±1) challenges with their oxygen equipment. Portability (including weight and size) and duration of oxygen supply were consistently reported as the most frequent challenges across all devices (Figure 1). In response to the question "Which challenge, if resolved, would make the biggest impact to you and how?," 47% of participants identified portability as the most important challenge to address to improve quality of life. Further priorities involved the duration of oxygen supply for GTs, flow capabilities for POCs, and accessibility for LTs (Figure 1). Although the duration of oxygen supply was a concern among all equipment types, flow capabilities for POCs and accessibility for LTs surfaced as unique challenges with the equipment. Examples of patient-reported challenges are provided in Table 2.

Weight. Weight arose as the most frequent concern among challenges with portability across all device types. Respondents self-reported a median weight of 8.0 lb (IQR, 5–10 lb) for their primary portable oxygen device, compared with a weight of 7.0 lb (IQR, 5–10 lb) identified by patients as desirable. Respondents with POCs further reported carrying a median of 1.00 (IQR, 0–2) spare battery, weighing an additional estimated 4 lb each (from manufacturing brochures).

Mobility, portability, and transportation. Nearly half of participants (46%) reported mobility limitations due to their oxygen equipment. One-third of respondents described needing help from another individual to carry their oxygen equipment (Figure E4). Among the 37% ($n = 306$) using a mobility aid, 64% ($n = 196$) attributed the need for their aid directly to the burden caused by their oxygen equipment. Both GT and LT users reported needing the most assistance (51% of both GT and LT respondents), compared with 42% of POC users.

Oxygen duration. When asked about the minimum time required from their portable oxygen while on the go, respondents reported needing a median of 3.0 hours (IQR, 2–4 h), a duration longer than what most current portable equipment can provide (Figure E5). At the median reported flow rate with activity for GT users (5.0 L/min), size D and E tanks (most common portable-size GTs at 2,200 psi) last approximately 1.4 hours and 2.3 hours, respectively. Similarly, the median reported POC battery life was 3.0 hours (IQR, 2–4 h).

Portable Device Burden

Sixty-three percent of respondents characterized the use of their portable oxygen device as inconvenient, strenuous, or extremely strenuous (83% of GT users, 64% of LT users, and 60% of POC users) (Figure 2). A perceived high burden, characterized as strenuous or extremely strenuous was most prevalent among GT users (51%), followed by LT users (37%) and POC users (29%). The pattern of a majority of GT and LT users with only a minority of POC users reporting high burden persisted across disease states and sex (Table 3). In addition, women reported a higher burden than men across all devices, but this was only significantly different for POCs.

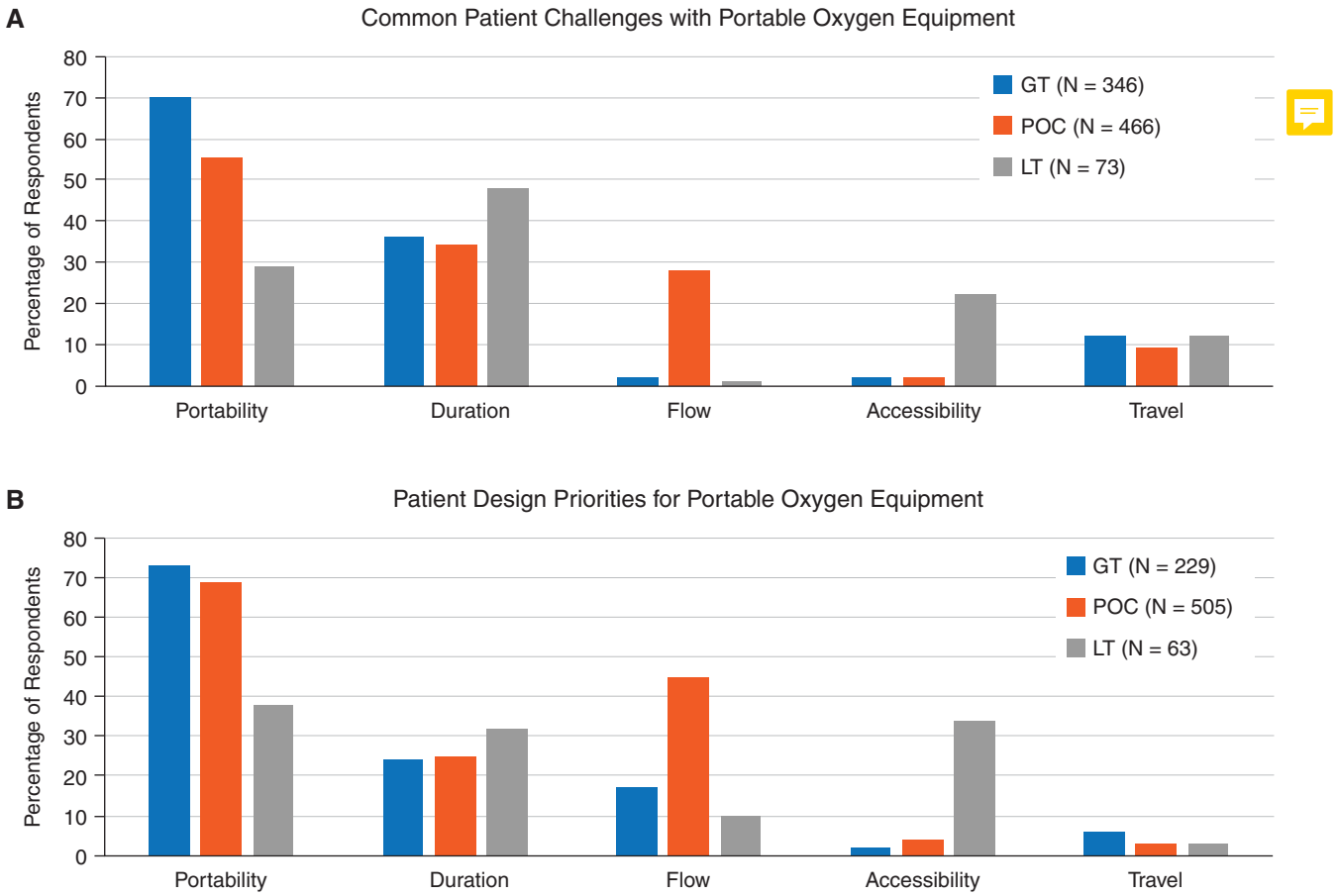

Figure 1. (*A*) Common challenges with portable oxygen equipment grouped by device type and category. (*B*) Patient design priorities (most desired issues to be resolved) with portable oxygen equipment grouped by device type and category. Patients were allowed to report as many challenges as they liked. Portability was considered a supercategory consisting of unspecified portability, weight, and size. GT = gas tank; LT = liquid tank; POC = portable oxygen concentrator.

Across disease states, there were no significant differences in reports of a high burden, despite that PH respondents tended to report a higher burden, followed by ILD and COPD respondents (Table 3). In direct comparisons of the device burden among patients who used both GTs and POCs, 46% of respondents perceived their GTs to be more burdensome than POCs (Figure 3). When comparing GTs with LTs, 61% reported GTs to be as burdensome as LTs, whereas LTs had a burden similar to that of POCs, with equal thirds perceiving a higher, the same, and a lower burden when comparing devices.

The POC User Perspective

The majority of responses to how a POC impacted mobility and independence were positive (82% positive, 9% negative, 9% neutral) (n = 461). Two comments exemplify the positive impact a POC has had on patient mobility:

"It's fantastic! In spite of its limitations, without it I would struggle to exercise and particularly to travel. My husband and I love to travel, often by plane, and my disease progression means it will become increasingly difficult to do so."

"I became more active and have no fear of going outside. It's like comparing a human that is sitting at home all the time, and the other one who can go wherever she/he wants. Comparing 0 and any other number. The difference is an infinite number of times."

Among the 37% of respondents without a POC, the most common reasons for not using the device were limitations in flow rate (55%), cost (54%), and availability (23%) (participants were prompted to select all that apply); only 4% did not feel a need for a POC. Of POC respondents, 47% reported having used a POC despite knowing it did not meet their oxygen needs at the time. The majority of patients with a POC reported purchasing their device out of pocket (52%) (Figure E6) and spending a median of $287 (IQR, $0–$700) on additional supplies, including but not limited to batteries, carrying cases, chargers, cannulas, and carts.

Discussion

This study extends the current literature to further define the patient experience with portable oxygen equipment. Whereas previous research investigated the types and frequency of challenges experienced with general LTOT (7, 11, 18), this study focuses on the greatest unmet needs with portable oxygen by examining future improvements most important to patients per device type and introducing burden as a metric for the adequacy of equipment.

Our findings suggest that current portable oxygen equipment is inadequate to

Table 2. Excerpts of patient quotes of challenges and limitations with oxygen equipment

Category	Challenges and Limitations with Current Portable Oxygen Equipment
Portability	"My portable oxygen tank is like pulling a boat motor behind me." "The portable isn't portable . . . I feel like I have a hippo hanging around my neck." "I can go for 2 to 4 weeks and not leave my house. Hubby does the shopping that I used to do. With what I have now it keeps me from being more active and I need that so much. I use a baby stroller to hold the tank that I do use." "Juggling the tank and my walker together. Pushing a grocery cart and pulling oxygen together. Mobility is hard."
Weight	"The weight of a POC adds to my exertion and causes increased shortness of breath while doing daily activities outside of my home." "The tanks and POCs are heavy to carry. Sometimes I'd rather stay home than be bothered with the equipment. I've always been active and it's really hard to deal with." "My oxygen tanks and POC are too heavy to carry. When I go out, I have my son or husband carry it for me." "I use the rollator to put the oxygen on as the weight of the concentrator and my purse get to me." "It is very hard for me to carry a ten-pound tank plus the back-up ones when I go somewhere. It is 30 pounds of weight total that I have to drag around if I want to go for longer than 2 hours if need be. " "I carry a 'D' tank in a backpack for portable oxygen, and it weighs 10 lbs which is very heavy. It only lasts me 1.5 hours on 4 liters continuous flow. I teach college level courses that are 3 hours in length, so this means I have to haul two, 10 lb backpacks with me, which is nearly impossible given other teaching supplies I may have to carry around with me." "Using my O_2 for exercise is very cumbersome, with the additional 10 lbs on my back."
Duration	"Not enough battery time. I have to lower my POC when going out so I can stay out longer." "Doesn't last long enough . . . 4 hours is NOT enough time to go to the lake fishing, or zoo with my nephew, or state fair in the summer, etc. A grocery shopping trip, yes . . . fun recreation, no." "Battery life is limited. I have 1 1/2 hours to get what I need done at 5LPM, then I have to stop because of the battery." "To watch my daughter play roller hockey I have to take 3 batteries. I miss birthday parties, graduations, and can't grocery shop anymore. I expect I will be leaving a job I love soon."
Adjustment of oxygen	"I wish we could get a remote control for a concentrator so that I can turn my oxygen up with activity. It's too hard for me to adjust it, so normally I just leave it where it is and get very short of breath." "The backpack option is difficult to get on and off and you can't reach the controls when you're wearing it." "If I ever need to turn my O_2 down (from 4 liters to 3 liters, for example), I have to completely take my backpack off, unzip it, change the setting, re-zip it, and then put it on my back again. Given how cumbersome this is during any activity (teaching, exercising, etc.), I tend not to do so and just keep the flow higher than lower (which uses up the O_2 more quickly). This is probably the most frustrating; that I don't have means to change the flow WHILE the backpack is on my back."
Accessibility	"I am so frustrated that concentrator companies and Medicare can't reach an agreement with the patient's comfort and health, the top priority, rather than $$$. Patients, particularly elderly patients, shouldn't have to drag around bulky gas tanks when there are other alternatives." "We have no access to liquid oxygen (too expensive says the supplier), so I must lug tanks around." "If you have a POC you can't get the small tanks for the quieter occasions like church/movies."
Flow	"The POCs provide low, pulse oxygen that does not go high enough for my needs when exercising (a required activity!)." "My POC is pulse delivery and only goes up to a pulse of 4, sometimes I need more." "A lightweight portable concentrator that goes past 3LPM. I only go to work. I can't get enough air to be active. A portable lightweight high output would be amazing." "If there were a POC that went high enough for me, I could actually have a life again and spend more time with my friends and family." "Be able to have a POC that could deliver a TRUE higher flow rate!" "My POC is pulse which makes me feel like I'm sipping air through a tiny straw. I'd feel much better with constant flow, but I can't get 5LPM out of a portable."
Cost	"I rent mine because they break down frequently and are prohibitively expensive to buy."
Anxiety	"I feel trapped at home because of the fear of running out and not being able to get more." "To be able to get out without the worry of running out of oxygen. Right now, I stay at my mother's house which is close to the doctors and hospital. My house is 2 hours away and I haven't been there for months."
Noise	"The small portable is somewhat loud if you are at church/movies or somewhere quiet."

Definition of abbreviations: LPM = L/min; POC = portable oxygen concentrator.

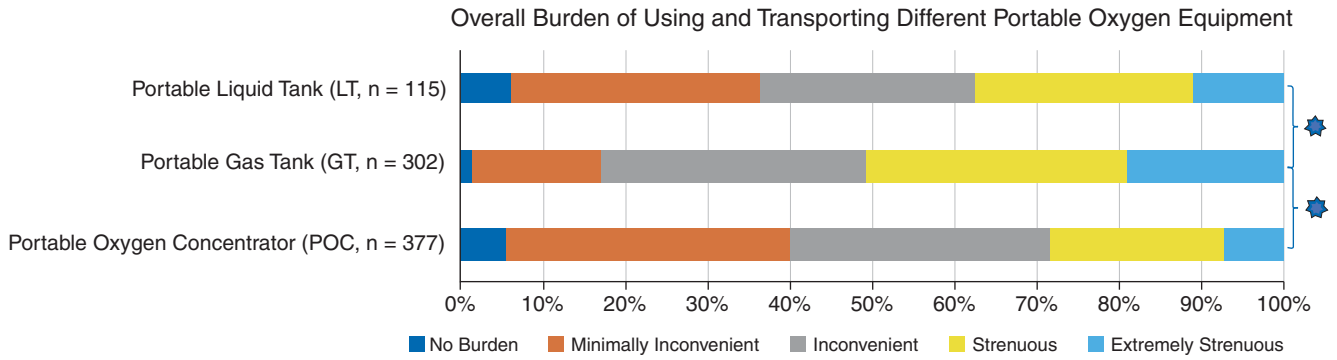

Figure 2. Frequency of Likert-scale responses for the burden of portable oxygen equipment. Each device was rated from "no burden" to "extremely strenuous" (scored 1–5). Significant differences, indicated by the blue star, were found between portable GTs versus portable LTs and POC versus portable GTs ($P < 0.001$ and $P = 0.0003$ respectively). GT = gas tank; LT = liquid tank; POC = portable oxygen concentrator.

Table 3. Clinical factors associated with higher perceived burden by oxygen device

	Portable GT		Portable LT		POC	
Clinical Factor	**Low Burden (No Burden to Inconvenient)**	**High Burden (Strenuous to Extremely Strenuous)**	**Low Burden (No Burden to Inconvenient)**	**High Burden (Strenuous to Extremely Strenuous)**	**Low Burden (No Burden to Inconvenient)**	**High Burden (Strenuous to Extremely Strenuous)**
Sex						
Female	63 (34%)	120 (66%)	12 (35%)	22 (64%)	102 (51%)	99 (49%)
Male	16 (46%)	19 (54%)	2 (50%)	2 (50%)	34 (76%)	11 (24%)
Disease state						
COPD	29 (39%)	45 (61%)	5 (36%)	9 (64%)	43 (57%)	32 (43%)
ILD	38 (38%)	61 (62%)	6 (32%)	13 (68%)	59 (55%)	48 (45%)
PH	34 (32%)	73 (68%)	5 (28%)	13 (72%)	62 (51%)	60 (49%)

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; GT = gas tank; ILD = interstitial lung disease; LT = liquid tank; PH = pulmonary hypertension; POC = portable oxygen concentrator.
At a two-sided proportion test with a significance level of 0.1; only "sex" for POCs (0.002) was found to be significantly different.

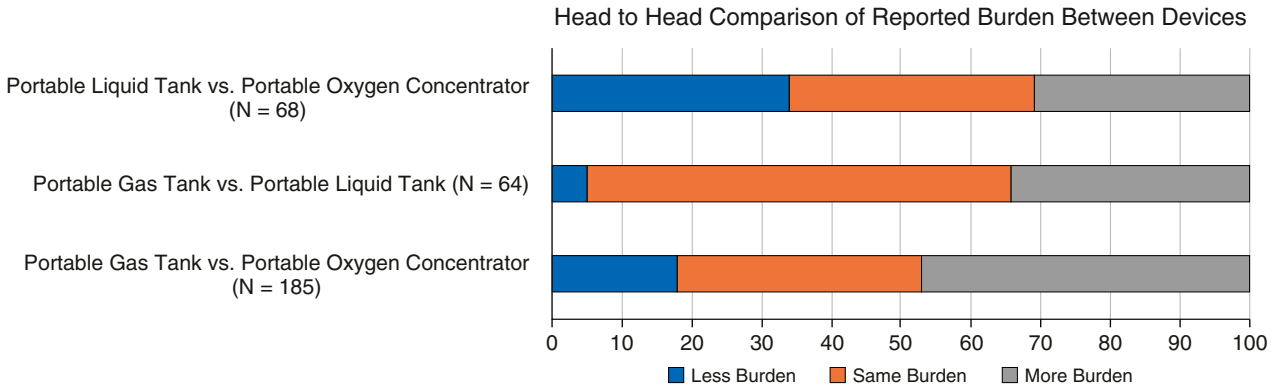

Figure 3. Head-to-head comparison of the burden among devices ever used. The graph indicates patients reported a Likert burden on device A compared with on device B. Only patients with multiple devices were considered. Some patients reported a burden for a device they currently do not own but have used in the past.

meet the lifestyle goals of LTOT patients and plays a significant role in perceived functional status and quality of life. Numerous challenges emerged, including portability and duration of oxygen supply, which is consistent with previous research (7, 11). However, current findings suggest that the frequency of challenges alone is insufficient in quantifying the impact of LTOT equipment on patient quality of life. When investigating the improvements to portable oxygen most important to patients, the most frequently

reported challenges did not directly align with patient priorities. Although portability and the duration of oxygen supply were the most frequently reported challenges, portability, followed by the duration of oxygen supply for GTs, accessibility to LTs, and limited oxygen flow capabilities for POCs ranked as patients' top priorities, highlighting unique challenges by device type. These challenges led to a burden felt across all equipment users, with 38% experiencing a high burden from their equipment (characterized as strenuous or extremely strenuous to use). The burden was highest among GT users (51% experienced a high burden). POCs were found to be the least burdensome equipment (29% experienced a high burden) and were most coveted by patients, to the point of being commonly used for its lifestyle benefits over meeting clinical needs. Importantly, nearly half of POC respondents reported using a POC despite it providing them with inadequate oxygenation, as it was perceived to be more convenient than alternative equipment.

Challenges with portable oxygen have been shown to hinder activities of daily living, exercise, socialization, work, and travel (7, 18). Portability (mainly weight) was raised as the highest priority for equipment improvements, with nearly half of respondents needing help to transport their portable oxygen equipment. Nonetheless, the overwhelming majority of POC users noted that the device contributed positively to their mobility and independence, highlighting the burden that patients will endure to maintain active lifestyles.

Time outside the home for portable LTOT patients is governed by the duration of oxygen provided by their equipment. Participants reported current equipment duration capabilities shorter than what is desired and needed to lead an active lifestyle, a finding consistent with those of previous investigations in which a majority of patients were unable to leave the home for more than 2 hours (7, 18). Improvements to the duration of oxygen supply were a top priority among GT users, with patients forced to ration their oxygen usage and transport additional GTs for longer duration outside of the home (18). Disease progression requiring higher oxygen flows further exacerbates the duration dilemma.

Nearly half of respondents reported using a POC despite knowing that their oxygen needs surpass what the equipment can provide to benefit from POCs' greater portability, lighter weight, rechargeable batteries, and ability to travel by air. The suboptimal nature of patient compliance with oxygen therapy has been briefly studied, initially linking the complex issue to factors that include patient education, clinical management of symptoms, and smoking cessation (19). However, little attention has been given to understanding the influence of oxygen equipment on adherence, which includes the influence of device characteristics and overall convenience. These results provide the new insight that equipment capabilities play a role in oxygen therapy compliance. With many patients choosing to underoxygenate to access more convenient equipment and with the ability to purchase a POC becoming mainstream, physician and durable medical equipment (DME) provider involvement in patient-product pairing is critical to meet clinical needs. The most highly rated U.S. Food and Drug Administration–approved continuous flow POC is currently rated at 3 L/min, with pulse flow and inspiration-synced POC systems claiming equivalencies up to 6 L/min (20). However, the true equivalence of pulse and inspiration-synced POCs is widely debated by patients and clinicians (4, 12, 21). This sentiment was echoed by respondents, with limited flow capabilities surfacing as a challenge and priority for POC innovation. Improved POC technology rooted in the patient perspective is needed to enable lifestyle goals while promoting proper clinical usage.

Although liquid oxygen is known for its extended supply duration and low noise profile, low Medicare reimbursement rates are phasing out the technology, provoking an outcry among high-flow patients. With the cost of LTs estimated as being four times higher than that of other portable oxygen systems (9), Medicare DME providers often prefer GTs over LTs because of the well-established infrastructure for management of GTs that minimizes logistical, equipment, and labor costs. Because the Centers for Medicare and Medicaid Services views oxygen equipment as modality neutral, few to no incentives exist for DME providers to supply more expensive equipment (11, 12, 18), leaving some patients with more burdensome equipment that does not meet their lifestyle needs. The official American Thoracic Society clinical practice guidelines on home oxygen therapy highlight the critical importance of access to LTs for patients needing greater than 3 L/min to reduce isolation from poor mobility and improve quality of life (9).

Sixty-three percent of respondents characterized their equipment as inconvenient, strenuous, or extremely strenuous to use, with a high burden characterized as strenuous or extremely strenuous reported by 38%. When compared across different clinical factors, women experienced a greater burden than men with POCs, which may be explained by differences in stature but does not explain why the impact of sex was not significantly different for heavier and bulkier equipment such as GTs and LTs. The impact of sex may be skewed by the omission of the sex qualifier in early iterations of the survey, warranting further investigation. Although there were different proportions of high-burden respondents across disease states, these differences were not found to be significant, suggesting that the burden caused by oxygen equipment is a widespread issue independent of the underlying respiratory condition.

Although POCs were found to be the least burdensome type of equipment, clear challenges remain with low flow rate capabilities and high cost. The majority of participants own a POC and are bypassing reimbursement for access to less-burdensome equipment when financially possible. The additional cost of POC supplies, including batteries, repairs, and transport cases, exacerbates the accessibility gap. Although advancements in oxygen technology (such as POCs) have led to improvements in mobility and independence, significant unmet needs remain with portability, oxygen flow delivery, supply duration, and accessibility to equipment to decrease the burden experienced by patients.

Limitations

Limitations to this study include a lack of generalizability, as respondents were a convenience sample of LTOT users who sought out online resources. The ability to participate in the survey may reflect greater healthcare access and socioeconomic status. There is a possibility for misinterpretation of the online survey questions as well as an inherent bias within patient self-reporting. Potential misinterpretation by patients of pulse versus continuous flow rates may influence flow rate trends. Objective weight measurements per device type were not obtained, limiting the accuracy of associations with a burden. The survey responses demonstrate an overrepresentation in PH and ILD populations compared with COPD disease prevalence, biasing responses toward

relevant disease trends; however, this study highlights previously understudied populations. As with prior research (7), the majority of respondents were women, which may not be representative of disease prevalence. Multiple hypothesis tests were performed, which potentially increases the risk for type 1 error. The low response rate to sex and burden questions may influence trends, warranting future research on the topic.

Implications and Future Work

This study highlights the burden and unmet needs with portable oxygen equipment and provides guidance for future innovation to improve the perceived burden and quality of life. Developing equipment to reduce the burden experienced by portable LTOT users as well as rethinking portable oxygen reimbursement policy are priorities. Future innovation should reflect the needs of the average portable LTOT patient: equipment lighter than 7 lb, oxygen duration longer than 3 hours, and continuous flow capabilities above 3 L/min. Research into oxygen titration behavior, the use of pulse oximetry, and patient understanding of oxygen therapy is also needed to provide more effective education and guidelines for oxygen management.

Conclusions

Although current portable oxygen equipment meets the clinical needs of some LTOT patients, burden and unmet needs clearly remain. Device portability, oxygen duration for GTs, access to LTs, and flow rate capabilities for POCs were identified as the most important and pressing challenges to address. In an era when oxygen equipment can be purchased with minimal clinical oversight, platforms to engage physicians and patients in oxygen education are critical to improve effective use of portable LTOT equipment and reduce the perceived burden. Moving forward, a collaboration among equipment manufacturers, equipment providers, payers, healthcare professionals, and patients will be required to promote device innovation and policy reform to meet the clinical and lifestyle needs of portable LTOT patients. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

Acknowledgment: The authors thank the U.S. COPD Coalition, the Pulmonary Fibrosis Foundation, and the Pulmonary Hypertension Association for input on survey development and distribution and thank the Center for Bioengineering Innovation and Design (Johns Hopkins University) for support in this research.

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