

Patient Perceptions of the Adequacy of Supplemental Oxygen Therapy

Results of the American Thoracic Society Nursing Assembly Oxygen Working Group Survey

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Abstract

Rationale: Pulmonary clinicians and patients anecdotally report barriers to home supplemental oxygen services including inadequate supply, unacceptable portable options, and equipment malfunction. Limited evidence exists to describe or quantify these problems.

Objectives: To describe the frequency and type of problems experienced by supplemental oxygen users in the United States.

Methods: The Patient Supplemental Oxygen Survey, a self-report questionnaire, was posted on the American Thoracic Society Public Advisory Roundtable and patient and health care–affiliated websites. Respondents were invited to complete the questionnaire, using targeted e-mail notifications. Data were analyzed using descriptive statistics, paired *t* tests, and χ^2 analysis.

Results: In total, 1,926 responses were analyzed. Most respondents reported using oxygen 24 h/d, for 1–5 years, and 31% used high flow with exertion. Oxygen use varied, with only 29% adjusting flow rates based on oximeter readings. The majority (65%) reported not having their oxygen saturation checked when equipment was delivered. Sources of instruction included the delivery person (64%), clinician (8%), and no instruction (10%). Approximately one-third reported feeling “very” or “somewhat” unprepared to operate their equipment.

Fifty-one percent of the patients reported oxygen problems, with the most frequent being equipment malfunction, lack of physically manageable portable systems, and lack of portable systems with high flow rates. Most respondents identified multiple problems (average, 3.6 ± 2.3 ; range, 1–12) in addition to limitations in activities outside the home because of inadequate portable oxygen systems (44%). Patients living in Competitive Bidding Program areas reported oxygen problems more often than those who did not (55% [389] vs. 45% [318]; $P = 0.025$). Differences in sample characteristics and oxygen problems were noted across diagnostic categories, with younger, dyspneic, high-flow users, and respondents who did not receive oxygen education, relating more oxygen problems. Respondents reporting oxygen problems also experienced increased health care resource utilization.

Conclusions: Supplemental oxygen users experience frequent and varied problems, particularly a lack of access to effective instruction and adequate portable systems. Initiatives by professional and patient organizations are needed to improve patient education, and to promote access to equipment and services tailored to each patient’s needs.

Keywords: dyspnea; quality of life; quality of health care; medical devices; mobility limitations

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More than 1 million Americans use home supplemental oxygen for a variety of lung conditions (1). National (1–6) and international (7) oxygen consensus conferences have proposed recommendations for prescribing and supplying oxygen, technology development, and patient education and support. However, limited data are available to quantify how well goals are being met from a patient perspective. Patient advocacy groups, health care professionals and patients report problems with equipment, services, reimbursement, and portable systems. Although supplemental oxygen is purported to help patients “continue with their social and professional lives” (8), patients report that current portable oxygen options relegate them to a “stay-at-home” lifestyle (9–12).

The socioeconomic and educational factors influencing supplemental oxygen services are complex. Increasing numbers of patients meet criteria for supplemental oxygen, a consequence of the large number of those diagnosed with chronic obstructive pulmonary disease (COPD) and other lung disorders (1, 13).

Oxygen is commonly provided as a benefit of the Center for Medicare and Medicaid Services (CMS), owing to the age and disability of recipients (14, 15). Consequently, CMS beneficiaries are affected by economic decisions from the federal Competitive Bidding Program (CBP) that determines reimbursement for their durable medical equipment (DME). CMS is required to solicit bids from licensed DME companies to provide equipment and supplies, including oxygen (16). The intent of the CPB is to reduce costs, ensure beneficiary access to quality services, and reduce beneficiary out-of-pocket expenses. CMS reviews submitted bids from DME companies, based on a complex formula, and awards contracts to those that meet quality and financial standards and offer the best price. Contracted suppliers must agree to accept assignment on claims and accept a single payment amount. The median of all winning bids for an item determines the amount (16). Results of this bidding process determine what services and equipment are available at each DME and are not uniform across providers. Most DMEs are moving to a cost-saving “nondelivery” model for home oxygen services, which excludes providing liquid oxygen.

In 2015, the American Thoracic Society (ATS) Nursing Assembly Planning

Committee addressed supplemental oxygen concerns. In 2016, the Nursing Assembly Oxygen Working Group (OWG) convened a multidisciplinary forum (*see* Figure E1 in the online supplement) to identify future initiatives. Five areas of concern emerged: 1) lack of data documenting oxygen users’ precise problems; 2) increased clinician time to complete CMS- and other payer-required documentation; 3) negative impact on supplemental oxygen users from decreased DME reimbursement; 4) gaps in oxygen education and training; and 5) absence of DME provider care standard metrics and quality measures.

This paper presents patient-reported data collected from supplemental oxygen users that identify the frequency and type of problems that they experience. Our goal was to seek perspectives of oxygen users as an initial step in improving delivery of this vital service.

Methods

The web-based Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (17) and E-Survey guidelines (18) directed the methodology for this analysis.

Design

This is a descriptive report of responses obtained using the “Patient Supplemental Oxygen Survey” (Figure E2), a voluntary self-report instrument. Respondents were a convenience sample of adults in the United States prescribed oxygen as a consequence of lung disease.

Survey Development

Content areas identified at the May 2016 ATS multidisciplinary meeting guided item development. Participants provided input from the perspective of multiple patient, advocacy, professional, and payer organizations. Three oxygen users participated throughout the process. ATS participants represented Nursing, Pulmonary Rehabilitation, Health Policy, Government Relations, and the Public Advisory Roundtable (PAR).

After this initial meeting, a draft paper survey was developed by the OWG chair (S.S.J.) and reviewed for content and item inclusion by five expert clinicians, each with more than 20 years of experience with oxygen-dependent patients. After revision,

the survey underwent a second review by the remaining OWG participants, and representatives from the U.S. COPD Coalition and American Lung Association (ALA). A consultant in psychometrics provided advice regarding format and structure.

The revised survey was piloted on paper in a third review by nine oxygen-dependent patients to assess question clarity and completion time. ATS staff then converted items into a SurveyMonkey electronic format. Five oxygen-dependent patients piloted online survey versions at two centers to confirm its usability and technical function, and minor changes were made.

The final online survey included 60 items, with a combination of multiple choice, Likert scale, and open-ended responses. Respondents were unable to “save” the survey to complete at another time, but could use a “back” button to review or change answers. The Stanford University Institutional Review Board approved the project with a waiver for informed consent. The first page included the purpose of the study, the length of the survey, the voluntary nature of completing items, and the investigator’s contact information. No health information was collected to identify respondents and no incentives were offered to respondents.

Survey Administration

The ATS Public Advisory Roundtable website posted the survey link from September 1, 2016 through October 24, 2016. Multiple pulmonary organizations placed the link on their websites, including the OWG, ALA, American Association of Cardiovascular and Pulmonary Rehabilitation, U.S. COPD Coalition, state societies, and the ATS web-based “Washington Bulletin.” Numerous clinicians provided flyers about the survey in their chest clinics, pulmonary rehabilitation (PR) programs, and support groups. Survey responses captured through SurveyMonkey were exported to SPSS. Response rate was determined by counting unique Internet provider addresses, with duplicates removed before analysis with the most recent entry used.

Statistical Analysis

Statistical analysis included descriptive summaries of categorical variables as frequencies and percentages, with χ^2 used to

test for significant differences. Standardized residuals of the associations tested by χ^2 analysis were used to assess the contribution of individual comparisons to the overall result. If multiple comparisons had residuals greater than the absolute value of 2, partitioned contingency tables were used to identify the comparisons with the greatest influence (19, 20). Continuous variables are reported as means and SD, with *t* test and ANOVA used to test for significant differences with Scheffé *post hoc* analysis used to identify where these differences occurred.

Results

Demographics

The final survey respondents ($n = 1,926$; Figure E3) 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 CBP area, 45% were unsure, and 11% lived in non-CBP areas. COPD (39%) and interstitial lung disease (ILD) (27%) were the most common diagnoses (Table 1). The majority were retired (47%) or disabled (41%), with only 23% working outside the home.

Respondents varied in time on oxygen, with most reporting usage from 1 year to more than 5 years and using oxygen 24 h/d. One-third of respondents used pulse or continuous flow rates equal to or exceeding 5 L/min during exertion. Dyspnea scores (modified Medical Research Council [mMRC]) were higher off than on oxygen (mean difference, 1.12; 95% confidence interval, 1.06–1.16). During the 12 months preceding the survey, 29% of respondents reported a hospital admission and 34% an emergency room visit.

Education

Most respondents (63%) had attended a PR program (Table 1) and 93% used pulse oximeters. Liter flow adjustment varied, with 35% using the prescribed flow, 22% adjusting flow based on “how short of breath she/he felt,” and 29% adjusted flow during exertion based on pulse oximeter readings. The majority (65%) related that they did not have their oxygen saturation checked when equipment was delivered to their home. Sources of instruction varied; the majority (64%) reported being trained by the delivery person. Only 8% were

Table 1. Sociodemographic characteristics, health utilization, and oxygen requirement of final cohort: $n = 1,926^*$

Characteristic	Total Sample (%)	Reported Problems (%)		
		Yes	No	P Value
Age, mean (SD), yr	64 (11)	63 (11)	65 (11)	<0.001
Female, %	72	54	46	0.001
Diagnosis, %				<0.001
COPD	39	44	56	
Interstitial lung disease	27	51	49	
Pulmonary hypertension	18	61	39	
Alpha-1 antitrypsin deficiency	8	60	40	
Lymphangiomyomatosis	4	70	30	
Other	5	55	45	
Employment, %				0.006
Retired	47	47	53	
Disabled	41	57	43	
Working full time	8	51	49	
Working part time	4	45	55	
Residence, %				0.04
Suburban	51	54	46	
Rural	28	46	54	
Urban	21	51	49	
Live in Competitive Bidding Area, %				0.02
Yes	44	55	45	
No	11	49	51	
Unsure	45	48	52	
Duration of oxygen use, %				<0.001
<1 yr	17	41	59	
1–5 yr	51	51	49	
>5 yr	32	57	43	
Oxygen requirement, %				0.006
Continuous (24 h/d)	60	54	46	
≥ 5 L/min exertion (pulse or cont)	31	56	44	0.004
Health care utilization, %				0.005
Hospital admission in past 12 mo	29	57	43	
Emergency room visit in past 12 mo	34	56	44	0.006
Education, %				0.17
Attended pulmonary rehab	63	53	47	
Education on home oxygen				0.000
Oxygen delivery personnel	64	51	49	
Health care personnel	8	43	57	
None	10	64	36	
mMRC dyspnea score, mean (SD)				0.28
Using oxygen	1.5 (1.2)	1.6 (1.2)	1.5 (1.2)	
Not using oxygen	2.6 (1.2)	2.7 (1.2)	2.5 (1.2)	<0.001

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; mMRC = modified Medical Research Council.

*Because of missing data, the number of respondents varies for some items.

trained by a clinician and 10% related they did not receive instruction (Table 1). Even after receiving instruction, 35% reported being either “very” or “somewhat” unprepared to operate equipment.

Respondents reporting “yes” to having oxygen problems more frequently lived in suburban areas (54%); had lymphangiomyomatosis (LAM; 70%), pulmonary arterial hypertension (PAH; 61%), alpha-1 antitrypsin disease (AATD; 60%), or ILD (51%); used oxygen longer (57% > 5 yr) and at higher flow rates (56% ≥ 5 L/min); had more frequent rates

of emergency room or hospital admissions during the past year (56 and 57%, respectively); reported higher dyspnea levels off of oxygen (mMRC, 2.7 vs. 2.5); and had not received oxygen education (64%). There was no difference in PR attendance rates between those groups reporting oxygen problems (53%) and those that did not (47%).

Equipment

Most respondents (80%) used a portable system outside the home, including portable oxygen concentrators (POCs) (33%), small

compressed gas tanks (20%), compressed gas “E” tanks (16%), compressed gas home-fill units (10%), and liquid oxygen home-fill units (13%). The type of portable system was not related to participants’ reports of problems with their oxygen systems (Table 2).

When leaving home, 44% used pulse settings and 26% used continuous flow, 16% switched between pulse and continuous, and 1% were unsure of their type of flow setting (13% did not use oxygen when leaving the house).

Of the 14% of respondents who were employed, 53% used oxygen at work, 29% did not need oxygen at work, and 18% responded that they should have but did not because of inadequate oxygen supply or concern for job security. The most common portable system used by those who worked was a POC (28%).

Mobility

Mobility was a concern; 38% reported being able to leave their home for up to 2 hours because of portable system capacity whereas 66% of respondents wanted their portable system to last 5–6 hours (Figure 1). Respondents reported their ability to travel (30%), socialize (22%), and keep their saturations at more than 90% (20%) was limited by their portable system.

Finances

Costs varied, with the majority (82%) citing a \$0–\$50/month copay (Table 2). Most respondents (60%) were unaware of copay amounts before receiving equipment. Numerous respondents reported paying out-of-pocket for equipment including POCs by 286 participants, batteries by 194 participants, and other items by 302 participants.

Problems Experienced

When asked “Have you ever had any type of problems related to your oxygen?,” 51% of respondents answered “yes.” Most respondents cited a wide range of problems, with an average of at least three or more problems per individual (average, 3.6 ± 2.3; range, 1–12) (Figure 2). The “biggest problem” identified by respondents was equipment malfunction (15%), lack of physically manageable portable systems (13%), and lack of a portable system that delivers high-enough flow (13%).

When asked what “one thing” they would change to improve their oxygen

Table 2. Experience using prescribed oxygen delivery system: *n* = 1,926*

Variable	Total Sample (%)	Reported Problems (%)		
		Yes	No	P Value
Type of portable oxygen system used				0.12
Portable oxygen concentrator	33	53	47	
Small compressed gas tanks	20	49	51	
Large “E” compressed gas tanks	16	52	48	
Liquid system	13	50	50	
Home fill system	13	62	38	
Length of time oxygen lasts away from home				0.060
About 1 h or less	11	59	41	
Up to 2 h	38	56	44	
Up to 4 h	32	49	51	
4–6 h	15	52	48	
More than 6 h	4	49	51	
Current portable system limits activities outside home				<0.001
Not at all	13	39 [†]	61 [†]	
Sometimes	35	52	48	
Frequently	23	57	43	
All the time	21	59 [†]	41 [†]	
Out-of-pocket oxygen copayment				<0.001
\$0	52	47 [†]	53 [†]	
\$1–\$50	31	53	47	
\$51–\$100	9	61 [†]	39 [†]	
\$101–\$200	5	66 [†]	34 [†]	
>\$200	3	54	46	

*Because of missing data, the number of respondents varies for some items.

[†]Cell significantly different (*P* < 0.05) as determined by examination of residuals and subpartitioning of χ^2 analysis.

experience, the most frequent response was “more portable tanks/supplies so I can leave home more frequently and for longer periods of time” (17%), followed by “providing a POC when I travel,” and “service/check equipment on a regular basis.” Almost one-half (40%) noted

waiting for servicing requests or supply deliveries. Most (70%) were unaware of a number or person to call to file a complaint about their oxygen problems. Patients living in a CBP area reported oxygen problems more often than those who did not (*P* = 0.025).

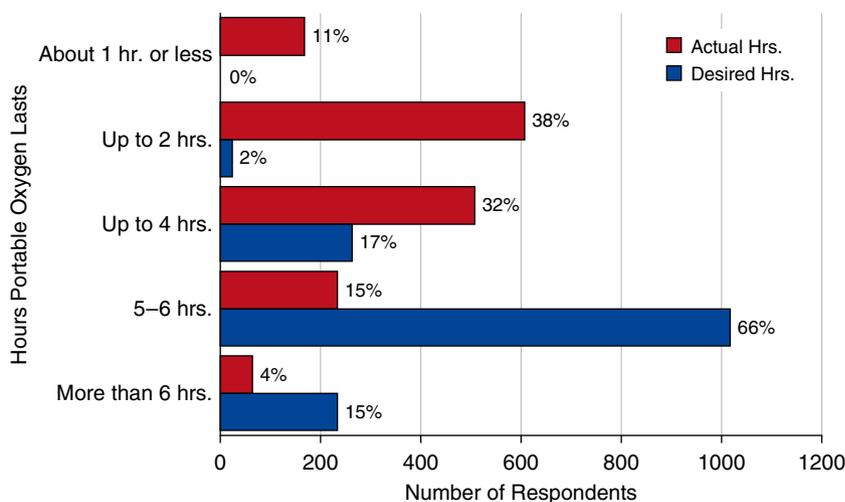


Figure 1. Actual versus desired hours that portable oxygen lasts.

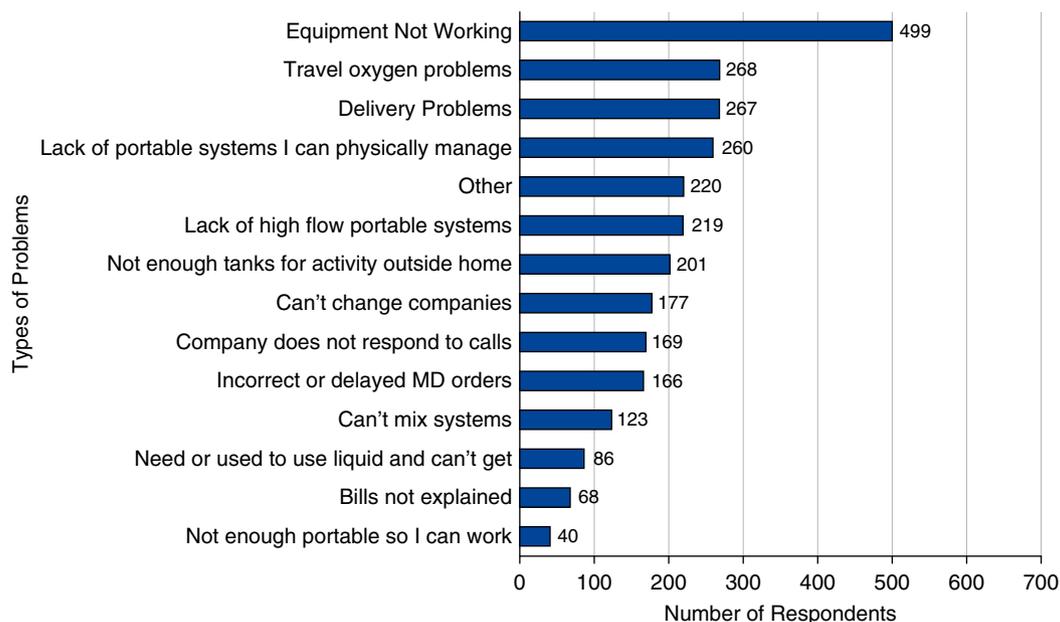


Figure 2. Frequency of types of oxygen problems reported by respondents who replied “yes” to having oxygen problems ($n = 899$; able to check more than one response).

The frequency of patients reporting “yes” to problems did not significantly ($P = 0.10$) vary by geographic location, with the reported rate of problems ranging from a high in the West of 56% to a low in the South Midwest of 43% (Figure 3 and Table E1).

Differences across Diagnostic Groups

There was no difference in self-reported hospital admission rates in the previous year across diagnostic groups, but self-reports of emergency room visit rates varied with COPD the highest (39%) and ILD the lowest (29%) ($P < 0.01$). There was no difference in the source of oxygen education between the diagnostic groups. Patients across all disease categories were equally affected in restrictions to mobility because of their portable oxygen equipment (Table 3).

Compared with other lung diseases, respondents with AATD lived in rural areas more often, and rarely used oxygen at settings equal to or greater than 5. Respondents with COPD had the highest rated dyspnea both on and off of oxygen and also had the most frequent emergency room admissions in the past year, in contrast to patients with ILD, who rarely received oxygen for more than 5 years, most frequently used oxygen at settings of 5 or higher, and had significantly lower frequency of emergency room use.

Respondents with LAM used high-flow oxygen, were younger, and more likely female, as were respondents with PAH. Respondents with AATD included the highest number using oxygen longer than 5 years.

The frequency of oxygen problems was significantly different across disease categories ($P < 0.01$); respondents with LAM reported the highest frequency (70%) and respondents with COPD the lowest (44%) (Table 1 and Figure 4).

Discussion

This survey is the first to elicit patient-reported experiences in a large cohort of supplemental oxygen users and reveals 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. Key themes revealed a focus on equipment function, portability, and adequacy of systems to support a mobile lifestyle. Respondents who were younger, more dyspneic, used high-flow oxygen, and received no oxygen education were more likely to report having oxygen problems.

Other patient advocacy groups have assessed oxygen problems in response to their oxygen-dependent constituents’ demands for action. The LAM Foundation surveyed 161 oxygen users in 2014. Of those, 33% reported problems obtaining oxygen (personal communication, LAM Foundation). The Pulmonary Hypertension Association surveyed 91 patients receiving supplemental oxygen and found that more than 60% experienced the following service problems: 25% waited more than 5 days for equipment to arrive, 42% had missing supplies, and more than 45% had misinformation or no support from the DME travel department (personal communication, Pulmonary Hypertension Association). The problems identified by respondents in this survey are consistent with those described in previous investigations (8, 21–23).

The impacted population of oxygen users is significant. Approximately 45–70% of patients with COPD use long-term oxygen therapy for 15 or more hours per day (24). A qualitative COPD study by Arnold and colleagues (21) explored factors comparable to those in our survey and identified 1) inappropriate equipment, 2) lack of individualized information and instruction from health care providers, 3) fear of “running out of oxygen,” 4)

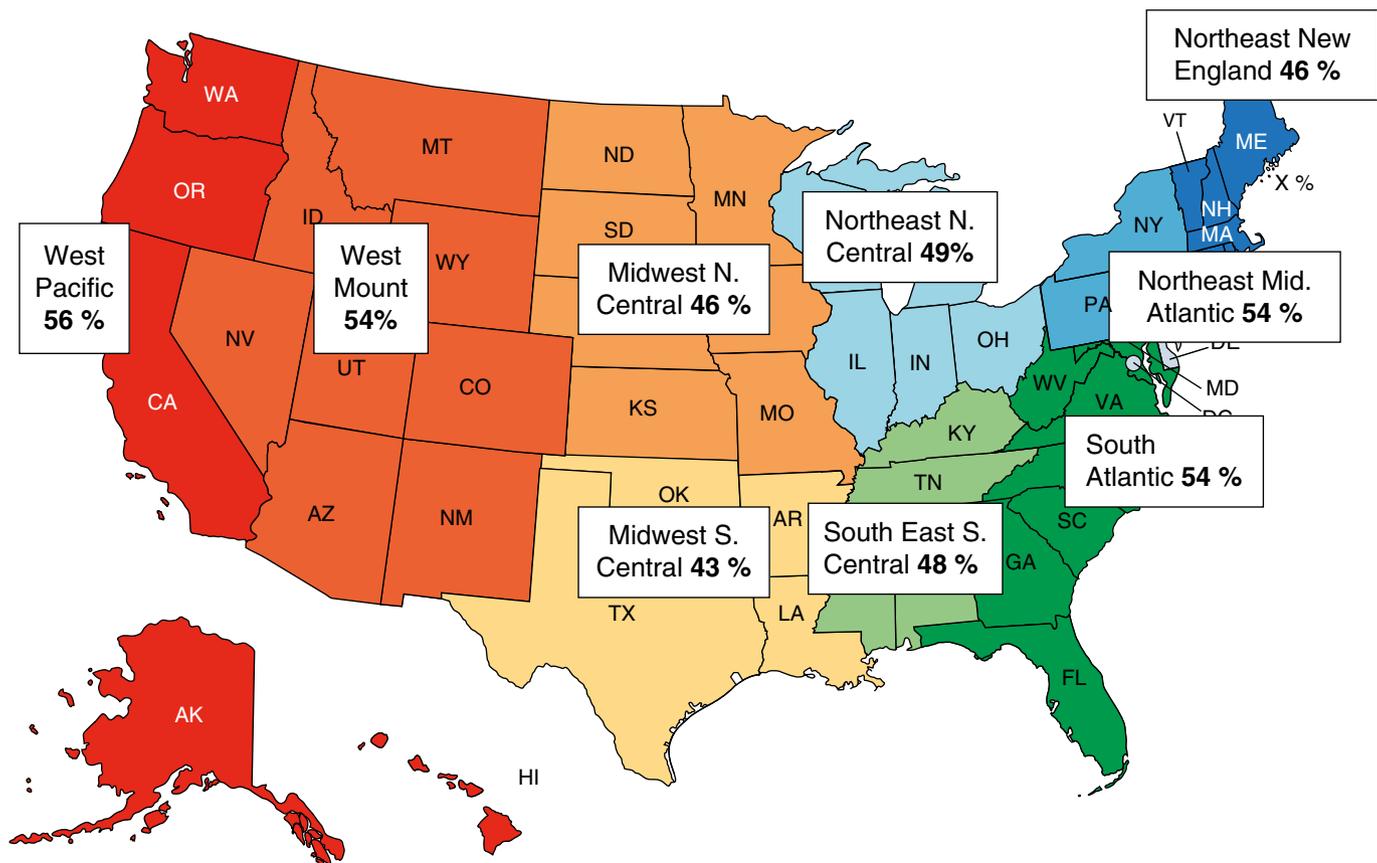


Figure 3. Percentage of respondents by region answering “yes” to having oxygen problems.

questioning or not experiencing the benefit of the intervention, and 5) not wanting to be seen with oxygen equipment in public. Issues of worry, physically unmanageable systems, machine breakdown, lack of instruction, and feeling “tethered” to stationary equipment were consistent with our results and those of others (22, 23). Informal caregivers report similar burdens of home oxygen use (25). In-depth interviews of five oxygen-dependent patients with ILD over a period of 12 months highlighted the need for “clearer expectations and trustworthy educational resources” (26).

Acuity level varied among these respondents, with 30% using high-flow oxygen. The perceived benefit of oxygen on dyspnea as measured by the mMRC was significant in this cohort, although one review found a range of effects of oxygen therapy on dyspnea at rest and during exercise in patients with ILD (27). The mMRC is a widely used scale that correlates well with other scales and health status

scores, and with clinical and pulmonary parameters (28). Objectively measured physical inactivity has been reported to be the strongest independent predictor of mortality in patients with COPD (29) and idiopathic pulmonary fibrosis (30). There is a strong relationship between the mMRC and physical activity levels in patients with COPD (31). Importantly, the level of dyspnea has a more significant effect on survival than disease severity based on FEV₁, and correlates with 5-year survival rates (32).

The combination of worse dyspnea when off oxygen with physically unmanageable portable systems contributed to respondent descriptions of substantial mobility limitations across all disease groups. Our analysis also confirmed that experiencing worse dyspnea off oxygen was associated with respondents reporting problems with their oxygen and greater use of health care resources (emergency room visits). Patients may have varied responses in terms of their perceived impact of oxygen

on their dyspnea (26). Considering many have few options, it should be evaluated on an individual basis.

In our survey, patients who received education from health care personnel were less likely to report oxygen problems compared with those educated by the delivery person or who received no education. The difference may be in the technical focus of instruction by the equipment delivery person compared with the clinical plus psychosocial approach by clinicians (“a conversation with the patient as a whole”) (8). Pépin and colleagues confirmed that instruction by a nurse or physiotherapist improved oxygen compliance in a cohort of patients with COPD (33). Katsenos and colleagues confirmed that lack of a clear oxygen prescription and instructions limited patient adherence in a cohort of patients with COPD (22), and other investigators note the importance of “managing expectations” for patients with ILD who have been newly prescribed oxygen

Table 3. Comparison of demographic characteristics and experience using prescribed oxygen delivery system by diagnostic group*

Characteristic	COPD	ILD	PAH	AATD	LAM	Other	P Value
No. of participants, <i>n</i> (%)	743 (39)	509 (26)	344 (18)	156 (8)	69 (4)	93 (5)	
Age, mean (SD), yr	67 (9) ³⁻⁶	66 (11) ³⁻⁵	60 (13) ^{1,2,5}	61 (9) ^{1,2,5}	55 (11) ^{1-4,6}	62 (12) ^{1,5}	<0.001
Female sex, <i>n</i> (%)	533 (72)	311 (61)*	300 (88)*	95 (61)*	69 (100)*	67 (72)	<0.001
Residence, <i>n</i> (%)							<0.003
Suburban	360 (49)	278 (55)	178 (52)	76 (49)	38 (56)	44 (48)	
Rural	225 (30)	122 (24)	89 (26)	54 (35)*	15 (22)	15 (17)*	
Urban	152 (21)	103 (21)	75 (22)	24 (16)*	15 (22)	32 (35)	
Duration of oxygen use, <i>n</i> (%)							<0.001
<1 yr	109 (15)	119 (24)	45 (14)	7 (5)	10 (15)	16 (19)	
1–5 yr	352 (48)	287 (59)	177 (54)	58 (40)*	32 (48)	40 (47)	
>5 yr	266 (37)	83 (17)*	106 (32)	80 (55)*	25 (37)	29 (34)	
Oxygen requirement, <i>n</i> (%)							
Continuous (24 h/d)	487 (66)*	298 (56)	191 (56)	94 (60)	22 (40)*	49 (53)	<0.001
≥5 L/min	133 (18)*	229 (47)*	103 (32)	48 (33)	29 (44)*	27 (33)	<0.001
mMRC score, mean (SD)							
Not using oxygen	2.8 (1.2) ^{3,5}	2.7 (1.2) ^{3,5}	2.2 (1.2) ^{1,2}	2.6 (1.2)	2.1 (1.2) ^{1,2}	2.4 (1.3)	<0.001
Using oxygen	1.7 (1.2) ^{2,3,5}	1.4 (1.2) ^{1,5}	1.3 (1.1) ¹	1.6 (1.2) ⁵	0.9 (1.0) ^{1,2,4,6}	1.6 (1.2)	<0.001
Health care use in 12 mo, <i>n</i> (%)							
Hospital admission	223 (31)	138 (29)	95 (29)	29 (20)	21 (30)	32 (37)	0.062
Emergency room	287 (39)	145 (29)*	107 (31)	47 (30)	23 (35)	30 (34)	<0.008
Pulmonary rehab, <i>n</i> (%)	476 (65)	345 (69)	159 (48)*	110 (71)	46 (67)	61 (66)	<0.001
Home oxygen education, <i>n</i> (%)							0.696
Oxygen delivery personnel	463 (64)	310 (63)	219 (67)	86 (60)	40 (60)	49 (57)	
Health care professional	56 (8)	36 (8)	29 (9)	10 (7)	3 (4)	8 (9)	
None	76 (10)	55 (11)	26 (8)	18 (12)	6 (9)	12 (14)	
Other	129 (18)	89 (18)	53 (16)	30 (21)	18 (27)	17 (20)	
Current system limits activities outside of home, <i>n</i> (%)							0.430
Not at all	92 (14)	56 (13)	42 (15)	16 (12)	8 (13)	8 (11)	
Sometimes	237 (37)	165 (38)	122 (45)	53 (39)	30 (48)	29 (40)	
Frequently	166 (26)	112 (26)	49 (18)	37 (27)	15 (24)	16 (22)	
All the time	149 (23)	105 (24)	59 (22)	29 (22)	9 (15)	19 (26)	

Definition of abbreviations: AATD = alpha-1 antitrypsin deficiency; COPD = chronic obstructive pulmonary disease; ILD = interstitial lung disease; LAM = lymphangioliomyomatosis; mMRC = modified Medical Research Council; PAH = pulmonary arterial hypertension.

*Cell significantly different ($P < 0.05$) as determined by examination of residuals and subpartitioning of χ^2 analysis, Scheffé *post hoc* ANOVA, analysis difference between group indicated as superscript: 1, COPD; 2, ILD; 3, PAH; 4, AATD; 5, LAM; 6, other.

(34, 35). Patients with COPD who did not have routine home follow-up by specialized staff have also been noted to experience worse survival rates than those who did (36). More recently, the training of patients using oxygen as peer oxygen educators is being investigated as another option to support home oxygen users (37), as well as utilizing respiratory care professionals to improve hospital discharge oxygen education for patients with COPD (38).

Completing a PR program did not make a difference in experiencing oxygen problems, which highlights the persistence of oxygen issues despite receiving education on indications for oxygen, use with exercise, and monitoring in a PR setting. Further investigation is needed to determine whether equipment problems reflect reimbursement constraints experienced by DME oxygen suppliers as opposed to patient education. Only one-third of respondents

titrated their oxygen in accordance with their saturations—a surprising finding given the high PR attendance rate.

In this cohort, 65% of respondents did not have their oxygen saturations tested on their delivered equipment. Recent reimbursement reductions to DME providers preclude using licensed respiratory care practitioners in the home. Assessment of exertional hypoxemia on pulse systems rarely occurs in the clinic setting because exercise oximetry is usually done using continuous flow, but portable units usually use pulse flow.

Most noteworthy is that one-half of respondents reported problems with their oxygen; with an estimated 1–1.5 million U.S. oxygen users the potential impact is enormous. The top three issues cited include equipment not working, lack of physically manageable portable systems, and lack of high-flow portable systems. The

issues revolving around equipment service from oxygen suppliers were described in free-text response options including wait times, equipment malfunction, being “stuck” in contracts, incorrect billing, and the inability to “mix” types of oxygen systems. Patients were unclear about equipment and service standards. Although most patients reported that their problem was eventually resolved, 70% of patients were unaware of the Medicare Ombudsman or COPD Information Line to report unresolved problems.

The restrictions on patients being able to be away from their home for more than 2–4 hours were substantial. These respondents listed having more portable systems to leave the house or travel for longer periods of time as the “one thing” they would change to improve their oxygen experience. CMS guidelines currently are entitled “Home Oxygen,” but these results

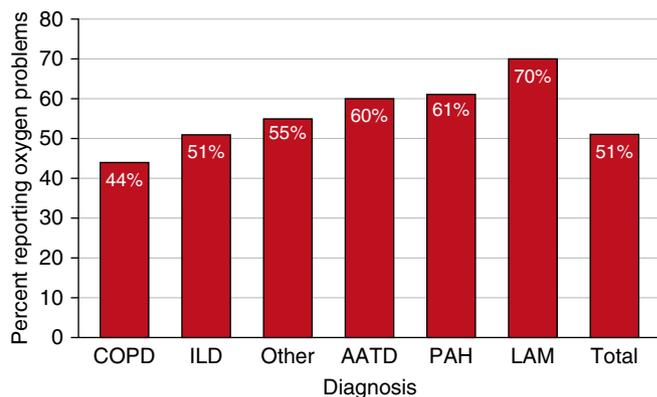


Figure 4. Percentage of respondents reporting oxygen problems according to diagnosis ($n = 887$ respondents who checked “yes” to having oxygen problems). AATD = alpha-1 antitrypsin disease; COPD = chronic obstructive pulmonary disease; ILD = interstitial lung disease; LAM = lymphangioleiomyomatosis; Other = infection, lung cancer, congestive heart failure, post lung transplantation, other; PAH = pulmonary arterial hypertension.

confirm that the majority of this cohort of supplemental oxygen users prioritizes the ability to be out of the home.

Problems related to oxygen were more frequently reported by women, those using oxygen for longer lengths of time, and those who experienced more breathlessness without their oxygen. Duration of therapy and symptom severity intuitively identify an oxygen user at risk for problems; the impact of sex needs to be tested in a sample with a larger male population. Respondents with LAM, PAH, and AATD had the highest rate of reporting problems, suggesting the need to identify ways to better meet the mobility needs of these individuals.

Future Directions

The complexity of optimizing supplemental oxygen for our patients is clear; there are issues of education, adherence, equipment, benefit, reimbursement, service quality, and clinician compliance. As health care professionals we can improve the oxygen prescription process, educate patients, and monitor treatment responses. However, if reimbursement constraints continue to impact oxygen suppliers, patients’ access to adequate portable oxygen systems will continue to be affected. The disappearance of liquid oxygen, the inability to provide adequate portable systems, and the limitations on extra tanks and batteries inhibit patients’ mobility, exercise, socialization, travel, and work.

After the first full year of implementation of the CBP, CMS reported no change in beneficiary health status outcomes. Although isolation and inactivity

are not generally measured health outcomes, they are clearly documented by this survey’s results as a negative impact from limited current portable oxygen options. Data exist that poor adherence to prescribed oxygen is associated with higher use of health care resources (39). Less clear, yet important, is that patients with hypoxemic lung disease may experience frailty and fatigue that challenges their ability to navigate the CMS complaints process and advocate for their needs.

There were suggestions of differences in respondent experience that support the need for studies designed to elicit problems influenced by diagnosis. Respondents with COPD reported a greater number of emergency room visits in the previous year and the highest dyspnea levels when off of oxygen, despite being the group reporting the lowest rate of “yes” to having problems with oxygen. Patients with ILD and LAM reported more frequent problems meeting their high oxygen flow needs.

Limitations

Findings of this survey describe the experience of a large cohort of oxygen users from all geographic regions of the United States. However, our respondents were a convenience sample of English-speaking oxygen users who responded voluntarily to an online survey, needed access to a computer, and may not represent the general population of oxygen users. Providing a paper option may have captured a wider spectrum of oxygen users. Most respondents stated they used pulse oximeters and an unusually high number

attended a PR program and, therefore, may have had stronger motivation for mobility outside the home. There was also a predominance of women; it is unknown whether (or how) sex influences responses.

Improved survey instructions might have decreased duplicate responses. Wording of some questions may not have provided enough options for patients, a limitation evident from the multiple responses received when “other” was offered as a free text option. Ethnicity and income levels were not assessed and may have provided important oxygen access variables. Selection bias therefore limits the generalizability of these results to all oxygen users.

Conclusions

More than one-half of supplemental oxygen users in this study experienced numerous and varied problems, with the overarching theme being one of restricted mobility and isolation. Equipment malfunction, lack of patient testing and education, and economic constraints were common. The need for high-flow and physically manageable portable oxygen systems to support mobility is a priority that professional societies, patient organizations, and durable medical equipment companies should urgently address. ■

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