

Patient Oxygen Therapy Survey

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(Original data collected in 2002)
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Introduction

Long Term Oxygen Therapy (LTOT) is growing in the US. New oxygen systems are being developed to meet the needs of a younger and more mobile patient. There is currently limited data on patient needs, applications and use of existing oxygen systems, which makes improvement of LTOT difficult for manufacturers, providers and clinicians.

Valley Inspired Products developed a patient questionnaire to solicit feedback from patients on their use and needs related to LTOT. Responses were solicited via the internet and through a patient newsletter.

The patient who would respond to this survey is on the higher end of the knowledge range for LTOT patients. The respondents may be motivated to learn about their disease, search the internet, attend meetings related to LTOT and/or network with other patients. Currently, this type of patient is in the minority of LTOT patients in the US. It is expected however, that this level of knowledge will be more typical in the future, as patients coming into the system have greater access to information via the internet.

There is no doubt that some of the answers are not representative of the majority of oxygen patient's experience. Those related to the type of equipment used, etc. may be greatly affected by the knowledge level of the patient. Other questions, such as those about patient mobility and provider services are likely to be better representative, as they would not be as affected by the patient's access to information.

Methods

A survey form was constructed with 19 questions regarding oxygen equipment, lifestyle and therapy. Additionally, patients were asked to provide their zip code and were given space to write comments.

The survey was publicized via several internet based patient 'list servers' and web sites. The survey was also circulated with a patient newsletter.

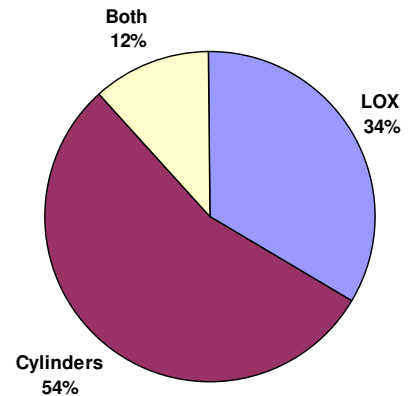
The results given in this summary were collected between June and December 2002. Duplicates were culled by matching similar responses from like zip codes. 413 valid responses were obtained from the internet and 82 from the newsletter. Full text of the survey is in appendix 1. Newsletter generated responses were kept separate from the internet responses. Unless otherwise noted, results shown are for internet responses only.

Results

What type of portable oxygen system do you use?

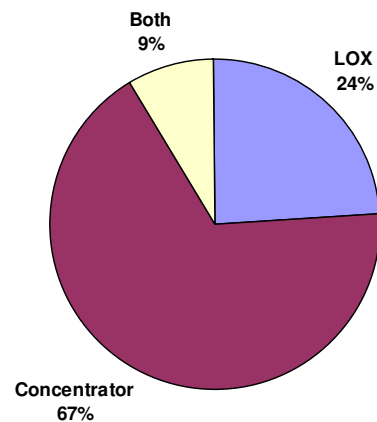
46% of respondents use a liquid oxygen (LOX) system or both LOX and cylinders. This is significantly higher than government and industry estimates (10-30%) and is likely a result of this population's education on options for oxygen equipment. 90 respondents said they use the 'Helios' portable (22%).

In the newsletter group, the 'LOX or both' portion was higher, 63%.



What type of stationary oxygen system do you use?

50% of patients using LOX for portable oxygen used a concentrator for stationary oxygen. This is termed a "Combo" or "Low-Loss" system.



Do you use an oxygen conserving device?

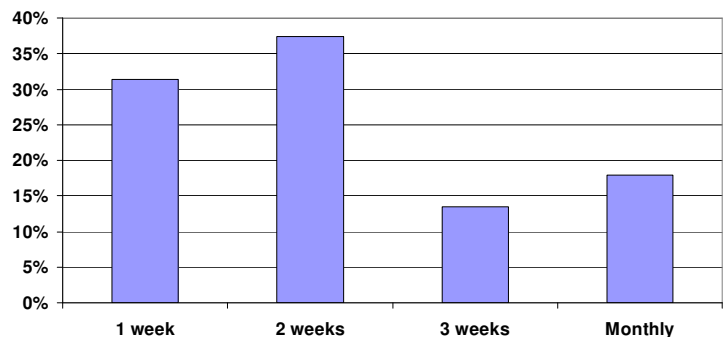
70% responded 'yes'

If you use cylinders, how many does your supplier deliver per week?

Median – 7.0 (standard deviation 6.2)

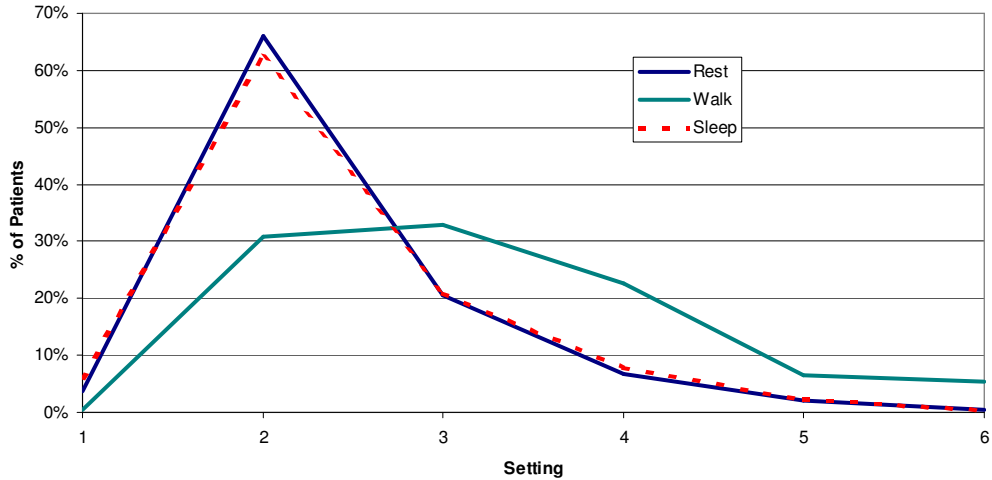
22% of respondents said that they get as many as needed.

How often does your supplier make deliveries?



What is your oxygen setting (for rest, exercise, sleep)?

Many patients reported a range of settings for a given activity. For purposes of this analysis, the maximum in the range was used. Setting number is somewhat misleading since flow settings are not necessarily equivalent between various delivery methods and devices.



Average (standard deviation) of numerical settings

Activity	Internet	Newsletter
Rest	2.4 (0.9)	2.3 (1.5)
Walk	3.3 (1.5)	2.9 (1.8)
Sleep	2.4 (0.9)	2.3 (1.7)

66% of internet patients reported a different setting for walking than rest vs 57% of newsletter respondents.

20% of patients reported a different setting for sleep than rest.

<i>Who prescribes your oxygen?</i>	Pulmonologist	74%
	General Practitioner	22%
	Other	4%

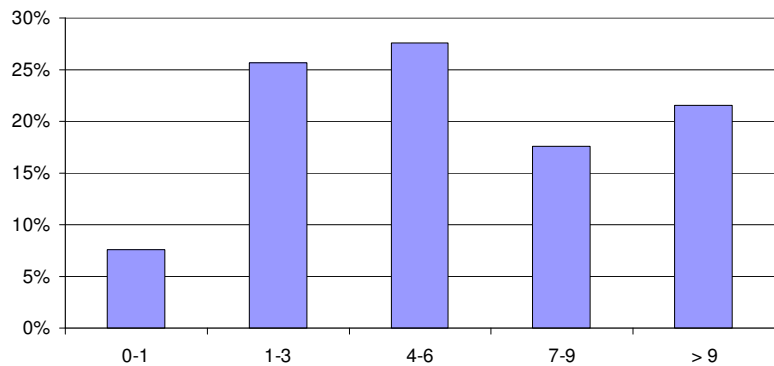
Do you use a personal oximeter?

Internet 61%
 Newsletter 20%

This is a response that might be very dependent on the high education level of the population. Patients discuss oximeters frequently on the internet lists.

How many times per week do you leave the house?

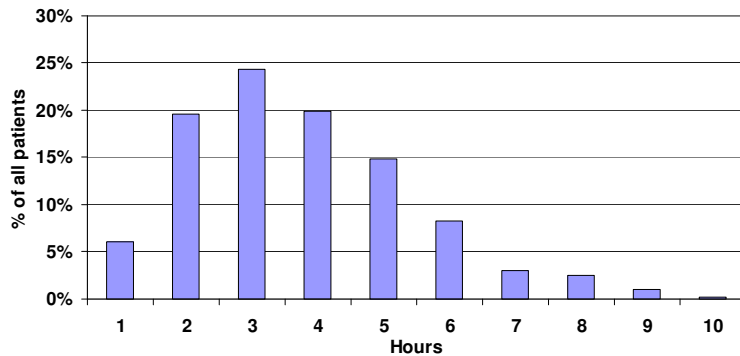
Average - 5.5 times per week



When you leave the house, how long are you gone?

If a range was given, the median number was used for analysis.

Average - 3.9 hours
 (standard deviation 1.7 hours)



How often do you leave the house more than once in a day?

65% responded at least once per week
 Average of those responding at least once per week:
 3.7 times per week (standard deviation 2.2)

There was a trend for patients using liquid oxygen to be gone longer and leave more often. In the table below, 'median duration' refers to a data set using the median duration when a range was given. 'max duration' means that the maximum was used.

	Cylinders	LOX	Difference
Trips per week	5.2	5.8	12%
Median Duration	3.69	4.05	10%
Max Duration *	4.52	5.13	13%

* statistically significant via t-test at $p < .05$

These differences may reflect the increased mobility offered by LOX, or the tendency of oxygen providers to utilize LOX for their more active patients.

Would you like to get out of the house more?

72% responded 'yes'.

Reasons checked for not being as mobile as one would like:

Portable doesn't last long enough	38%
Portable is too heavy	47%
I don't get enough cylinders	3%

Percent of respondents checking 'portable is too heavy':

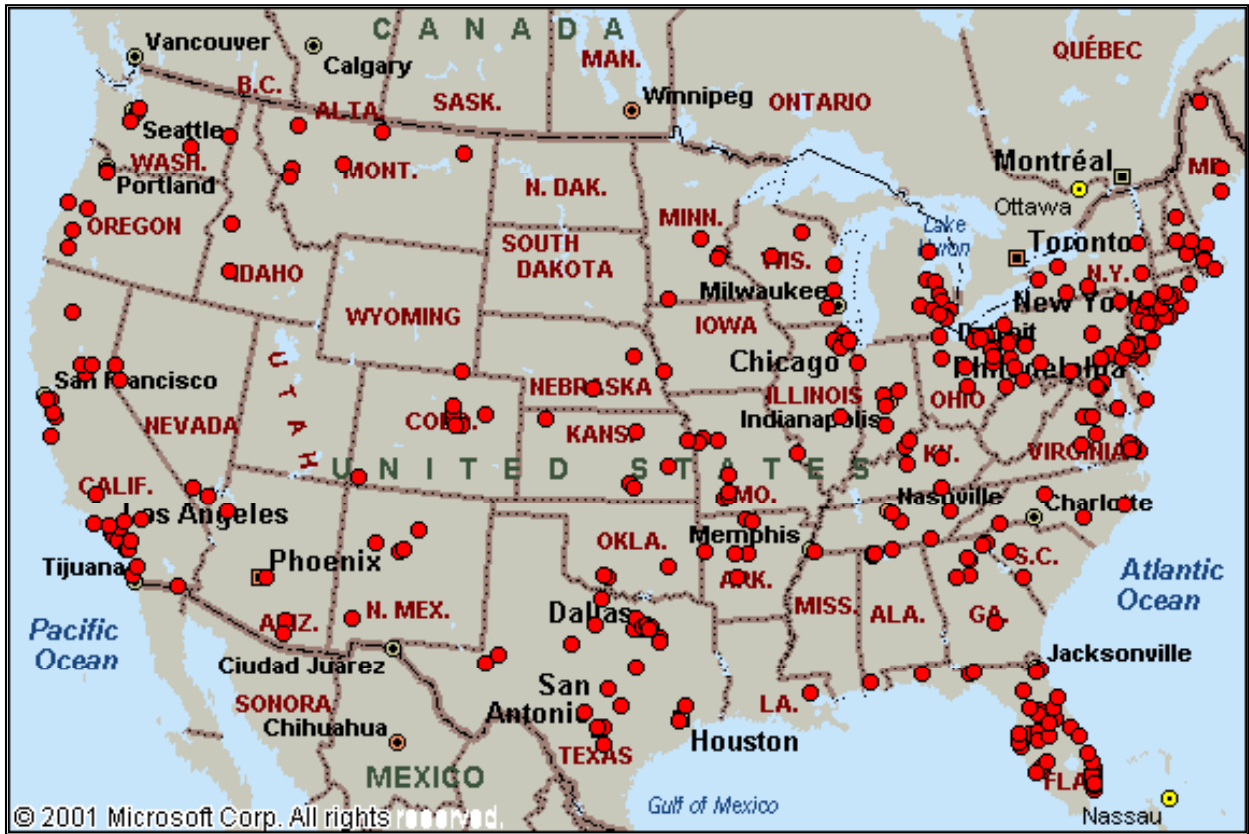
- Helios (4 lb) users 20%
- All cylinder users 59%
- All liquid portable users 29%
- Conserving device users 44%
- Non-conserving device users 53%

How many times per year do you travel with your oxygen?

57% stated that they travel some.

Average of those who travel = 4.0 times per year (standard deviation 5.6)

Distribution of zip codes from the internet responses. 90% of responses included a zip code. Newsletter responses were almost all from the Minneapolis/St. Paul MN area.



The authors wish to thank the patients and groups that contributed to this study:

EFFORTS – www.emphysema.net

COPD List – www.copd-support.com

COPD Alert – www.copd-alert.com

Portable Oxygen: A User's Perspective - www.portableoxygen.org

The American Lung Associate of Minnesota

Appendix 1

Oxygen Therapy Survey

For patients currently receiving long term oxygen therapy.

This research is being conducted by Valley Inspired Products to help educate manufacturers, clinicians and providers about the nature of oxygen therapy. Please respond only once. All individual responses will be confidential, and we are not collecting any identifying information.

1. What type of portable oxygen system do you use? Liquid Cylinders Both
2. What type of stationary oxygen system do you use? Liquid Concentrator Both
3. Do you use an oxygen conserving device? Note: Any system that gives you oxygen only when you take a breath counts. Yes No
4. What is the model of your portable oxygen device?
5. If you use cylinders for portable oxygen, how many cylinders does your supplier deliver?
6. How often does your supplier make a delivery?
1-week 2-weeks 3-weeks monthly
7. How often do you leave the house?
0-1 per week 1-3 per week 4-6 per week 7-9 per week 10 or more
8. If you leave the house more than once per day, how many days per week do you do this?
9. When you leave the house, how many hours are you generally gone?
10. Would you like to get out of the house more?

If so, is your oxygen limiting you by:
Not lasting long enough
Not getting enough cylinders
Being too heavy
- 11 How many times per year do you travel with your oxygen?
12. Do you use a personal pulse oximeter? Yes No
13. What is your oxygen setting for rest?
14. What is your oxygen setting for walking?
15. What is your oxygen setting for sleeping?
16. Who prescribes your oxygen?
General Practitioner
Pulmonologist
Other
17. Please enter your zip code or country if outside the USA.
18. Comments: