

Explaining Adherence to Supplemental Oxygen Therapy

The Patient's Perspective

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OBJECTIVES: To describe and explain the patterns of adherence to supplemental oxygen in individuals with hypoxemic chronic obstructive pulmonary disease (COPD).

DESIGN: Qualitative study of a case-series of patients with COPD who use supplemental oxygen.

SETTING: Denver, Colorado.

PARTICIPANTS: Community-dwelling, English speaking individuals with hypoxemic COPD receiving long-term supplemental oxygen therapy.

MEASUREMENTS: Forced expiratory lung volume, in liters, at one second (FEV1), the St. George's Respiratory Questionnaire, Brief Symptom Inventory, semistructured investigator-administered interviews.

RESULTS: Respondents from a demographically representative sample with moderate to severe COPD (average age, 69; average FEV1, 1.1) described 3 distinct patterns of adherence to supplemental oxygen therapy: as-needed use, part-time use, and full-time use. For many individuals, the pattern of adherence changed with time and reflected their struggle to optimally manage their health, symptoms, physical function, and social milieu. Adherence to oxygen tended to increase with time and was often associated with significant personal compromises.

CONCLUSION: Adhering to oxygen therapy is a complex and difficult task with many barriers, including the physical difficulty of using the oxygen, self-consciousness and a sense of social stigma, lack of perceived benefit, and fear of deleterious side effects from treatment. Improving adherence may involve understanding the process of adapting to oxygen use and addressing the many barriers to therapy.

KEY WORDS: COPD; supplemental oxygen therapy; adherence; quality of life.

J GEN INTERN MED 2002;17:749-755.

Supplemental oxygen therapy offers many benefits in the treatment of hypoxemic chronic obstructive pulmonary disease (COPD). Supplemental oxygen therapy reduces mortality,¹ improves self-reported sleep quality and general comfort,² increases exercise tolerance,²⁻⁵ reduces polycythemia and pulmonary hypertension,⁶ normalizes EEG patterns,⁷ and improves cognitive function⁸ and certain measures of neuropsychiatric function such as

memory, intelligence, motor skills, abstraction, and perceptual motor ability.⁹

Despite the many physiological benefits of supplemental oxygen therapy, efforts to demonstrate a benefit in subjective quality of life have been disappointing. The only prospective study examining quality of life as a function of supplemental oxygen therapy failed to show a benefit.⁹ Furthermore, adherence to oxygen therapy is low—55% when measured using indirect indices¹⁰ and below 40% when more direct measures are used.¹¹ This lack of adherence further suggests that patients may not strongly perceive the benefits that researchers have described.

Some of the negative impacts of oxygen therapy may help explain this apparent paradox. Oxygen equipment can be heavy, bulky, and cumbersome. Nasally administered oxygen can cause some loss of taste and smell^{12,13} and can have unpleasant cosmetic effects.^{13,14} Nevertheless, no literature exists describing patients' rationale for their level of adherence or their process of adapting to supplemental oxygen therapy. Improving adherence to oxygen therapy and minimizing the negative impacts of the therapy require understanding the subjective experience of the therapy. The goal of this study is to describe and explain the patterns of adherence to supplemental oxygen therapy.

METHODS

A total of 27 participants were enrolled in the study. The first 7 participated in a pilot study. Six of the seven were recruited from the waiting area of the pulmonary clinic at National Jewish Medical and Research Center in Denver Colorado, a referral center specializing in pulmonary medicine. One participant was referred to the principal investigator by her primary physician. The participation of these 7 was limited to a semistructured interview.

The remaining 20 participants were recruited through their oxygen supply company. Potential participants were contacted initially by their oxygen supplier, who queried their interest in participating in a study about quality of life and oxygen use. The phone numbers of those interested were given to the principal investigator. A total of 140 phone numbers were collected. The company did not tabulate the total number of clients contacted in this manner, so the denominator cannot be determined.

The study protocol was approved by the Colorado Multiple Institutional Review Board. The principal investigator contacted all prospective participants by phone. Each participant underwent a brief phone interview to determine suitability for inclusion in the study. Respondents were excluded if they did not carry the diagnosis of "COPD" or "emphysema," if they did not speak English, if they had been hospitalized in the 3 months prior to the

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interview, or if they did not have an active prescription for supplemental oxygen. Each was offered \$30 for their participation.

Purposive sampling was employed in selecting subjects from the list in order to ensure an equal distribution of men and women. Forty-nine potential participants were contacted. Seventeen (37%) were excluded because they did not have COPD. One individual did not speak English. Eleven individuals (22%) declined to participate. Of the remaining 91 numbers on the list, 58 were never called and 33 numbers were called but the caller was unable to reach the potential subject. Ultimately twenty participants were enrolled. Nineteen were interviewed in their homes. One participant, at his request, was interviewed in the office of the principal investigator.

Prior to the interview, each respondent received 2 instruments by mail, the Brief Symptom Inventory (BSI) and the St. George's Respiratory Questionnaire (SGRQ). These instruments were included to provide a description of the disease severity (SGRQ) and psychiatric status (BSI) of the sample.

The BSI is a 53-item self-report symptom inventory designed to reflect the psychological symptom patterns of psychiatric and medical patients. The instrument is graded on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"), with higher score indicating greater severity of symptoms. It is scored on 9 symptom dimensions, but only 3 were relevant to this study: somatization, depression, and anxiety.¹⁵ Respondent scores were bundled, and the group was compared to non-ill community norms and norms for a psychiatric outpatient population.

The SGRQ is a 76-item, self-administered instrument. It was designed to "quantify the impact of diseases of chronic airflow limitation on health and well-being and to be sufficiently sensitive to respond to changes in disease activity."¹⁶ Scores are tabulated into 3 components: symptoms, activity, and impacts; a summary total score is also calculated. SGRQ scores correlate highly with a number of measures of disease activity including forced expiratory lung volume, in liters, at 1 second (FEV1) and forced vital capacity, cough, sputum production, frequency of wheezing, dyspnea grade, anxiety, depression, and negatively with 6-minute walking distance.¹⁶ Participants in this study used the American Syntax version.¹⁷ SGRQ total scores were interpreted relative to the study by Ferrar et al. comparing SGRQ to the 1995 American Thoracic Society (ATS) statement on diagnosis and care of patients with COPD. This ATS guideline divided COPD into 3 stages based on FEV1. Ferrar et al., in turn, correlated these stages with SGRQ score.¹⁸ Stage I, the mildest stage of COPD, defined as an FEV1 >49% predicted, had a mean total SGRQ score of 34. Stage II, defined as an FEV1 35% to 49% predicted, had a mean SGRQ of 42. Stage III, the most severe, defined by FEV1 <35% predicted, had a mean SGRQ of 55.

As a basic measure of pulmonary function, each participant had an FEV1 measured at the time of the interview using the ENACT AirWatch device, a hand-held

digital device capable of measuring FEV1 with a high degree of accuracy.¹⁹

Each participant also participated in a semistructured interview of 30 to 60 minutes in duration. During the interview, participants were queried about their diagnosis, the circumstances of their oxygen prescription, their patterns of oxygen use, perceptions of efficacy, beliefs regarding oxygen and their illness, and their experiences with oxygen at home and in social environments.

ANALYSIS

Interviews were taped and transcribed. Transcriptions were proofed against the audiotape by the interviewer, who corrected any discrepancies. The transcriptions of 4 interviews were lost by the transcription service. In these 4 cases, the interviewer's field notes were used for thematic analysis.

Data collection and analysis occurred in 2 distinct phases. The first 7 participants were part of a pilot study. Using methods informed by grounded theory, the principal investigator interviewed each participant and performed a preliminary analysis of each transcript once it was completed. This preliminary analysis informed the next round of data collection as the semistructured interview was modified to better explore emerging themes. Once the pilot interviews were complete, the principal investigator and a group of 6 qualitative researchers analyzed and coded these interviews independently. The group then met and discussed the coding schema. Disagreements were resolved through discussion until consensus was reached in each case. The basic themes and codes identified in this process informed the interview structure, the analytical framework, and the study design of the second phase.

The second phase of analysis involved 20 subjects. Again, the principal investigator performed a preliminary analysis of each interview after it was completed, and adapted the interview structure to explore themes as they emerged. Data analysis during this phase was performed using the Atlas.ti software program (version 4.1, Scientific Software Development, Berlin). Several iterations of formal coding and analysis were performed both during and after the data collection. During this phase, the principal investigator met regularly with a senior anthropologist to review and critique the emerging analysis. Disagreements were resolved by consensus.

Sample size was determined, not by number, but by theoretical saturation. At the point at which several consecutive new participants failed to contribute either any new themes, or to challenge any existing themes, recruitment was stopped.

Several additional steps were employed to ensure the trustworthiness of the results. When the analysis was completed, 2 participants were given a 50-page document describing in detail the results of the study, including the textual data from which the conclusions were obtained. They were asked to read the document and answer 2

questions: "Does this document describe your experiences with using oxygen?" and "Does the document accurately interpret the quotes that are included?" Both participants responded "yes" to both questions, and while they both offered additional personal anecdotes, they did not offer any additional critiques or concerns. Three independent physician reviewers reviewed the same document to see if the results appeared valid relative to their experience as clinicians with patients who used oxygen and to see if the interpretation of the textual data appeared valid relative to the text itself. The 3 reviewers included a psychiatrist with training in medical humanities, an internist with experience in qualitative methods, and a pulmonologist with 40 years of experience in treating patients with COPD and studying the effects of supplemental oxygen. Each felt the results of the analysis were consistent with their clinical experience and reflected an accurate interpretation of the supporting textual data.

The process of analysis was consistent with the guidelines published in the *Journal of the American Medical Association* for ensuring valid results in a qualitative study.²⁰

RESULTS

The demographics of the study sample are shown in Table 1. One subject (female, age 73) failed to complete the SGRQ and the BSI and another (male, age 58) failed to complete the BSI. Neither responded to follow-up phone requests to complete the instruments.

By spirometry and SGRQ, the sample largely consisted of individuals with moderate to severe COPD (Table 1).

Eighteen participants completed the BSI. In the dimension of somatization, the study sample differed significantly from a non-ill community norm but not from an outpatient psychiatric population. Both depression and anxiety symptoms were higher than the non-ill community norm but lower than in the outpatient psychiatric population (Table 2).

Patterns of Oxygen Use

While 3 subjects were initially prescribed only nocturnal oxygen, at the time of their interview, all subjects had been prescribed continuous oxygen. Despite their doctors' prescription, only 4 reported initially using oxygen continuously when it was so prescribed.

Respondents described 3 distinct patterns of adherence to oxygen use: part-time, full-time, and as-needed use. Once adopted, these patterns were not fixed, but changed as each individual perceived their needs to change. Most individuals described some time in their illness careers when they employed at least 2 of these patterns. Because of the evolving nature of the qualitative data collection during the study, and because 4 tapes were lost and not transcribed, it was not possible to assign a precise description of every respondent's pattern of use over time.

Table 1. Description of Study Sample

	N = 27	Standard Deviation	Range
Male, n (%)	13 (48)		
Ethnicity, n (%)			
White	24 (88)		
African American	3 (11)		
Mean age, y	69	9.62	56 to 94
Marital status, n (%)			
Married	14 (52)		
Equipment, n (%)			
Compressed portable	4 (15)		
Liquid portable	15 (56)		
Unknown	8 (30)		
Has seen a pulmonologist, n (%)	17 (63)		
Participated in rehab, n (%)	10 (37)		
Education, n (%)			
College graduate	3 (11)		
Some college	5 (19)		
High school or less	10 (37)		
Unknown	7 (26)		
Mean FEV1*	1.11	0.61	0.3 to 2.58
SGRQ* and ATS disease stage, n (%)			
>Mean SGRQ score for stage III—severe	13 (68)		
>Mean SGRQ score for stage II, ≤mean SGRQ score for stage III—moderate to severe	2 (11)		
>Mean SGRQ score for stage I, ≤mean SGRQ score for stage II—mild to moderate	2 (11)		
<Mean SGRQ score for stage I—mild	2 (11)		

* Only 19 participants had spirometry and SGRQ measures. FEV1, forced expiratory lung volume, in liters, at 1 second; SGRQ, St. George's Respiratory Questionnaire; ATS, American Thoracic Society.

Part-time Oxygen Use. Eight study participants described their current pattern of oxygen use as part-time, and an additional 8 subjects described part-time use at some point in the past. These individuals described making categorical decisions regarding when to use or not use their oxygen. Usually this involved omitting oxygen under specific circumstances. For example, while all respondents used oxygen for part of the day in their homes, part-time oxygen users often did not use oxygen for specific activities outside the home. Activities where oxygen was omitted included attending church, dining out, shopping, going to the movies or the theater, going to work, and attending certain social occasions. Even though these individuals omitted oxygen in these circumstances, most part-time users kept an oxygen source nearby for a backup in case they felt they needed it. Usually the backup was kept in the car.

As-needed Oxygen Use. Three subjects described a period of as-needed oxygen use. As-needed oxygen-users used oxygen for symptom relief. For these individuals, oxygen

Table 2. Selected Measures from the Brief Symptom Inventory (BSI)

	Sample (N = 18)	Community Non-ill Norm (N = 719)	Outpatient Psychiatry Norm (N = 1,002)
Somatization	Mean = 1.143 SD = 0.62	Mean = 0.29 SD = 0.40 P < .001	Mean = 0.83 SD = 0.79 P < .09
Depression	Mean = 0.868 SD = 0.63	Mean = 0.28; SD = 0.46; P < .0001	Mean = 1.80 SD = 1.08 P < .0002
Anxiety	Mean = 0.57 SD = 0.40	Mean = 0.35 SD = 0.45 P < .03	Mean = 1.70 SD = 1.00 P < .0001

was a way to treat dyspnea, improve exercise tolerance, or recover more quickly from exertion. Said one respondent about his attitude toward oxygen use:

I think about oxygen like I think about aspirin: if you have a headache, you take an aspirin. It's as simple as that. (Male, age 94, ATS stage II)

Full-time Oxygen Use. The stated intent of full-time oxygen users was to never be without supplemental oxygen. Four of 27 respondents adopted this pattern of use with their initial prescription. Eight people described evolving to full-time use after a period of part-time use. For these individuals, their physician's initial prescription and rationale for oxygen use was reason enough. The rest of the full-time oxygen users came to this pattern of use only after a period of as-needed or part-time use.

Full-time oxygen users described 2 exceptions to their full-time use of oxygen. Activities that could not be accomplished with a cannula in place constituted 1 exception to full-time use. Examples of this included changing clothes, shaving, or carrying something that required both hands. Voluntary trials without oxygen constituted the other exception. A trial without oxygen involved sitting or walking for a period of time without oxygen in order to monitor symptoms. Respondents used these trials to test the severity of their disease and their level of dependence on oxygen.

Adopting a Pattern of Adherence: The Domains of Self-Management

Ultimately the pattern of oxygen use adopted by any individual reflected their personal experiences and values and their efforts to optimally manage their lives. Four domains of self-management were described that affected adherence: functional management, health management, social management, and symptom management.

Functional Management. Functional management involved managing the physical tasks of daily living. Whether oxygen helped or hindered these daily tasks was the principal question. Most respondents described a

tension between the functional limitations caused by weight and bulk of the oxygen equipment and whatever improvement in strength or stamina they perceived from using the oxygen. For example, some felt that the physical burden of the oxygen apparatus made shopping more difficult and therefore were less likely to use oxygen in this setting. Others felt that oxygen enhanced their stamina and thus made the task easier and were more likely to adhere to their oxygen prescription. Some respondents who used a compressed portable oxygen source were incapable of lifting the canister alone and thus were unable to participate in certain activities without assistance.

A few individuals found ways of adapting that minimized the functional restrictions of oxygen. One man rigged his recreational vehicle with liquid oxygen so that he could go camping and fishing. Another man found a way to run an oxygen line to an upstairs bedroom and was thus able to live on 2 floors of his house without the hassles of frequently recharging a portable unit. Others found ways to move or carry their equipment that was easier or else haggled with their doctor, their insurance company, or their oxygen providers until they got lighter weight equipment.

Health Management. Health management involved answering the question, "How do I optimally manage my health?" Respondents struggled to decide whether using oxygen enhanced or compromised their health. Their information came from multiple sources. Every participant had been told by their doctor that oxygen was good for their health, and yet some believed that oxygen could be harmful. Some experienced side effects that they attributed to oxygen use. For example, several respondents described nasal dryness and nosebleeds, and one felt oxygen caused lightheadedness. Some respondents had been warned by their doctors that using too much oxygen could be deleterious to their health, and that warning raised concerns about the safety of oxygen in general. Some respondents were fearful of using oxygen, because they had extrapolated concepts from other disease processes that they applied to the use of oxygen. For example, some respondents were concerned that they might become addicted to oxygen. Said one:

It does bother me to feel this way, because I wonder, am I addicted to it? See, I started at 1 and I am up to 4 liters now. (Female, age 85, ATS stage III)

Two individuals felt that oxygen might weaken their lungs and render them less able to breathe without it. One gentleman summed up his concerns this way:

I can't let this (the oxygen) do all the work. I have to make my lungs work too. Like a back brace. You wear a back brace all the time and it's going to weaken your back and weaken your muscles. (Male, age 67, ATS stage III)

Thus, while patients perceived that adhering to a doctor's prescription generally promoted their health, a physician's advice was not the only source of information

considered in making health decisions. Many respondents felt that they had to remain vigilant themselves and retain independence in their decisions to be an adequate steward of their own health.

Many respondents described an evolution that gradually occurred in their sense of what it meant to optimally manage their health that in turn caused some evolution in their pattern of adherence. Sometimes their priorities changed as a function of new information from their doctor, from a pulmonary rehabilitation program, or through other educational resources. More frequently, their health beliefs changed as a result of personal experience. Some became aware that common tasks such as mowing the lawn, doing laundry, or climbing the stairs were increasingly difficult, and increased their oxygen use as a result. Some described a medical event such as a severe exacerbation of their symptoms or a bout with pneumonia and increased their use of oxygen as a result of these experiences. Two respondents increased their oxygen use after experiencing panic and intense dyspnea in a moment when they believed they might run out of oxygen. Many, over time and through such experiences, simply came to believe that their illness was more severe and merited a higher level of adherence to oxygen.

Social Management. Social management involved negotiating the social milieu of daily life. The most complex of the 4 domains, optimizing social management, involved answering a number of questions. How is my role and status in the family and community optimally maintained? Does oxygen use compromise my social status in the community or my role in the family? Several themes emerged in answering these questions as they related to oxygen use, including embarrassment, self-consciousness, fear of burdening or inconveniencing others, concerns about appearing weak or sick, and a sense of shame, both about prior smoking and accepting dependence on a substance such as oxygen. Examples of some of these themes are illustrated in the following quotes:

I feel like everybody is staring at me. I don't know if they are or not, but that is the way I feel. I just feel like a freak. (Female, age and ATS stage unknown)

I just hate to have it up my nose and everybody looking and feeling sorry, and I don't like it. (Female, age 73, ATS stage unknown, FEV1 = 0.71)

It (oxygen) devastated me. I have always been the caretaker in my family. I didn't want anyone to have to take care of me. (Female, age 60, ATS stage III)

I'm pretty vain. I don't like to see...you know...carrying that stuff you know. I'm supposed to be a macho man. (Male 67, ATS stage III)

I think I feel like it's shameful because I have to do it because I smoked. (Female, age 73, ATS stage III)

Most issues in social management represented barriers to adherence with oxygen and involved a desire to continue to appear healthy and independent. Nevertheless,

some respondents did describe social pressures that encouraged adherence to oxygen. Social pressure to use oxygen came primarily from friends and family members who pressed the patient to comply with their doctor's recommendations. Some respondents also described a sense of duty to heed their doctor's advice and an internally driven sense of guilt that they felt when they ignored it.

As in health management, for some participants, the elements considered in social management evolved over time. Some were able to overcome their fears or sense of self-consciousness by simply returning to a normal routine with family and friends. Pride in maintaining a high level of function and preserving independence was, for several respondents, a means of affirming their self-worth and overcoming their sense of isolation and embarrassment. One woman described how, after completing a pulmonary rehabilitation program, her world opened up again when she returned to her usual activities.

It opened a whole new vista for me. All of a sudden I was getting more active. I was doing the grocery shopping, and the laundry, and driving, and just becoming self-sufficient, which was what I used to do. I started volunteering then (in the rehab program) as a way of thanking them, you know, for saving my life. (Female, age 69, ATS stage unknown)

Symptom Management. The last domain is symptom management. Minimizing dyspnea was a powerful motivator among study participants. Some respondents felt that using oxygen reduced their dyspnea dramatically. Others could tell little difference in how they felt whether they were using oxygen or not. For those who felt their symptoms were improved with oxygen use, this factor tended to promote adherence to oxygen. Respondents who felt little immediate benefit in symptom relief struggled more with the role of oxygen in their lives. Those who felt symptom relief tended to rely heavily on this indicator in making decisions about oxygen use.

Balancing the Domains of Management. Optimizing function in one domain often came at some cost in terms of managing another; thus the pattern of oxygen use an individual adopted reflected a set of competing constraints based on their own individual values. One example was a respondent who felt that optimizing health management and social management required some extreme compromises. Optimally managing her health required continuous use of oxygen because she believed she would perish quickly without it, and yet she could not use oxygen in public and maintain her sense of her own social standing. Because she felt so self-conscious about being seen by friends and acquaintances while using oxygen, she rarely went out of her home. She was comfortable wearing oxygen around strangers, though. She described her preferences this way.

I never go out with oxygen. I tried to go out without it and it was too difficult. Finally I just quit that. If I were out of

town, it (oxygen) wouldn't bother me around strangers. It's my friends, and they're all going to say, "What if you quit that smoking?" (Female, age and ATS stage unknown)

The compromises she accepted were that she would use oxygen continuously but would only leave the house when it was absolutely necessary, like attending a doctor's appointment. She was able to manage her affairs with the help of a full-time health aid she had hired, who did her shopping and cooking, and that of her son, who helped with her financial interactions.

Every respondent described some sense of compromise in the decisions they made regarding their own use of oxygen. For some, the compromises were viewed as minimal or had been minimized by time and experience. For others, like the woman above, the compromises were profound and affected his or her quality of life daily.

Moving Toward Full-time Use

As described above, many respondents who reported full-time use of oxygen, came to that pattern of use after a period of part-time or as-needed use. Respondents described a series of 3 stages in their path toward increased oxygen use: initiation, negotiation and compromise. Each stage is organized around a question.

Initiation. The first stage, the stage of initiation, involves answering the question, "Do I need oxygen at all?" Given that all respondents were using oxygen, all respondents in this survey ultimately answered that yes, they did need it in some manner.

Negotiation. The second stage, the stage of negotiation, involved answering the question, "Given that I do need oxygen, under what circumstances do I need it or will I use it?" This is the stage of the as-needed and part-time users. These individuals negotiated the role oxygen would play in their lives and activities, deciding whether to include the use of oxygen in their activities or whether to continue the activity at all.

Compromise. The third stage, or the stage of compromise, involves answering the question, "Given that I cannot be without oxygen, what activities will I continue to participate in?" This is the stage of full-time oxygen use. The compromises made by individuals at this stage were at times profound. For those who were unable or unwilling to incorporate oxygen into an activity, using oxygen meant giving up that activity. Different respondents described the things that they gave up in order to use oxygen, and these included dining out, going to church, going to movies or the theater, and as described above, going out at all. Individuals at this stage of reckoning with their illness described a profound sense of loss. Many felt that their very identity and sense of self-worth were threatened and that they were powerless to change that fact.

DISCUSSION

This study demonstrates that adhering to supplemental oxygen therapy is difficult and adapting to the use of oxygen is a complex process. Most oxygen users evolve in their level of adherence to oxygen over time as they, through experience, trial, and error, struggle to balance the competing demands of managing their health and their symptoms with their daily activities and their social milieu. Using oxygen, even under the best of circumstances, involves making compromises that, for some, may represent profound losses of independence, autonomy, and self-perception.

Supplemental oxygen is highly efficacious for hypoxemic COPD. The Nocturnal Oxygen Therapy Trial documented a 50% reduction in mortality among those who use oxygen continuously compared to nocturnal use only.¹ Despite the efficacy of this therapy, adherence is poor. With such benefits to therapy, it is incumbent on physicians to work aggressively to improve adherence to therapy among their patients who use oxygen.

The majority of the existing literature on adherence to oxygen therapy focuses on measuring adherence behavior. While this information is useful, it is inadequate if the goal is to improve adherence to therapy. In order to change adherence behaviors, we must understand not just what people do, but why.²¹ This study is the first to describe how individuals use oxygen and why they adopt the adherence behaviors that they do. As such, this information is crucial in interpreting the existing quantitative data describing the high rates of nonadherence with oxygen therapy and in planning interventions to improve adherence.

The information in this study should have immediate clinical utility. Study respondents described many reasons why they did not use their oxygen. Some barriers would have simple remedies if only the patient discussed his or her concerns with a physician. For example, individuals unduly limited by the weight and bulk of compressed oxygen in an e-tank could be switched to a liquid system at less than half the weight. Similarly, misconceptions about oxygen use, like the fear of addiction, could be addressed easily if they were ever discussed. More difficult to address are those highly personal barriers to oxygen use. Stigma, isolation, and embarrassment were commonly expressed themes, but most respondents viewed their personal circumstances as unique and thus not amenable to intervention by others. Nevertheless, some overcame even very personal barriers to oxygen use through discussing their concerns with others. Whether the ultimate source of this assistance was a rehabilitation program, a support group, family members, or friends, the physician is in a key position to facilitate these processes in improving adherence; yet to do so requires first discussing the patient's experience with oxygen.

With one exception, all respondents thought highly of their physician, and not a single respondent blamed their doctor for the difficulties they had with oxygen use. Yet their doctors were not included in their struggles over how and

when to use oxygen. Most respondents described a single conversation with their doctors about oxygen that occurred at the time of their initial prescription. If physicians are going to facilitate the use of oxygen for patients, then they must discuss its use with them on an ongoing basis.

Improving adherence is not the only reason to discuss a patient's experience with oxygen with them. Illness of any form is isolating and frightening. The conspicuous nature of the oxygen apparatus makes it an advertisement of illness. No other chronic medical therapy is so public. While oxygen can relieve symptoms and alleviate some of the physical suffering attendant to COPD, it can create suffering as well. Repeatedly, respondents described a sense of embarrassment, stigmatization, and isolation that was a direct result of using oxygen around others. Minimizing the suffering that occurs as a side effect of oxygen use should also be a goal. Those who found relief found it by discussing their experience with others. Physicians should initiate and facilitate this process.

This study has several limitations. The majority of the data analysis and all of the interviews were performed by the principal investigator alone. This raises concern that the data collection or interpretation were biased or in some way untrustworthy. To protect against this, 5 of the interview transcripts were reviewed and coded by 6 different readers. Two individuals who used oxygen and three physicians also reviewed the completed analysis and supporting data and agreed with the interpretations and conclusions. The purpose of this qualitative study is to describe and explain patterns of adherence to oxygen therapy among individuals with hypoxemic COPD. Because of the sample size and the nature of qualitative data, it is neither possible nor appropriate to attempt to quantify each of the findings. All the adherence behaviors described in the study were self-reported and were not confirmed with any objective measures of oxygen use; therefore it is not possible to say how many hours each subject used oxygen or how accurately their self-reported use describes their actual oxygen use. The study sample is too small and not diverse enough to account for cultural variations in oxygen utilization and illness experiences that may occur in certain ethnic groups. Additionally, all subjects lived in Colorado or New Mexico; thus, regional differences and the effect of altitude cannot be discriminated in this study.

This study is the first to systematically describe and explain the patterns of adherence to supplemental oxygen therapy. Future research should focus on operationalizing these findings to measure them in a broader population, to correlate these domains with objective measures of oxygen adherence, and to design interventions to improve adherence to oxygen therapy.

Kutner, Richard Martinez, and Tom Petty, who reviewed the analysis and the supporting data and to Dr. Fred Wamboldt for his assistance and advice.

This work was supported by a grant from the Division of General Internal Medicine, University of Colorado Health Sciences Center, Denver, Colo.

REFERENCES

- Nocturnal Oxygen Therapy Trial. Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease. *Ann Intern Med.* 1980;93:391-8.
- Block AJ, Castle JF, Keitt AS. Chronic oxygen therapy treatment of chronic obstructive pulmonary disease at sea level. *Chest.* 1974; 65:279-88.
- Leggett RJE, Flenley DC. Portable oxygen and exercise tolerance in patients with chronic hypoxic cor pulmonale. *BMJ.* 1977;2:84-6.
- Stewart BN, Hood CI, Block AJ. Long-term results of continuous oxygen therapy at sea-level. *Chest.* 1975;68:486-96.
- Vergeret J, Brambilla C, Mounier L. Portable oxygen therapy: use and benefit in hypoxaemic COPD patients on long-term oxygen therapy. *Eur Respir J.* 1989;2:20-5.
- Levine BE, Bigelow DB, Hamstra RD, et al. The role of long-term continuous oxygen administration in patients with chronic airway obstruction with hypoxemia. *Ann Intern Med.* 1967;66:503-12.
- Brezinova V, Claverly PMA, Flenley DC. The effect of long-term oxygen therapy on the EEG in patients with chronic airway obstruction with hypoxemia. *Bull Eur Physiopathol Respir.* 1979; 15:603-9.
- Krop HD, Block AJ, Cohn E. Neuropsychiatric effects of continuous oxygen therapy in chronic obstructive pulmonary disease. *Chest.* 1973;64:317-32.
- McSweeney AJ, Grant I, Heaton RK. Life quality of patients with chronic obstructive pulmonary disease. *Arch Intern Med.* 1982; 142:473-8.
- Walshaw MJ, Lim R, Evans CC. Factors influencing the compliance of patients using oxygen concentrators for long-term home oxygen therapy. *Respir Med.* 1990;84:331-3.
- Phillips GD, Harrison NK, Cummin ARC. A new method for measuring compliance with long-term oxygen treatment. *BMJ.* 1994;308:1554-5.
- Burns BH, Howell JBL. Disproportionately severe breathlessness in chronic bronchitis. *Q J Med.* 1969;38:277-94.
- Heimlich HJ. Oxygen delivery for ambulatory patients: how the micro-trach increases mobility. *Postgrad Med.* 1988;84:68-79.
- Hoffman LA, Dauber JH, Ferson PF. Patient response to transtracheal oxygen delivery. *Am Rev Respir Dis.* 1987;136:153-6.
- Derogatis LR, Melisaratos N. The brief symptom inventory: an introductory report. *Psychol Med.* 1983;13:595-605.
- Jones PW, Quirk FH, Baveystock CM, Littlejohns P. A self-complete measure of health status for chronic airflow limitation. The St. George's Respiratory Questionnaire. *Am Rev Respir Dis.* 1992;145: 1321-7.
- Barr JT, Schumacher GE, Freeman S, LeMoine M, Bakst AW, Jones PW. American translation, modification, and validation of the St. George's Respiratory Questionnaire. [abstract]. *Clin Ther.* 2000; 22:1121-45.
- Ferrar M, Alonso J, Morera J, et al. Chronic obstructive pulmonary disease stage and health-related quality of life. *Ann Intern Med.* 1997;127:1072-9.
- Martin RJ, Pak J, Kunselman SJ, Cherniak RM. Assessment of the AirWatch lung function monitoring system. *J Allergy Clin Immunol.* 1999;103:535-6.
- Giacomini MK, Cook DJ. Qualitative research in health care—the results of the study valid. *JAMA.* 2000;284:357-62.
- Steiner JF, Earnest MA. The language of medication taking. *Ann Intern Med.* 2000;132:926-30.

The author would like to thank Drs. Kitty Corbett and John Steiner for their invaluable assistance throughout the process of this study, and Dr. Steiner for his editorial help and advice in preparing this manuscript. Additional thanks to Drs. Jean