
CONFRONTING COPD IN AMERICA: EXECUTIVE SUMMARY

OVERVIEW

Chronic obstructive pulmonary disease (COPD), is an umbrella term used to describe airflow obstruction that is associated mainly with emphysema and chronic bronchitis.

COPD affects tens of millions of Americans. One estimate is that 16 million patients have been diagnosed with some form of COPD and as many as 16 million more are undiagnosed.¹ New government data based on a 1998 prevalence survey suggest that three million Americans have been diagnosed with emphysema and nine million are diagnosed with chronic bronchitis.² COPD is the fourth leading cause of death in the United States, accounting for more than 112,000 deaths in 1998.³

Yet surprisingly little is known about COPD beyond its clinical nature, its population prevalence, and its mortality rate. Studies of the disease burden on COPD patients are scarce, and the social and health care costs of the disease have not been well quantified. As a result, there are limited data about COPD symptoms and severity, disability or activity limitations, lifestyle impact, social and psychosocial consequences, health care utilization and current patterns of treatment.

Confronting COPD in America was designed to help answer some of these questions and unmask one of the nation's least-understood public health problems. It is the largest and most comprehensive survey to date of patient and provider knowledge, attitudes and behavior related to COPD. Among the issues it explores are the frequency and severity of symptoms, the burden of illness, healthcare utilization, disease management and treatment, and quality of life issues.

The survey yields several major findings, such as:

- COPD imposes a profound burden on patients, including medical emergencies and hospitalizations, work absenteeism and activity limitations. This, in turn, results in significant physical and emotional impact on patients.
- Dyspnea, or shortness of breath, associated with COPD causes significant activity restrictions, interfering with the everyday tasks most people take for granted: dressing, washing, talking and sleeping.
- Both doctors and patients agree that the outlook for COPD has improved in recent years, and both recognize the benefits of treatment. Yet the symptoms and disease burden patients report suggest that they are not achieving the level of treatment success that they believe is possible.
- Doctors and patients also agree that there is a strong need for better education about COPD and the best ways to manage the disease.

Figure 1: Study Design for Survey

STUDY DESIGN FOR SURVEY

Population	Sampling Frame	Interview Length	Final Sample Size
Persons aged 45 and older diagnosed as having emphysema, chronic bronchitis, or chronic obstructive pulmonary disease, or meeting symptomatic definition of chronic bronchitis	National Probability Sample of 27,000 Households Screened by Random Digit Dialing	34 minutes	573
Primary Care Doctors in Direct Patient Care in Outpatient Setting	AMA/AOA listings	26 minutes	100
Respiratory Specialists in Direct Patient Care in Outpatient Setting	AMA/AOA listings	22 minutes	103

The survey findings are particularly important because, despite the large and growing number of Americans affected by COPD, it remains a relatively invisible disease to the general public. As America ages, it will be increasingly important to understand one of the leading causes of death and disability among middle-age and older Americans.

The survey was conducted between August 2 and November 21, 2000. Telephone interviews were completed with a national sample of 573 COPD patients. The sample was identified by systematically screening a national sample of 26,880 U.S. households to find patients 45 years and older who had been diagnosed with COPD, emphysema or chronic bronchitis, or whose symptoms matched a strict definition of chronic bronchitis. A national sample of 203 physicians — 100 primary care physicians and 103 respiratory specialists — was also interviewed as part of the survey (Figure 1).

Confronting COPD in America was conducted by Schulman, Ronca and Bucuvalas, Inc. (SRBI), a national public-opinion research firm. Dr. Stephen Rennard of the University of Nebraska Medical Center served as an advisor. The survey was funded by GlaxoSmithKline, one of the world's leading research-based pharmaceutical and healthcare companies.

WHO HAS COPD?

Confronting COPD in America

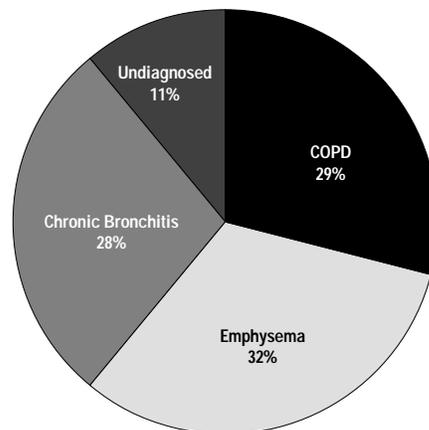
focuses on persons ages 45 and older who have been diagnosed with COPD or its components, emphysema and chronic bronchitis. Nearly equal proportions of COPD patients reported diagnoses of COPD (29%), emphysema but not COPD (32%), and chronic bronchitis but not emphysema or COPD (28%). In addition, 11% of the survey sample was made up of persons who met a stringent symptomatic definition of chronic bronchitis*, but who had never been diagnosed as having COPD, emphysema or chronic bronchitis (Figure 2). While the actual population prevalence of undiagnosed COPD is much greater than this would suggest, this subsample of symptomatic but undiagnosed COPD patients provides important insights into the management of undiagnosed COPD.

COPD is frequently thought of as a disease of the elderly. Yet half (50%) of all COPD patients surveyed are under 65 years old, and nearly a quarter (22%) are under 55 (Figure 3). The average age at diagnosis was 53 years.

The vast majority of persons with COPD (87%) describe themselves as white. The proportion of persons with COPD who consider themselves African-American (7%), mixed (3%) or other race (3%) is substantially lower than the expected population proportions for those races (Figure 3). This may be due in part to lower smoking rates among minority groups in the past, a possible underdiagnosis of COPD in these populations, or some combination of these factors.

* Respondents in this category had to report that, for at least two years, they have suffered from persistent (at least three months/year) bronchitis or coughing with phlegm/sputum from the chest.

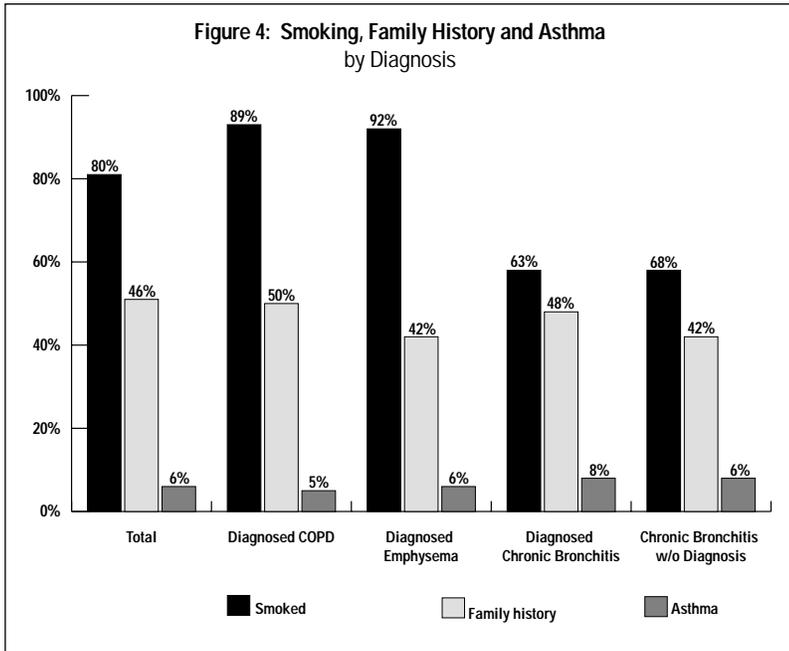
Figure 2: Primary Diagnosis: Patients with COPD



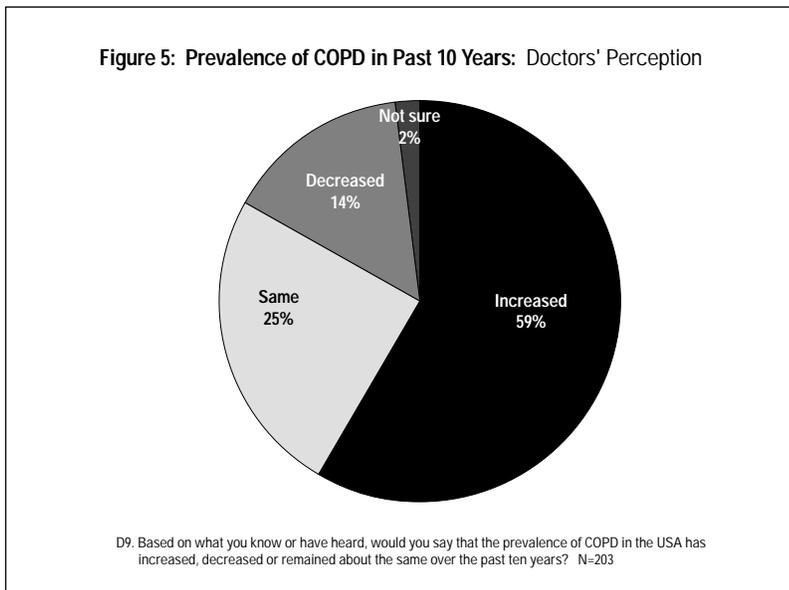
Q1-3. Have you ever been diagnosed by a physician as having: emphysema, chronic bronchitis, chronic obstructive pulmonary disease (COPD)?
 Q1-2. How many months in the past 12 months have you had bronchitis or chronic coughing with phlegm/sputum from the chest? For how many years have you had?

Figure 3: Demographic Profile of Persons with COPD in USA

AGE	
45-54	22%
55-64	28%
65-74	29%
75+	21%
GENDER	
Male	40%
Female	60%
RACE/ETHNICITY	
White	87%
Black	7%
Mixed	3%
Other	3%
WORK STATUS	
Employed full time	18%
Employed part time	7%
Unemployed	6%
Retired	52%
Homemaker	4%
Too ill to work	13%
EVER SMOKED	
Yes	80%
No	18%
TOTAL	(573)



While COPD is often considered to be a disease mostly of male smokers, more women than men (60% vs. 40%) qualified for the survey. Nine out of ten persons with a diagnosis of COPD (89%) or emphysema (92%) are current or former smokers. About three out of five persons with diagnosed (63%) or symptomatic (68%) chronic bronchitis have a smoking history (Figure 4). Yet nearly one in five (18%) of all of these patients have never smoked (see Figure 3).



There appears to be a strong familial association with COPD.** Half the persons with a diagnosis of COPD (50%) report that members of their immediate family outside of their household have had COPD, emphysema or chronic bronchitis. Similar proportions of persons diagnosed with emphysema (42%), and persons with diagnosed (48%) or symptomatic (42%) chronic bronchitis, have a family history of COPD (Figure 4).

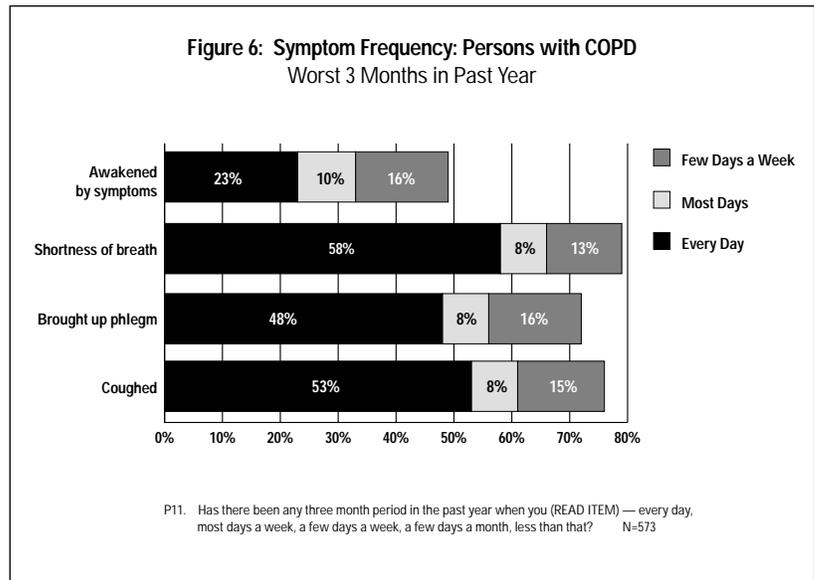
The survey reveals that most physicians believe that COPD is on the rise. Nearly six out of ten physicians (59%) say that the prevalence of COPD in America has increased in the last 10 years (Figure 5).

** It is unclear if this familial association is related to genetic factors, environmental factors, or both.

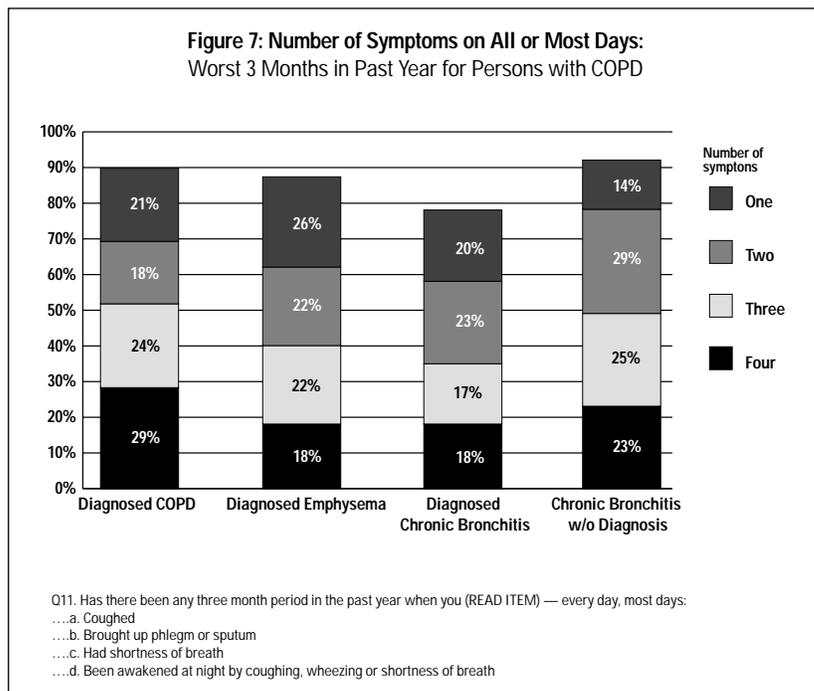
SYMPTOM FREQUENCY AND SEVERITY

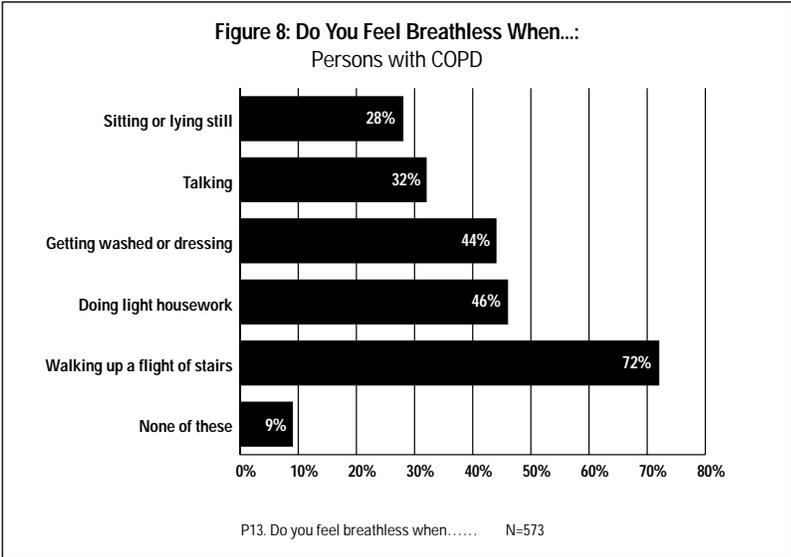
Although COPD symptoms are chronic rather than episodic, the severity of symptoms may vary during the year. Hence, patients were asked about the frequency of their symptoms during their worst three-month period in the past year (Figure 6). During that time period:

- 79% had been short of breath at least a few days a week; 58% had shortness of breath every day.
- 76% had coughed at least a few days a week; 53% had coughed every day.
- 72% had brought up phlegm at least a few days a week; 48% had brought up phlegm every day.
- 49% had been awakened at night by coughing, wheezing or shortness of breath at least a few days a week; 23% had been awakened by these symptoms every night.



The vast majority of persons diagnosed with COPD (90%) said they had one or more COPD symptoms either every day or most days during their worst three-month period in the past year. Surprisingly, a similar percentage of persons with undiagnosed COPD (91%) also reported one or more of these symptoms every day or most days (Figure 7).

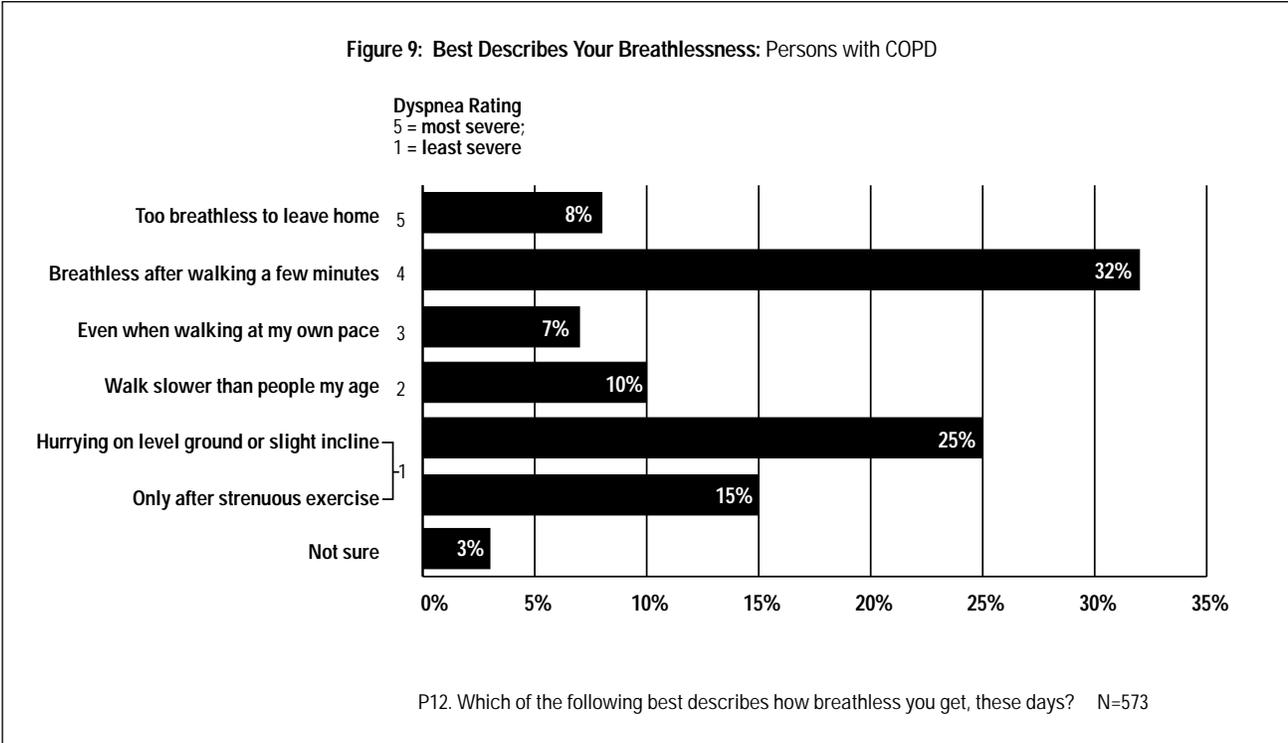




Impact of Breathlessness on Activities

The impact of breathlessness on every-day activities is striking (Figure 8):

- 28% have difficulty breathing even when sitting or lying still
- 32% get short of breath when talking
- 44% get short of breath when washing or dressing
- 46% get short of breath when doing light housework
- 72% feel breathless when walking up one flight of stairs



Patients were asked to rate their condition according to the Medical Research Council five-point breathlessness scale (Figure 9):⁴

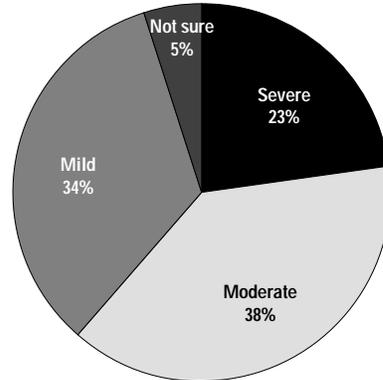
- 8% are too breathless to leave the house — the most severe level of dyspnea
- 32% have to stop for breath after walking a few minutes

- 7% get breathless even when walking at their own pace
- 10% walk slower than most people their age
- 25% get breathless when hurrying on level ground or walking up a slight incline
- 15% get breathless only after strenuous exercise — the mildest degree of dyspnea

Despite this level of functional impairment, not even a quarter (23%) of COPD patients describe their condition as “severe.” Thirty-eight percent describe their COPD as “moderate,” and another third (34%) describe their condition as “mild” (Figure 10).

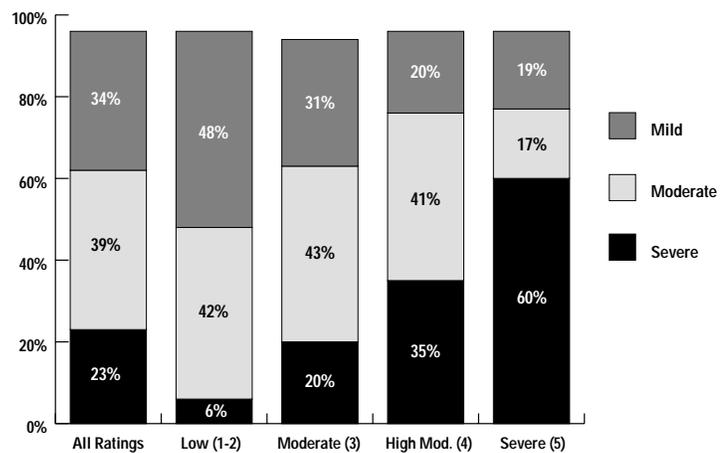
Indeed, there is a significant disparity between patient perceptions of their disease severity and the degree of severity indicated by the MRC breathlessness scale. A surprising 36% of persons with the most severe degree of breathlessness describe their condition as “mild” or “moderate” (Figure 11).

Figure 10: How Severe is Your (Condition)?
Persons with COPD



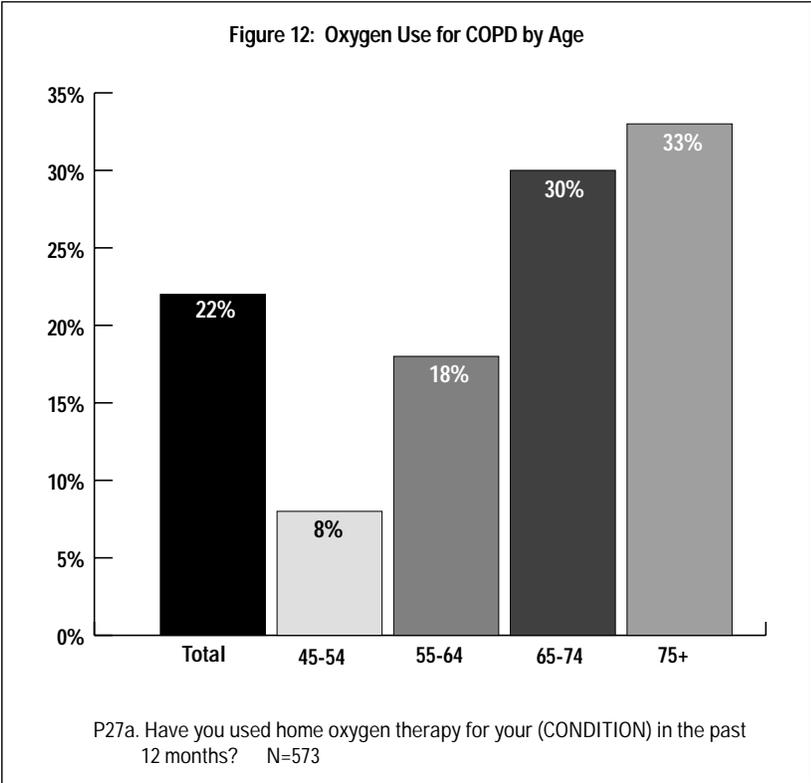
P4. Overall, how severe is your (CONDITION), now? Is it severe, moderate or mild? N=573

Figure 11: Perceived Severity of Respiratory Condition
by Degree of Breathlessness (MRC Scale)



MRC Scale Rating (Degree of Breathlessness: Least → Most)

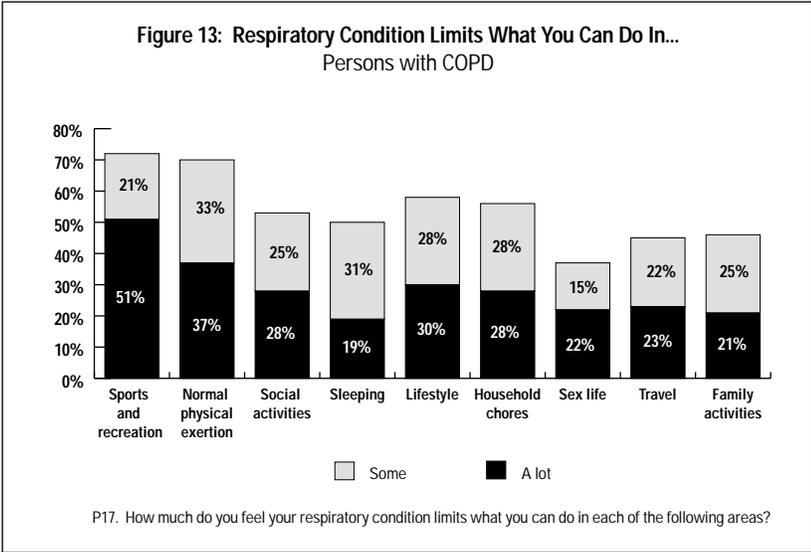
P4. Overall, how severe is your (CONDITION), now? Is it severe, moderate or mild? N=573



Symptom Severity and Age

The survey findings corroborate the clinical observation that COPD tends to get worse as patients get older: Use of home oxygen therapy, an indicator of disease severity, increases from 8% among 45-54 year olds to 33% among patients 75 and older (Figure 12).

Yet surprisingly, younger patients report more severe and frequent symptoms than do older patients. One possible explanation for this counterintuitive finding — older patients, not younger patients, should be reporting more severe and frequent symptoms — is that younger patients are more acutely aware of their symptoms. Older patients may have grown so accustomed to living with COPD that they tend to underreport their symptoms.



BURDEN OF DISEASE

Physical Limitations

A majority of COPD patients say their condition limits what they can do (some or a lot) in (Figure 13):

- Normal physical exertion (70%)
- Lifestyle (58%)
- Household chores (56%)
- Social activities (53%)
- Sleeping (50%)

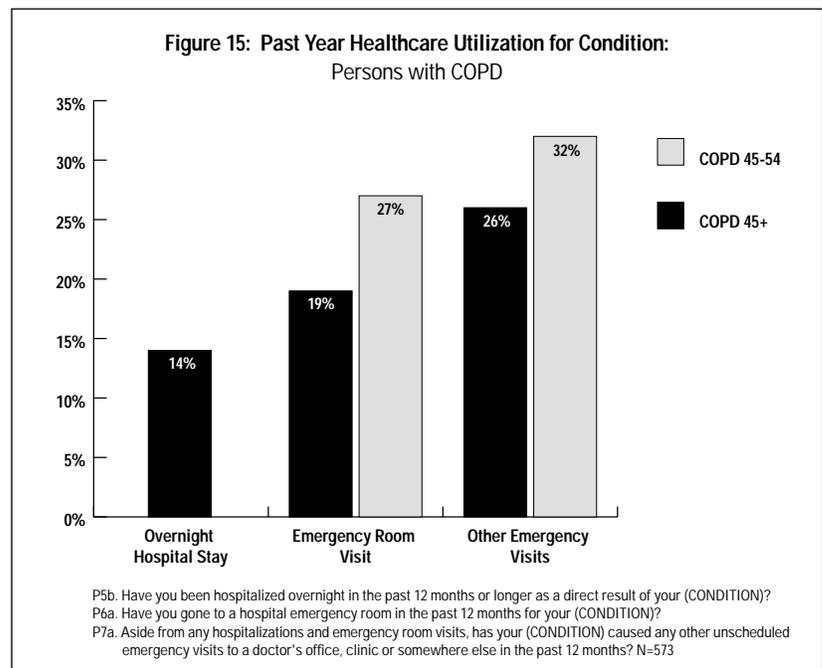
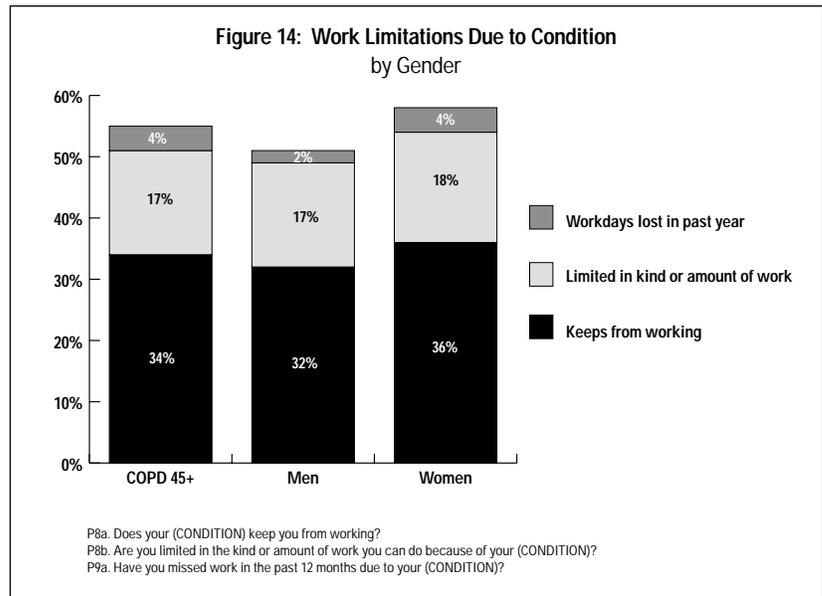
Half of persons with COPD (51%) report that their condition limits their ability to work (Figure 14):

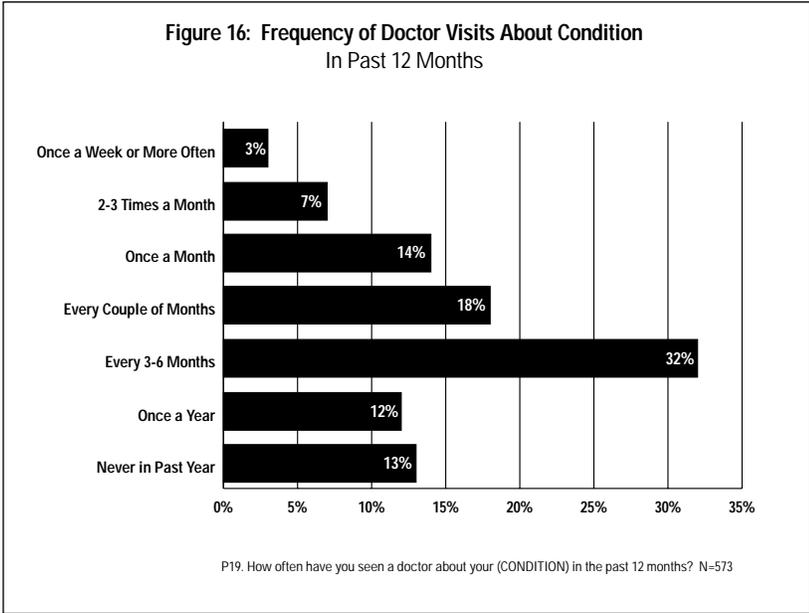
- 34% say that COPD keeps them from working
- 17% say their condition limits them in the kind or amount of work they can do

It is also important to note that measures of work limitation most likely understate the disease burden because more than half of these persons are already retired (see Figure 3).

The disease burden of COPD is also seen in the demand for urgent or emergency medical care. Among persons 45 and older with COPD (Figure 15):

- 14% were hospitalized overnight in the past year for their condition
- 19% had emergency room visits in the past year for their condition
- 26% had other emergency visits in the past year for their condition





This use of urgent care among COPD patients is surprising given the frequency of regularly scheduled physician visits they report. In addition, just as younger patients report more severe and frequent symptoms than do older patients, there is also a greater degree of healthcare utilization among younger patients (i.e., those ages 45-54):

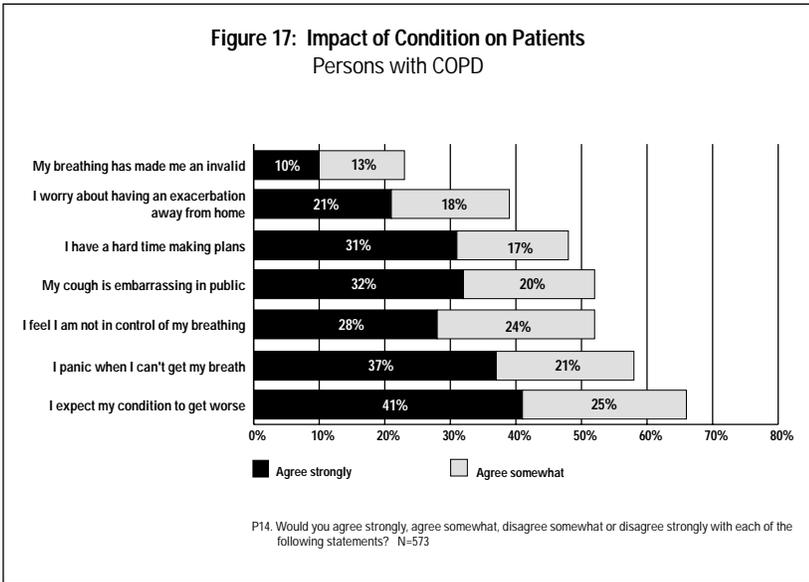
- 27% had emergency room visits in the past year for their condition.
- 32% had other unscheduled emergency visits for their condition.

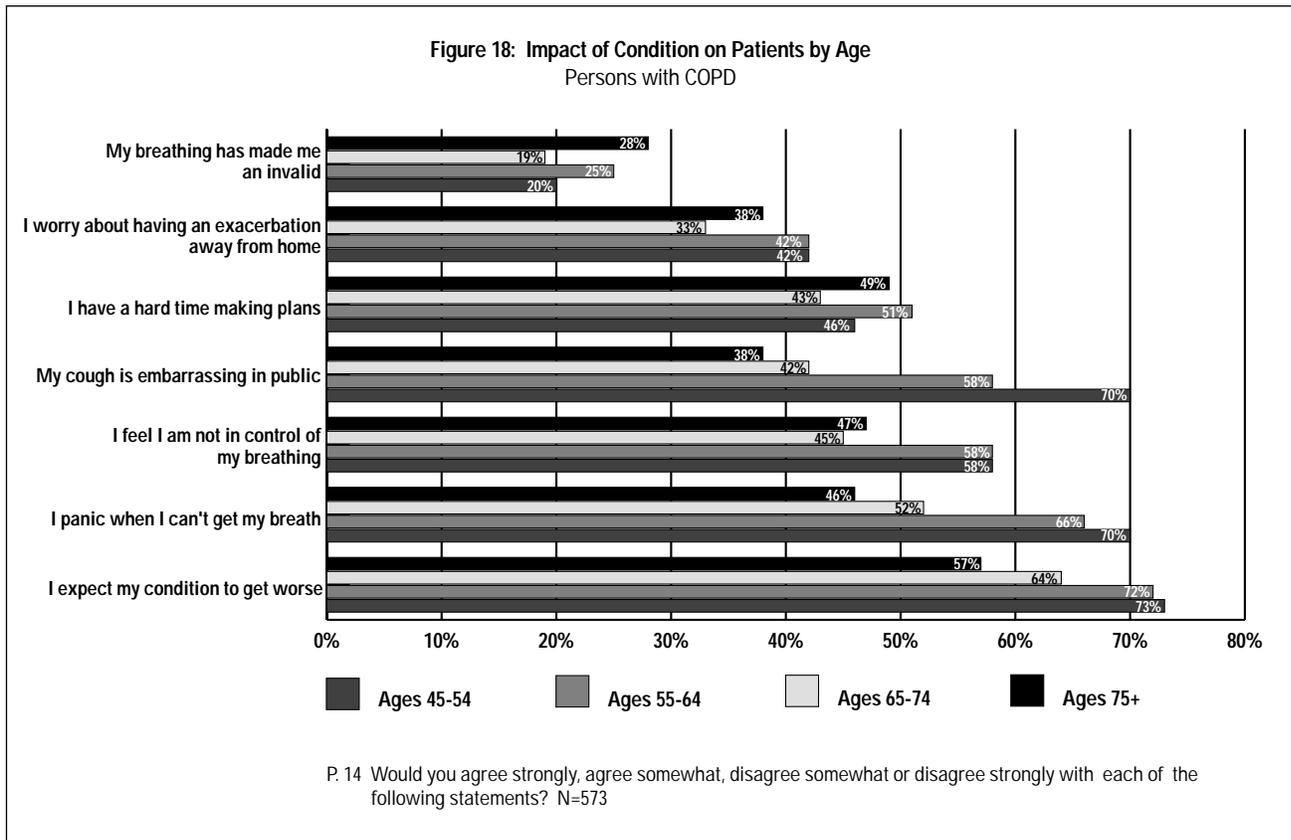
Doctor visits are relatively frequent for persons with COPD (Figure 16). Nearly a quarter (24%) see a doctor for their condition at least once a month and a total of 74% see a doctor at least a few times a year. However, 13% have not seen a doctor about their condition in the past year.

Psychosocial Impact

Nearly a quarter (23%) of patients say their breathing problems have made them an invalid (Figure 17). Even larger proportions of persons with COPD say they:

- worry about having an exacerbation away from home (39%)
- have a hard time making plans because of their condition (47%)
- feel that they are not in control of their breathing (52%)
- panic when they cannot get their breath (58%)
- admit that their coughing is embarrassing in public (52%)
- expect their condition to get worse (66%)



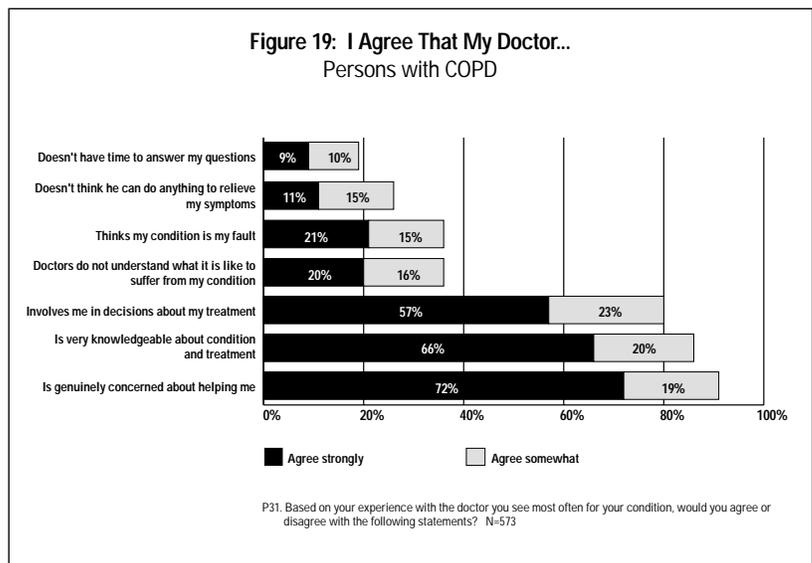


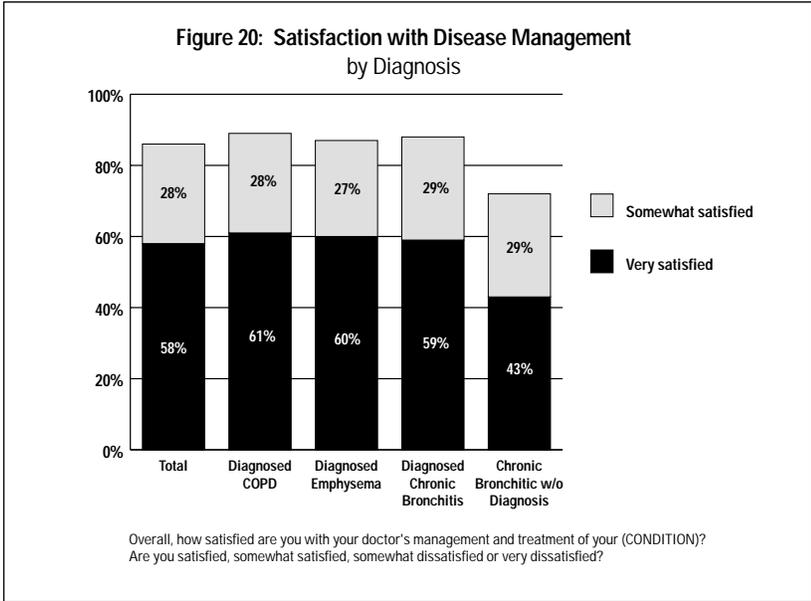
It is noteworthy that the apparent psychosocial impact of COPD appears to vary with age, and that — on five out of seven measures — younger patients appear to be more distressed by their condition than do older patients (Figure 18).

PHYSICIAN CARE AND COPD MANAGEMENT

COPD patients give their doctors high marks for knowledge and care (Figure 19):

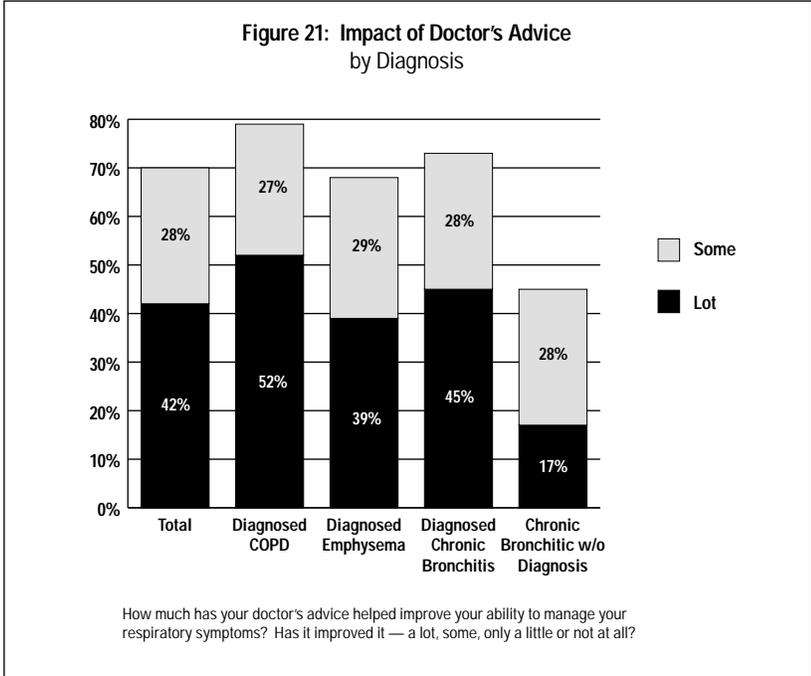
- 91% say their doctor is “genuinely concerned about helping me”
- 86% say their doctor is knowledgeable about their condition and treatment
- 80% say their doctor involves them in decisions about their treatment





On the other hand, some COPD patients indicate significant problems in doctor-patient interactions:

- 36% say doctors do not understand their suffering from the condition
- 36% say their doctor thinks the condition is their fault
- 26% say their doctor doesn't think he can do anything to relieve their symptoms
- 19% say their doctor doesn't have time to answer their questions

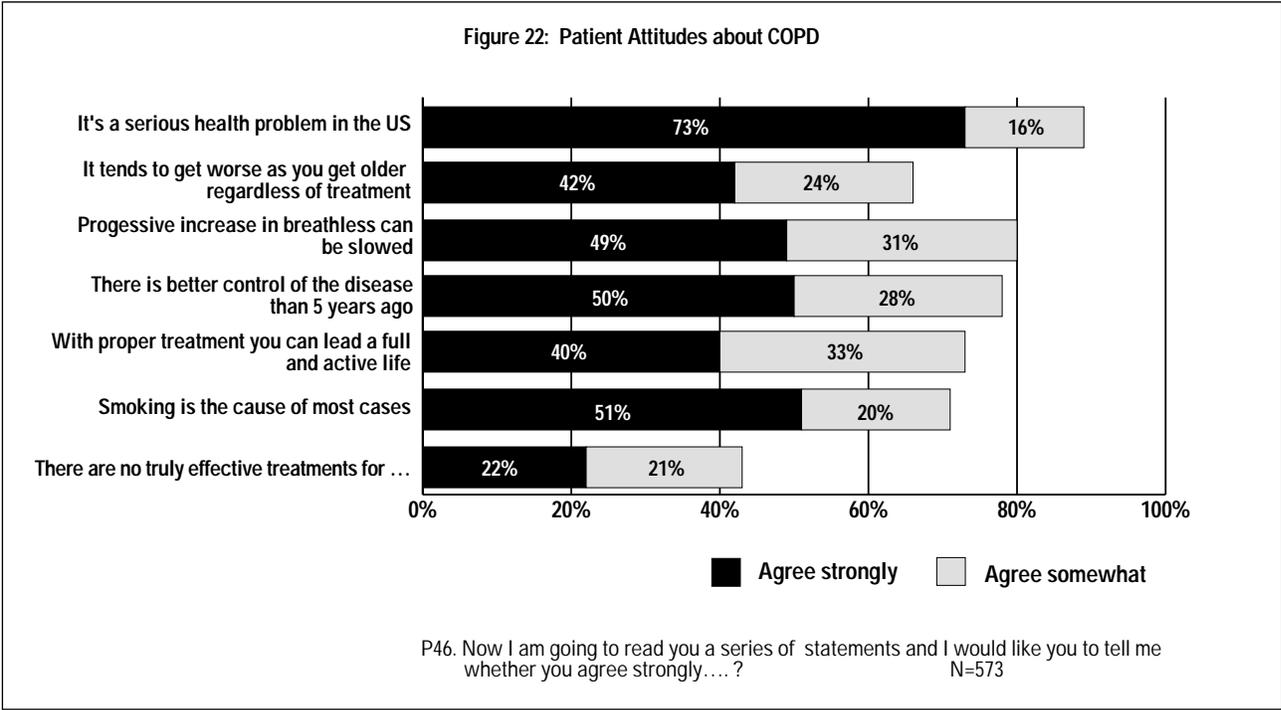


Overall, most patients are satisfied with their care. Six out of seven say they are very (58%) or somewhat (28%) satisfied with their doctor's management of their condition (Figure 20). But less than half (42%) say their doctor's advice has helped improve their ability to manage their condition "a lot" (Figure 21).

Patients overwhelmingly agree (89%) that COPD is a serious health problem in the US, but they are also optimistic about new developments and the benefits of proper management (Figure 22). Though two thirds (66%) acknowledge that COPD tends to get worse with age

regardless of treatment, most have positive attitudes about treatment:

- 80% feel that the progressive increase in breathlessness can be slowed
- 78% feel that there is better control of the disease than there was five years ago
- 74% feel that with proper treatment you can lead a full and active life



Doctors share their patients' optimism (Figure 23):

- 76% of doctors say that the long term health outlook for persons with COPD is better now than it was 10 years ago.
- Most of these physicians (78%) attribute this improvement to better medications.

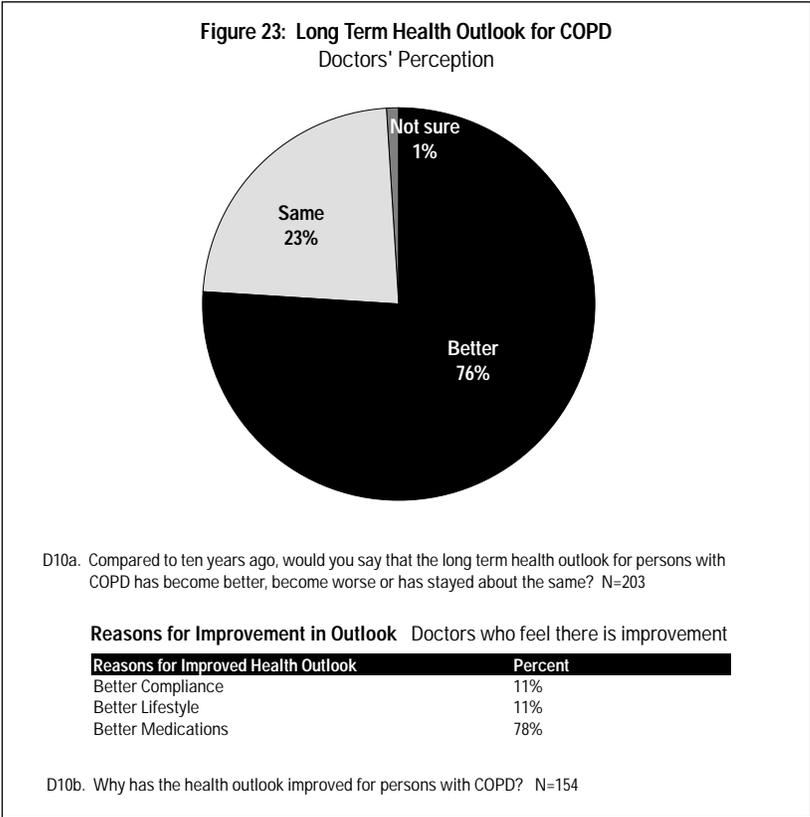
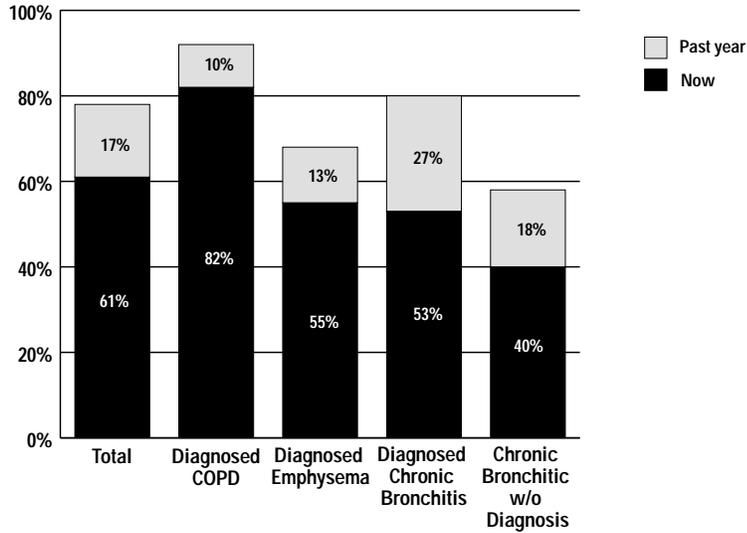


Figure 24: Prescription Medicine Use for Condition by Diagnosis



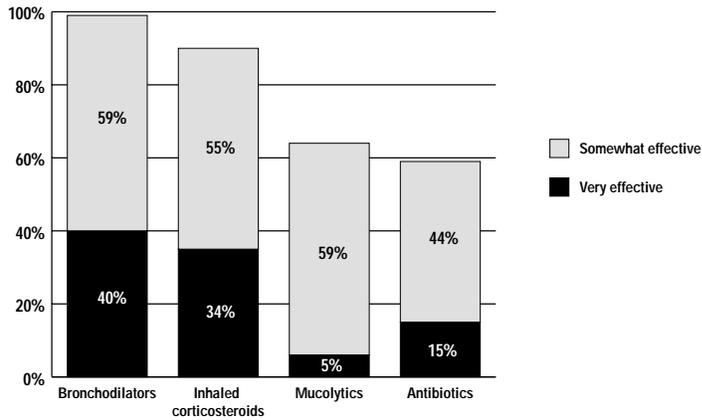
Are you taking any prescription medicine for (CONDITION)? When was the most recent time that you took a prescription medicine for (CONDITION)?

TREATMENT ATTITUDES AND PRACTICES

Only 61% of COPD patients report that they are currently taking any prescription medicine for their condition; another 17% say they have taken prescription medicines in the past year, but are not doing so currently (Figure 24).

Doctors rated bronchodilators (40%) and inhaled corticosteroids* (34%) as very effective in the treatment of mild to moderate COPD. Nine out of ten doctors say that bronchodilators (99%) are somewhat effective for mild to moderate COPD (Figure 25). Similarly, nine out ten (89%) believe that inhaled corticosteroids are somewhat effective for mild to moderate COPD.

Figure 25: Effectiveness of Selected Medications in Mild to Moderate COPD: Doctors



D25-28. How effective are (ITEM) in the treatment of mild to moderate COPD? Are they usually — very effective, somewhat effective, not too effective or not effective at all? N=203

Substantial proportions of doctors report that they would normally prescribe the following to “all or most” newly diagnosed patients (Figure 26):

- Short-acting beta agonists (67%)
- Inhaled corticosteroids (62%)
- Anticholinergics (47%)
- Long-acting beta agonists (48%)

* Currently, the role of inhaled corticosteroids in COPD therapy is not well defined, and they are not yet approved for COPD in the U.S. However, clinical trials are underway.

Virtually all doctors (96%) said they would normally prescribe flu vaccinations to all or most newly diagnosed patients with moderate, or Stage 2, COPD (Figure 26).

The percent of persons with COPD who report taking specific types of prescription medicines for their condition is substantially less than the proportion of physicians who say they would prescribe these medications for moderate COPD. One

notable disparity: While about the same proportion of physicians say they would recommend long-acting beta agonists (47%) as often as anticholinergics (48%), substantially fewer patients reported taking long-acting beta agonists (7%) than anticholinergics (19%) in the past year (Figure 27).

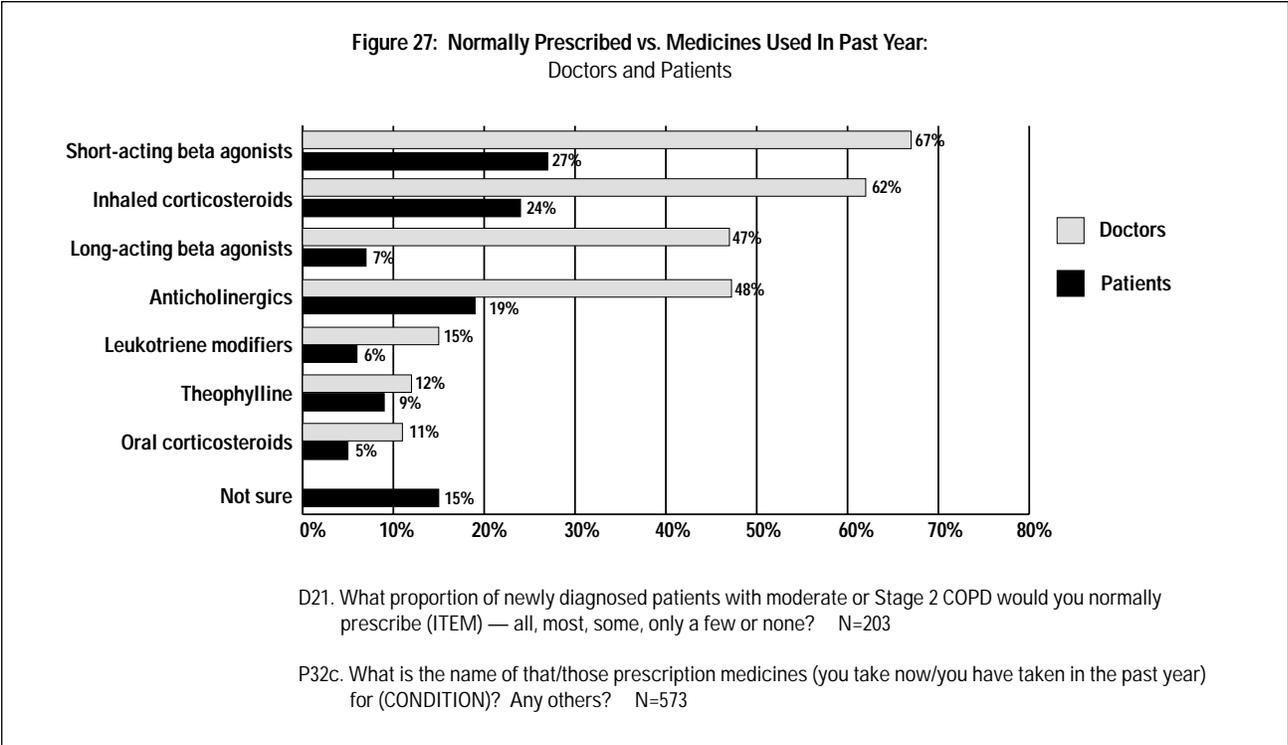
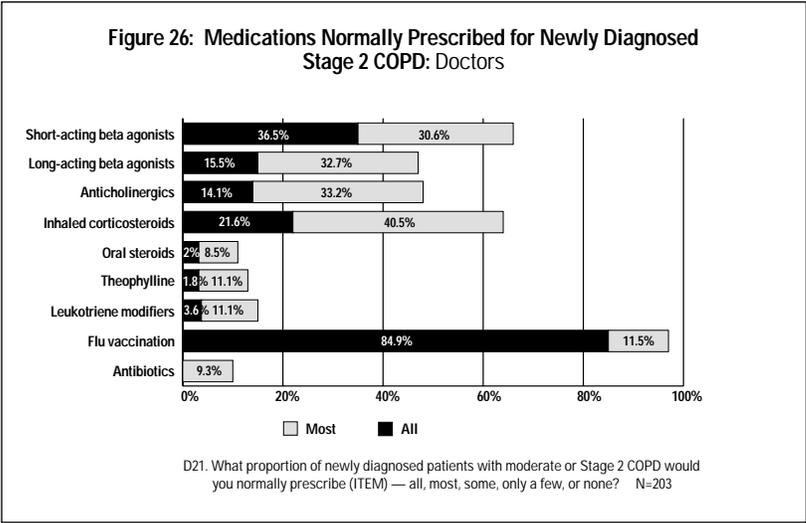
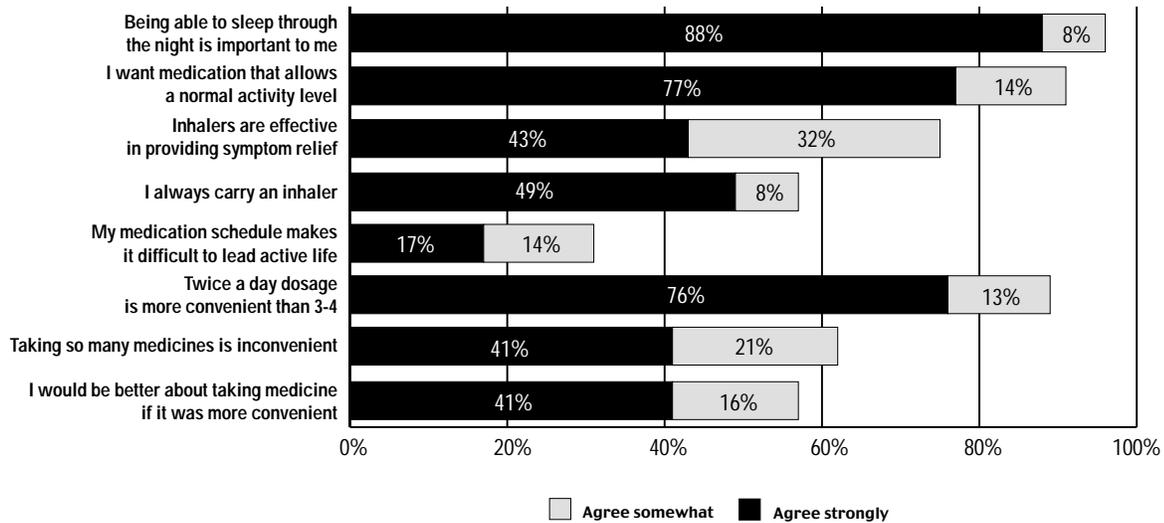
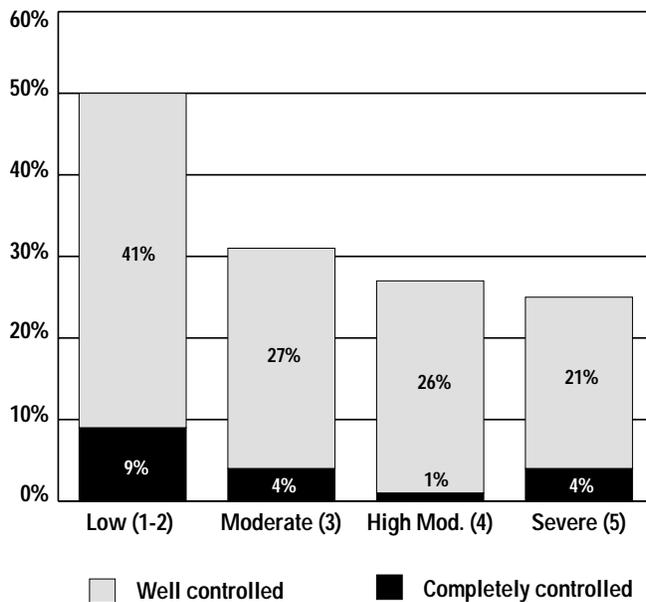


Figure 28: Attitudes about Treatment for COPD:
Persons with COPD



P47. I would like to know whether you agree or disagree with each of the following statements about treatment...
N=573

Figure 29: Perceived Control by Severity
Degree of Breathlessness (MRC Dyspnea Scale)



Patient attitudes toward treatment, which may be informed by the medications they are taking, suggests that patients perceive a “treatment burden” in addition to a disease burden (Figure 28):

- 31% say their medication schedule makes it difficult to lead an active life
- 62% say that taking so many medicines is inconvenient, and 57% say they would be better about taking their medicine if it were more convenient
- 89% agree that twice a day dosage would be more convenient than 3-4 times a day

OVERESTIMATION OF CONTROL

A central problem in disease management is that COPD patients tend to overestimate their degree of symptom control. The survey shows that patients' self-perception of disease control is not in keeping with more objective measures of disease severity. One in four (25%) patients with the most severe degree of breathlessness say that their COPD has been completely or well controlled in the past year, as do 27% of patients with the next most severe level of breathlessness (Figure 29).

In addition (Figure 30):

- 42% of patients who say that their COPD has been “completely” or “well controlled” over the past year also said there was a three-month period during that time when they had shortness of breath every day.
- One in four (24%) of those who say their COPD has been “completely” or “well controlled” over the past year also said their condition restricts them “a lot” in normal physical exertion.
- More than a quarter of patients who say their COPD has been “completely” or “well controlled” over the past year also said they get short of breath while getting washed or dressing (28%), or doing light housework (29%).

This underscores the need for better education: If patients underestimate the severity of their condition, or do not realize that it can be better controlled, they might be less likely to seek the care they need.

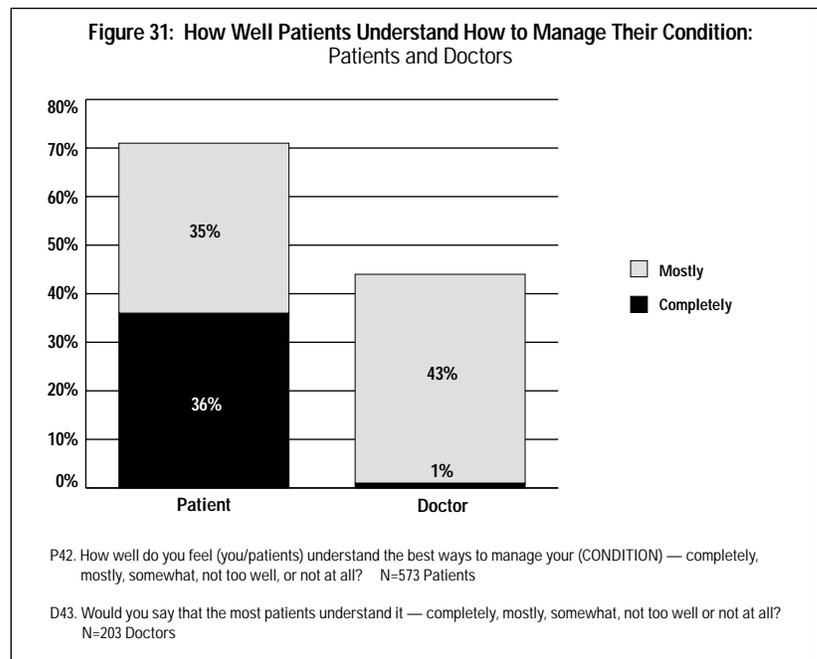
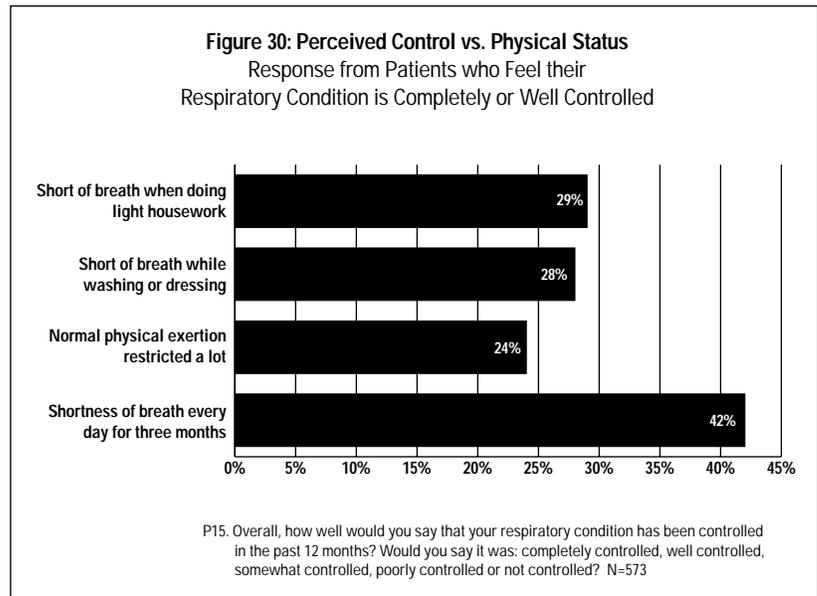
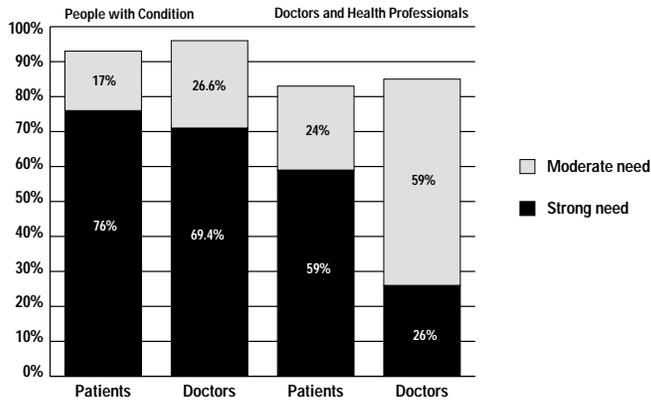


Figure 32: Need for Better Education
Patients and Doctors



P43/D45. How much need do you think there is for better education of PEOPLE WITH COPD about their condition and its treatment? Do you think there is a strong need, moderate need, or not much of a need? N=573
 PP44/D46. How much need do you think there is for better education of DOCTORS about the management of COPD? Do you think there is a great need, moderate need, or not much of a need? N=203

NEED FOR BETTER EDUCATION

The survey reveals that although COPD patients in general say they feel relatively informed about their condition, they and their doctors also recognize that there is a significant need for better education — particularly in terms of the best ways to manage COPD.

One important finding is that doctors and patients disagree about how well patients understand the best ways to manage their condition (Figure 31). Although 71% of patients say that they either

completely (36%) or mostly (35%) understand the best ways to manage their condition, only 44% of doctors say that most patients completely (1%) or mostly (43%) understand how to manage their condition.

Yet both doctors and patients agree that there is a need for better education about the management of the condition (Figure 32):

- 76% of patients and 69% of doctors agree there is “strong need” for better patient education about their condition and treatment.

Two other areas where better education might be particularly useful:

- **Underdiagnosis:** Since 11% of survey participants show symptoms of the illness yet have not been diagnosed with COPD (see Figure 2), there may be a vast number of Americans who are suffering and not getting proper treatment. Educational campaigns may be able to alert undiagnosed patients to COPD symptoms and urge them to seek further information from their doctors.
- **Treatment options:** Given patient complaints about the inconvenience of medications (see Figure 28), it might be useful for patients to talk with their healthcare providers about ways they can simplify their treatment regimen.

CONCLUSIONS

In addition to the major findings outlined in the overview, there are several general conclusions that can be drawn from the survey findings:

- COPD is a debilitating disease. Shortness of breath and other symptoms take a tremendous toll on patients.
- There is a significant gap between the level of disease control that patients report and more objective indicators of the impact and severity of their condition. This disparity may reflect patients' underestimation of the degree to which COPD can be managed and therefore a troublesome tendency to accept their condition as the best that can be expected.
- Doctors and patients agree there is a need for better education about ways to manage the disease. Patients should talk to their doctors about simple treatment options to improve lung function.

Methodological Notes

The survey actually comprises two separate surveys, each based on telephone interviews with national probability samples of:

- COPD patients, defined as persons ages 45 or older who had been diagnosed with COPD, emphysema, chronic bronchitis, or who met a stringent symptom criteria for undiagnosed chronic bronchitis. A total of 573 persons with COPD were interviewed. This sample was identified by systematically screening a geographically stratified national sample of 26,880 US households by telephone.
- Doctors, including 100 physicians from adult primary specialties of general practice, family practice and internal medicine, and 103 specialists in pulmonology. National probability samples were drawn from each of these populations.

Patient and physician interviews were conducted by telephone from August to November, 2000. Patient interviews averaged 34 minutes in length, while the physician interviews averaged 22-26 minutes in length.

The maximum expected sampling error is ± 4.1 percentage points at the 95% confidence level for a sample of 573 (e.g., patient survey), while the maximum expected sampling error for a simple random sample of 100 (e.g., primary care doctor survey) is ± 9.8 percentage points at the 95% confidence level.

Confronting COPD in America may be considered a landmark study in research on chronic obstructive pulmonary disease because:

- The survey is one of the most comprehensive surveys about COPD conducted with a national probability sample of persons with COPD ever conducted in the U.S. The 34-minute patient interview covers a broader range of subjects, including symptoms, morbidity, treatment and quality of life, in more depth than any previous national probability survey of COPD in America.

- The questionnaires for the surveys of the healthcare providers were designed to permit comparisons with patient responses. The study therefore offers insight into the different perspectives of patients and providers on treatment and other issues.

References

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