Taking Her Breath Away

The rise of COPD in women

Disparities in Lung Health Series

AMERICAN LUNG ASSOCIATION
Fighting for Air
Preface

I have personal experience in living with and trying to persevere with a severe lung disease, COPD, that at present has no cure. I was diagnosed with very severe COPD in 2001, and consider myself fortunate to have had access to the best available medical care and treatment. Over these thirteen years, I have become a patient advocate for those who have no voice; attempting to raise the level of awareness of COPD.

Sadly, COPD is now a disease in which women have reached a grim parity with men. In the American Lung Association report you are about to read, you will learn that since 2000 the disease has actually claimed the lives or more women than men in this country each year. Twelve years after my own diagnosis, COPD is still under-diagnosed and under-treated. This alarming and important information in “Taking her Breath Away: The Rise of COPD in Women”, gives voice to the millions of women living with this disease.

In this sixth volume of their “Disparities in Lung Health Series”, the American Lung Association heralds a sense of urgency and asks that our leadership in public health and healthcare invest much-needed attention and resources to address COPD.

There are many good people and organizations toiling in the vineyards for COPD, but I want to challenge all of us to do even more. As you read this report and consider the call to action, please keep in mind those of us who try to live with dignity while our ability to breathe and to function diminishes. We who have COPD can take pride in what we accomplish, can hope to better control our symptoms, can hope to improve our quality of life. We can hope that we are closer to better treatments and to the day when cures for COPD are finally reality.

Courage!

Grace Anne Dorney Koppel
Patient Advocate
NIH, National Heart Lung Blood Institute "Learn More, Breathe Better" Campaign
COPD Foundation, Board Member

Jean R.
Jean lives in Iowa and started having trouble breathing in 1985. She was convinced it was because she was overweight and “out of shape”. At first diagnosed with asthma, in 2000 she was diagnosed with COPD. By 2002 she was on oxygen 24 hours a day, and in 2003, Jean was in the hospital and in respiratory failure. According to Jean, her doctor “laid the cards out on the table” and told her that if she wanted to survive with any quality of life, she needed to lose weight, exercise and follow her treatment plan.

Jean fortunately had quit smoking in 1992, after 30 years of cigarettes. She used that same determination to lose 100 pounds and build up an exercise program. She also became a patient advocate for COPD, learning all she could and participating in support groups.

Today Jean says she is like a new woman. She no longer needs to use oxygen and still follows her treatment plan. She does notice that on days when the air quality outside is poor, she has to be very careful and has difficulty breathing. Today she fights for clean air and healthy lungs for all.

Marilyn K.
Marilyn was born in 1925 in Detroit, Michigan. With a master's degree in education, she was instrumental in developing the Head Start program in Detroit. As a child she often had bronchitis. Like many of the "modern" women at the end of World War II, she began to smoke cigarettes at age 20 and quit when she was 35. Following several bouts of pneumonia, she was diagnosed with COPD shortly after 2000.

She continued to be active, even after needing to use portable oxygen starting in 2006. Up until 2012, Marilyn was the one who still drove her car, picking up and taking her friends to events. Eventually, she developed peripheral artery disease and needed 5 surgeries in 16 months, having greater difficulty with healing after each. Her progressive COPD and diminishing quality of life led her to say "I'm on a slippery slope with this disease and really don't want to continue on like this".

This vibrant, lovely mother of seven, did not survive her final surgery in January 2013. She leaves a legacy of perseverance and learning for so many.
Taking Her Breath Away

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Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive lung disease that slowly robs its sufferers of the ability to draw life-sustaining breath. It is the third leading cause of death in the United States, surpassed only by heart disease and cancer, and is not decreasing nearly as quickly as the other two. There is no known cure. Because most people with COPD have a history of smoking, it was for many years thought of as a disease of older white men, who have, as a group, smoked at higher rates over a longer time than any other. But as gender roles and smoking behavior have changed in recent decades, so too has the profile of COPD. The number of deaths among women from COPD has more than quadrupled since 1980, and since 2000, the disease has claimed the lives of more women than men in this country each year.
Women are biologically, emotionally and culturally different than men, and these differences impact the way they experience COPD. A growing body of evidence suggests that women may be biologically more susceptible to the lung damage caused by tobacco smoke and environmental pollutants. Women with COPD tend to develop the disease at a younger age, and are more likely to be of lower socioeconomic status. Women are also less likely to be diagnosed properly with COPD than are men who go to their doctors with the same histories and symptoms. Women living with COPD have a more difficult time quitting smoking, have more disease flare-ups and use more healthcare resources. They also suffer more from co-occurring chronic conditions, including depression, and have an overall lower quality of life.

The rising toll of COPD in women in the U.S. is inextricably linked with the history of tobacco use and the marketing efforts of the tobacco industry over the past 100 years. Starting in the 1920s, changing gender roles and aggressive targeted cigarette advertising contributed to a dramatic increase in smoking rates among women. Sadly, those old TV ads that declared to women “you’ve got your own cigarette now,” have resulted in a steep rise in COPD and other tobacco-related illnesses in those women as they have aged. It may be decades before the health consequences of the tobacco boom among women are fully realized.

Fortunately, there are a number of positive steps that can be taken to make a difference in the burden of COPD in women now. These include continuing the expansion of laws and policies that reduce tobacco use and exposure to secondhand smoke, increasing the focus on women and gender-specific treatments in COPD research and clinical trials, and making changes to healthcare practices that will improve diagnosis and referral to services such as tobacco cessation counseling and pulmonary rehabilitation for women. Most importantly, the leadership in public health and health care at the national, state and local levels must embrace a sense of urgency and invest much-needed attention and resources in addressing COPD.
A Greater Burden of Disease

The numbers, like the disease itself, are breathtaking. More than 7 million women are living with COPD, and millions more have symptoms but have yet to be diagnosed. COPD is a disease that brings with it a heavy burden on patients and families. It often means years of poor health, lost productivity and healthcare expenses. Women with COPD experience the disease differently than men, in ways that increase their burden and decrease their quality of life.

More Deaths: 10 Years and Counting

In 2009, nearly 70,000 women in the U.S. died the slow, long-suffering death that COPD brings. This was more deaths than the year before, which was more than the year before that. In fact, the number of deaths from COPD among women has quadrupled since 1980. Before then, COPD was primarily a disease of men. In 1979, the number of men dying from COPD was almost three times that of women. By the year 2000, COPD had claimed the lives of more women than men for the first time, and women now account for roughly 53 percent of all deaths attributed to COPD in this country. (Figure 1)
About COPD

COPD is a lung disease that makes it progressively harder to breathe. The word “obstructive” in COPD means that the flow of air in and out of the lungs is reduced. COPD comprises two main conditions—chronic bronchitis and emphysema—which can coexist. With chronic bronchitis the lining of the airways becomes swollen and produces a lot of mucus. With emphysema the walls of the air sacs in the lung get broken down, the air spaces get larger and stale air gets trapped.

More than 14 million people have been diagnosed with COPD, and as many as 24 million may actually have the disease, including many who are undiagnosed. Smoking is the major cause of COPD. Pollution or irritants in the air can also cause COPD. A small number of people have a rare inherited form of COPD called alpha-1 antitrypsin deficiency (AAT) which occurs about equally in men and women. Lung infections such as a cold or some other illness, or exposure to harmful pollutants can also cause a sudden worsening of COPD symptoms known as an exacerbation, or disease flareup. Exacerbations can result in hospitalization and accelerate the loss of lung function, eventually leading to serious long-term disability and death. COPD is often not diagnosed until the disease is very advanced, because people do not recognize the early warning signs. Sometimes people think they are short of breath or less able to do the things they are used to doing because they are “just getting old.”

Although there is no known cure for COPD, there is much that can be done to treat and help manage the disease if it is found early. The goals of treatment for COPD are to relieve symptoms, prevent disease progression, reduce the frequency and severity of disease flareups, improve health status, increase exercise tolerance and prolong life. The type of treatment changes with the needs of the patient, depending on the severity of their disease. The most important first step is to protect the lungs from further damage by quitting smoking, reducing exposure to air pollutants and keeping up with influenza and pneumonia vaccinations. Patients with mild COPD are often prescribed a quick-relief inhaled medicine to use as needed. If that does not control symptoms, other medications are added. Pulmonary rehabilitation programs, which combine exercise therapy with education and support, have been shown to help control symptoms and improve daily functioning at all stages of disease. Patients with severe COPD should add long-term oxygen therapy and consider surgical intervention.
More Cases: The Trend Continues

Of the 14.7 million people who have been diagnosed with COPD, 58 percent of them are women. After taking into account the differences between the sexes in age, ethnicity, income, education and smoking status, women are 37 percent more likely to have COPD than men.3

COPD usually takes many years to develop, and the prevalence of the disease in both women and men increases with age. Women have higher rates of COPD than men throughout most of their lifespan, although it appears that they are especially vulnerable before the age of 65. When controlling for differences in ethnicity, income and education, women ages 45-64 are 51 percent more likely than men of the same age to have the disease. This drops to 21 percent more likely when comparing women and men 65 years of age and older.3 (Figure 2)

The profile of the “typical” woman with COPD is not that different from the “typical” man with the disease. She is most likely to be white, to reside in a southeastern or Appalachian state and to have an income below the poverty level.6 There is however a striking difference between the sexes in the connection between income level and rates of disease. Like tobacco use, COPD is primarily a disease of the poor, and prevalence rates for both women and men rise as income levels fall. But poverty appears to have a greater impact on women, whose rates of disease rise more sharply as their income level falls.3 (Figure 3)
Taking Her Breath Away: The Rise of COPD in Women

About the Data

There are two national surveys that collect data on COPD prevalence—the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS). The NHIS is the principal source of information on the health of the civilian, noninstitutionalized population of the United States. Survey respondents are asked two separate questions:

- Have you been diagnosed with chronic bronchitis in the past 12 months?
- Have you ever been diagnosed with emphysema?

Unfortunately, combining data from these two questions for an overall estimate of COPD prevalence would result in an overestimation of disease as many individuals report diagnoses of both diseases.

The Behavioral Risk Factor Surveillance System (BRFSS) provides COPD prevalence data by state. In contrast to the NHIS, the BRFSS uses one question to assess overall COPD prevalence:

- Have you ever been told by a doctor or health professional that you have COPD, emphysema or chronic bronchitis?

Data from 2011 mark the first year that questions on COPD prevalence estimates by state are available. To allow for better comparison between the methods of the two surveys and the effect of phrasing the question differently, future versions of the NHIS will include the COPD question from the BRFSS.

More Illness, More Health Care

COPD patients consume enormous amounts of health care over the course of their illness. Even when doing well, they juggle numerous doctor visits and multiple prescriptions. Women with COPD have more frequent disease flareups, have more co-occurring conditions and use more healthcare resources than men. Between 1995 and 2004, outpatient visits for COPD made by women increased 54 percent while visits by men increased only 1 percent, with women surpassing men for number of visits in 2000. Since 1993, women have also surpassed men in number of hospitalizations due to the disease. In 2010, 57.2 percent of the 715,000 hospital discharges due to COPD were in women.

Most older COPD patients are also dealing with one or more other serious chronic conditions, including cardiovascular disease, hypertension and diabetes, many of which are also closely associated with a history of tobacco use and exposure to cigarette smoke. Osteoporosis, depression, stroke, congestive heart failure, inflammatory bowel disease and diabetes have all been reported as more common in women compared to men with COPD. The research on heart failure and other cardiovascular disease has yielded conflicting results, with some studies finding that men with COPD are at greater risk from cardiovascular diseases than women with COPD, and other studies finding the opposite.

These multiple diseases and their treatment can interact in damaging ways. For women with both COPD and cardiovascular disease, low levels of oxygen in their blood increases stress on the cardiovascular system. Some of the medications that are used to treat COPD also pose a risk to cardiovascular health. More than half of all COPD patients have osteoporosis, and the condition is more common in women than men. It is also potentially worsened by the use of steroid medications. Osteoporosis can have a dramatic effect on the health status and prognosis of women with COPD, as a single broken vertebra can result in a 4-8 percent decline in breathing capacity.
Greater Risk and Susceptibility

The degree to which a person is at risk of COPD depends on the interplay of two factors: their level of exposure to disease-causing agents, such as tobacco use or environmental toxins; and their personal susceptibility, which depends on genetics, age, overall health status and other variables. The reasons why women face a higher burden of illness and death from COPD than men are a complex mixture of both factors. Socially constructed gender roles have resulted in disparities in exposure to harmful environments. And biological gender differences appear to make women more susceptible to harm from those exposures.

Smoke and Mirrors: Changing Gender Roles and the Influence of the Tobacco Industry

Smoking is well established as the primary cause of COPD. Inhaled smoke, either directly from smoking or from secondhand smoke, causes inflammation of the airways in the lungs. Tobacco smoke contains thousands of chemicals that are broken down into substances that cause irritation and inflammation in the lung. As a person continues smoking, damage to the lung tissues builds up and results in chronic inflammation and even destruction of airways in the lung, which eventually may result in the onset of COPD.

Cigarette smoking was rare among women in the early 20th century, but started increasing after advertising targeting women began in the late 1920s. Lucky Strike was one of the more prominent tobacco companies at the time that launched an extremely successful "Reach for a Lucky Instead of a Sweet" campaign, which focused on women’s concern about their weight. These advertising trends resulted in gains in the number of female smokers and lasted through World War II, when a large portion of women entered the work force. In 1968, Philip Morris introduced Virginia Slims, the first cigarette created specifically for women. With the advertising slogan “You’ve Come a Long Way Baby,” and imagery that emphasized autonomy, glamour and thinness, Virginia Slims was massively appealing to women’s newfound sense of liberation.

By 1973, less than six years after the introduction of Virginia Slims, the rate of 12-year-old girls who had started smoking increased by 110 percent.

These days, the tobacco industry continues to prove itself remarkably adept at identifying and targeting women’s interests and vulnerabilities. In 2007, R. J. Reynolds launched Camel No. 9, a cigarette packaged in a black box with hot pink and teal colors. The products were advertised as “Now available in stiletto” and “dressed to the 9s.” The next year, Philip Morris debuted a new “purse pack” version of its Virginia Slims, the designs of which were quite similar to women’s cosmetics.

Fortunately, thanks to a growing awareness of the health effects of smoking, coupled with the rise of the tobacco control movement, the percentage of women and men who smoke has been declining. However, this decrease has not yet impacted COPD death rates in women, since some of those young Virginia Slims girls are still getting sick. As with many chronic conditions, COPD has a lag period between when one starts smoking and the onset of the disease itself, during which lung damage accumulates and progresses into irreversible damage. The smoking rate among women did not increase until a much later date than men, and even then remained noticeably lower. Similarly, the COPD death rate for men increased earlier than among women and has remained somewhat higher, although the gap is narrowing. (Figure 4)
Figure 4
Time Delay Between Smoking & COPD Death — By Sex

- Men began smoking earlier than women
- Women began smoking in the 1920s
- World War II. Smoking becomes socially acceptable
- 1964 - Surgeon General's Report recognized harm of smoking
- 1968 - Virginia Slims "you've come a long way, baby"
- 1971 - Eve
- 2007 - Camel No. 9

CDC. NHIS and NVSS.21
More Harm from Environmental Exposures

Exposure to environmental pollutants occurs at home, at work, in public places and outdoors. If women are more at risk of COPD from smoking, it would seem plausible that other pollutants might also affect them more than men. Unfortunately, very few studies on the impact of occupational or environmental exposures on COPD have examined specific differences between the sexes. However, the fact that women with COPD are 1.5 times more likely to have never smoked than men with COPD (29 percent compared to 19 percent) indicates that women are more susceptible to lung damage from secondhand smoke and other pollutants. There is some evidence that this increased vulnerability starts in early childhood. Several studies in children have found that exposure to environmental tobacco smoke and air pollution causes a greater reduction in lung growth and breathing ability in girls than in boys.

Secondhand smoke is one of the major environmental contributing factors to the development of COPD. It contains the same harmful particles that cause inflammation and damage to the lungs as direct smoking. Most secondhand smoke exposure occurs in the workplace and in the home, and as smokefree workplace policies have become more widespread, the home is increasingly the source of greatest exposure for family members, most often women and children. A U.S. study found that women who are exposed to similar levels of secondhand smoke have a greater risk for lung damage and disease than men.

According to a national health survey, almost 15 percent of deaths from COPD are attributable to occupational exposures to harmful materials. Women with jobs in personal services, agriculture, textiles, rubber and plastics and sales all had higher risk of developing COPD than men doing comparable work. Women are particularly sensitive to biological dusts, such as pollen, animal dander, insect parts, fungi and bacteria. Exposure to biological dust, along with mineral dust and gas fumes, significantly increases the chance of developing COPD later in life for women, but not in men, with the risk increasing with the duration of the exposure. Some of the jobs in which women face higher exposure to biological dusts are in health care, food and textile manufacturing, visual arts and cleaning.

Outdoor air pollution also appears to affect women’s respiratory health more than men’s, although the evidence is somewhat mixed on whether women are more susceptible, or more exposed or perhaps both. Living near a busy roadway exposes residents to high levels of particulate matter air pollution, which is known to cause significant illness and death from respiratory and cardiovascular causes. Several researchers have found that long-term exposure to traffic-related pollutants reduces lung function in urban women, and increases their risk of developing COPD.
Biological Differences Increase Susceptibility

While smoking and other harmful exposures partially explain why COPD rates in women have risen so drastically in the past decades, the numbers do not quite add up. Women are less likely than men to smoke, and those who do smoke consume on average fewer cigarettes per day. Yet for the same amount of tobacco use, women are more likely to develop symptoms of COPD earlier, and have more severe disease. Something else is clearly going on. There is growing evidence that women are biologically more susceptible to COPD. A uniquely female combination of anatomy and physiology results in more harmful particles getting into the lungs and staying there, where they cause an exaggerated immune response that actually increases the damage done in the airways.

Female lungs are smaller than men’s, with narrower airways and less respiratory muscle to power inhaling and exhaling. As a result, the concentration of cigarette smoke and other lung irritants is higher within the lung airways of women when inhaled. Studies have also found that female smokers inhale deeper and hold their breath for a longer time than male smokers. This means there is greater exposure to these damaging toxins. The smaller structure of the lungs also makes women more susceptible to a condition called bronchial hyper-responsiveness. This is a condition where the lung’s airways narrow too easily or too much in response to stimuli like smoke and allergens. The affected airways become thickened and inflamed, which makes breathing more difficult and damages tissue over time. In women, cigarette smoke is the primary contributor to bronchial hyper-responsiveness, but has little to no effect on the development of the condition in men.

Female sex hormones, specifically estrogen, play a role in worsening the lung damage from smoking in women as well. Estrogen increases the rate at which nicotine is broken down in the body, but it does not increase the rate that the body gets rid of these harmful compounds. As one continues to smoke, the harmful compounds build up in the lung more for women, causing stress to the lung and damage to the organ. This increased metabolism of nicotine may also explain why it is much more difficult for women to quit smoking than men.
Under-Diagnosed and Under-Treated

Although gender differences in COPD treatment have not received adequate attention, it is clear that women with COPD have some serious challenges and special needs that impact their ability to manage their disease and maintain their optimal health. These include delay in getting properly diagnosed, greater difficulty maintaining abstinence from smoking, higher rates of anxiety and depression and lower overall quality of life.

Gender Bias in Diagnosis

The first step in getting proper treatment for any condition is getting a proper diagnosis. For women with COPD, that can be a problem. Because COPD has long been thought of as a man’s disease, many clinicians still do not expect to see it in women and so miss the proper diagnosis. This gender bias is consistent with a well-established pattern in diagnosing other tobacco-related diseases such as coronary artery disease.35

When a patient goes to her doctor to discuss breathing problems, the doctor must interpret the information provided to form a diagnosis. It is a subjective process in which the doctor naturally draws upon his or her own perceptions and experiences. One researcher confirmed this situation by presenting physicians with a case study that included symptoms, medical history and smoking behavior typical of someone with COPD. Half of the physicians were told that the hypothetical patient was female, and the other half were told that the patient was male. Only a slight majority of the physicians correctly identified COPD as the most probable diagnosis. And those who thought the patient was female were significantly less likely to be correct. Asthma was the most common alternative diagnosis, especially for the female “patient.”35

Women are definitely under-diagnosed and under-treated. It is tragic to hear our patients express disappointment that they suffered so long before their disease was recognized.

- Chris Garvey, RN
Although physical symptoms and a history of exposure to risk factors are valuable indicators of COPD, the recommended way to diagnose COPD is to also perform a standardized breathing test known as spirometry. Unfortunately, spirometry is widely underutilized, particularly in primary care settings where most initial COPD diagnoses are made. One large global study of COPD patients found that only 40 percent of all participants reported ever having had the test. Here again gender bias put women at a disadvantage. The researchers found that even after adjusting for disease severity and smoking history, women were less likely than men to have been given a spirometry exam.

Effectiveness of Medications

Research into the question of whether COPD medications work the same way in men and women has yielded conflicting results. There has been little investigation at all of how gender differences in body size and shape affect the way inhaled medicines get into the lungs. Historically, the proportion of men in COPD clinical trials has ranged from 65 to 100 percent. Since the mid-1990s, sensitivity to the need to include women in research studies has increased, and the U.S. Food and Drug Administration now requires that drug safety and effectiveness trials include women. It is important to note, however, that just including women in research does not solve the problem unless researchers specifically evaluate gender differences in response to drug therapies.

Access to Care

COPD is an expensive disease, often involving large healthcare costs for disabled patients who have reduced or no ability to earn a living. A large phone survey of men and women with COPD conducted in 2006 found that lack of or inadequate healthcare coverage had a substantial negative impact on COPD patients’ use of crucial health services. More than a quarter of the respondents said that cost or lack of insurance coverage had kept them from going to the doctor, filling a prescription or going to the hospital. Although this study did not analyze the survey results separately by gender, it is reasonable to assume that women with COPD are disproportionately impacted by the cost of health care. Women in general have lower incomes and have higher out-of-pocket medical expenses than men, making them more likely to struggle to afford the care they need.

We need to address the issue of training physicians to diagnose COPD properly. Spirometry is required to make a correct diagnosis.

- MeiLan Han, M.D.
Knowledge, Attitudes and the Role of Stigma

Once women with COPD get a proper diagnosis, there is little evidence to suggest that they are treated differently than men by the clinicians who care for them. However, surveys have found that between 25 and 50 percent of primary care physicians are unaware of the professional guidelines for the diagnosis and treatment of COPD. Even clinicians who claim to be familiar with the guidelines do not necessarily follow them, and there are distressingly frequent reports of treatment practices that are not considered optimal care, including inappropriate use of systemic steroids, underuse of pulmonary rehabilitation, infrequent immunization and the incorrect belief that current smokers cannot benefit from treatment.41,42

Patients with COPD, both men and women, have also been shown to have low levels of knowledge about their condition. A large survey conducted in 2006 found that the COPD patients were far less knowledgeable about measures of their lung capacity and breathing ability than they were about their cholesterol numbers and blood pressure, despite similar amounts of clinical testing. Lack of patient knowledge about COPD contributes to problems managing treatment, which may in turn reduce feelings of control, increase anxiety and reduce quality of life.41,43

Men and women have different ways of getting information about their disease and different ways of coping. Investigations looking at gender-related differences are clearly needed.

– MeiLan Han, M.D.

Patients are highly sensitive to the stigma associated with a smoking-related illness like COPD. One study found that more than 40 percent of both women and men thought their doctors judged their COPD to be self-inflicted.36 Another small study of women with COPD found that respondents believed their physicians were biased against them as female smokers.44 This perception of stigmatization, whether accurate or not, can result in a patient’s reluctance to seek care.45 Doctors with a negative attitude or unrealistic pessimism about the prognosis for their COPD patients have been shown to be less likely to treat or refer adequately.43

Patients’ perceptions about illness can also have a strong impact on the effectiveness of treatment and health outcomes. Although there is no evidence of gender differences in patient knowledge about COPD, men and women do differ in their perceptions. Despite similar access to the healthcare system, women are more likely than men to feel that they have difficulty reaching their physician, and that the amount of time their doctor spends with them is insufficient. They are also more likely than men to say that they get information about COPD from sources other than their doctor. This may be due in part to a well-recognized communication gap between male physicians and their female patients. But it also likely reflects a coping style that is more dependent on interpersonal interaction.46
Treatment Differences

Smoking cessation

Smoking cessation is the single most important disease management strategy available to patients with COPD who are still smoking. Quitting smoking has more of a positive impact on health status and disease progression than any other type of treatment.5 For women with COPD, the benefits are particularly high. One large, five-year study of smokers with COPD looked at the change in breathing ability over time in a group of men and women who quit smoking compared to a group who did not. In the first year, everyone who quit smoking showed significant improvement in their breathing ability, but the benefit in the women was more than twice as great as that in men. Over the course of the study, the lung function of all the participants gradually declined, as is to be expected with COPD. When looking at the five-year results for the study, men who stopped smoking had an endpoint lung function that was not different from their starting one. However, women who stopped smoking still saw significantly improved lung function at the end of the study.47

Considering the fact that stopping smoking has such clear and immediate benefits, it is surprising how little is known about the particular issues that women with COPD face when trying to quit. When looking at the population as a whole, women who smoke make quit attempts about as often as men, and they are more likely to seek counseling and medication to support their efforts.48 Unfortunately, they have less success quitting than men, whether or not they use cessation medications. The reasons for this remain unclear, but may be related to the fact that female smokers are more psychologically and emotionally dependent on tobacco, and more vulnerable to depression during quitting.49 Smokers who are depressed are known to be more likely to relapse after a cessation attempt. Experts recommend that cessation services for women be tailored to their specific needs and concerns, including social support.50

Pulmonary rehabilitation

Pulmonary rehabilitation is a physician-supervised treatment program that combines exercise training, self-management education, counseling and social support to maximize a patient’s functional ability and quality of life. In a series of sessions over a six- to 12-week period, participants work with nurses, respiratory therapists and health educators on specific activities tailored to individual conditions and needs. This approach has been proven effective to reduce shortness of breath, improve strength and ability to perform daily tasks and cut healthcare costs.51 Experts widely agree that pulmonary rehabilitation should be a core component of the management plan for all patients with COPD.5

Several studies have found that women experience greater improvements in shortness of breath after a standard-length program.52–54 This is noteworthy because, in general, women with COPD report more problems with shortness of breath impacting their daily functioning and quality of life. There is some evidence that women do not retain their physical improvements as well as men, perhaps because they are less likely to keep up a rigorous exercise regimen. They do, however, get considerable benefit from the social support aspects of the program.52,55

Exercise not only lets me live, it enables me to have a life.

– Jean Rommes

In spite of its proven effectiveness, pulmonary rehabilitation is greatly underutilized. It is estimated that only 2 percent of the COPD population has access to an existing program.51 A shortage of trained providers, lack of knowledge about the program and low level demand from primary care physicians are all factors that need to be addressed. Little is known about whether or not women are less likely to be referred to pulmonary rehabilitation than men. But in cases where insurance coverage and ability to pay are a limiting factor, women are presumably at a disadvantage. Fortunately for older COPD patients, Medicare adopted new rules covering pulmonary rehabilitation services in 2010.
Self-Management and Quality of Life

Self-management of COPD is complex and often includes making major lifestyle changes and keeping track of numerous medications. Unfortunately, many people living with COPD don’t seem to self-manage their disease very well. A survey of COPD patients in Australia found that lack of adherence to prescribed treatments was higher than what is typically found with other conditions. The reasons appeared to be a combination of unintentional responses—"I get confused about my medication"—and intentional responses—"I vary my recommended management based on how I am feeling."56

There is not much information available about differences in how men and women with COPD self-manage their disease and stick with prescribed therapies. One study of COPD patients in the hospital emergency department found that, compared to men, women had taken fewer self-management steps in the early stages of their symptom flareup, used less medication and waited longer before seeking emergency care.57 This is of concern because delay in seeking treatment for a COPD flareup has been linked with slower recovery, increased risk of hospitalization and overall lower quality of life.58

When I landed in the hospital with respiratory failure, my prognosis did not look good. My doctor laid all the cards on the table and told me exactly what I need to do if I wanted to live and live with any quality of life. I was filled with fear—it is really scary when you can’t breathe. I wanted to live. My husband needed me. I had a lot to learn, but I was actually motivated by the challenge.

– Jean Rommes

Perception of disease-related stigma can lead to reluctance to use beneficial treatments that “mark” patients with the disease in the public eye. This is a problem for people living with COPD, particularly for those patients with advanced disease who need to use supplemental oxygen. Studies show that a range of only 40–70 percent of patients who have been prescribed oxygen use it as directed.59
Quality of Life

Health-related quality of life is a well-accepted measurement that is used to assess the impact of disease on patients’ daily lives, activity and well-being. Instruments that measure quality of life include questions about symptoms, mobility, social interaction and emotional behaviors. Quality of life is an important measurable outcome in patients with COPD, and has been shown to be a good predictor of mortality, hospitalization, healthcare utilization and response to treatment.

The quality of life for women with COPD is impacted earlier in life, and is worse overall than that of men with similar severity of disease. This is due, at least in part, to a strong relationship between shortness of breath and quality of life, and the fact that women experience more problems with shortness of breath. It is important to note that the concept of shortness of breath is not the same thing as measurable lung function. It is a subjective experience of breathing discomfort, which for people with COPD is affected by degree of airway obstruction, levels of oxygen in the bloodstream, strength of the muscles that are needed for breathing as well as psychological factors.

In addition to shortness of breath, women’s quality of life is mostly affected by impairment of their social and emotional well-being. Anxiety and depression are two of the most common co-occurring conditions in COPD patients, and have a major impact on quality of life. A comparative study of the rates of anxiety and depression in people with and without COPD found that compared to the control group, the COPD patients were 3.1 times more likely to suffer from anxiety and 6.8 times more likely to suffer from depression. The women with COPD had the highest levels of both anxiety and depression.

Women with COPD are clearly at risk of being caught in a downward spiral. Poor quality of life and increased anxiety and depression contribute to a lack of adherence to treatment regimens, more frequent emergency visits and significantly more relapses. Frequent symptom flare-ups in turn further decrease quality of life and worsen the severity of disease. Unfortunately, the psychosocial aspects of COPD are not well recognized or addressed in primary care settings where most COPD patients are diagnosed and treated. Studies have found that less than one-third of COPD patients with depression and anxiety were receiving appropriate treatment, and many primary care physicians express surprise that depression is a common problem for patients with COPD.

In the last six months of her life, everything became such an effort. She got depressed because she was not able to do anything and had lost her independence. She told me knowingly, “I’m on a slippery slope and don’t want to continue like this.”

– Lynn S., daughter of Marilyn K.
Not-So-Benign Neglect

Considering COPD has recently moved from the fourth to the third leading cause of death in the U.S., it is troubling that the disease is still largely overlooked or omitted from the public health system's planning and programs. There appears to be little or no focus on COPD at the Centers for Disease Control and Prevention (CDC), the nation's leading public health agency. It is not included on the list of 17 different programs run by the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). The Preventive Health and Health Services Block Grant Program does not include COPD among chronic diseases it addresses. In fact, a frequently-asked-questions document about the CDC’s Coordinated Chronic Disease Prevention and Health Promotion Program omits mention of the disease completely: “The focus of the program is on the top five leading chronic disease causes of death and disability (e.g., heart disease, cancer, stroke, diabetes and arthritis) ...”

In an attempt to encourage a greater federal response to the disease, the United States Senate, in its Fiscal Year 2012 report, tasked the National Heart, Lung and Blood Institute (NHLBI), in conjunction with the CDC, to develop a national COPD action plan. This comes after the publication of a document by the CDC in 2011 titled Public Health Strategic Framework for COPD Prevention, which did not result in any meaningful action. The NHLBI is expected to move forward with an action plan in 2013, which advocacy organizations and patient groups are hopeful will at last give the nation a coherent, impactful and funded effort to address the public health role in prevention, treatment and management of this disease.
Recent Successes

Fortunately, there are pockets of activity in the public and private sectors where progress is being made to address the staggering needs of women at risk of or living with COPD.

Using Data for Public Health Planning

There has been a long-standing paucity of nationwide data collected about COPD compared to other serious diseases. In 2011, for the first time, a state-level COPD prevalence question was added to the annual Behavioral Risk Factor Surveillance System (BRFSS), co-sponsored by the CDC and NHLBI. It asked a sample of adults in all 50 states, the District of Columbia and Puerto Rico if they had ever been told by a physician or other health professional that they have COPD. In additional, state health departments were encouraged to add an optional set of questions to ask people who answered yes to the first question for more information about their symptoms, medications, use of health care and quality of life. Twenty-one states, DC and Puerto Rico all elected to include the optional module.

In years to come, as the BRFSS results accumulate, policymakers and public health advocates will be better able to track and analyze trends in prevalence and overall burden of disease at the national, state and local level. Being able to answer questions like “Which subgroups of people have the highest rates of COPD?” and “Why do COPD patients in my state use more healthcare resources than average?” will be invaluable in formulating policy change and targeting education efforts to help the people who need it most, including women. For this to happen, though, it is imperative that the CDC and all 50 states continue to support the BRFSS, and that the optional module is universally adopted.

Raising Awareness

Increasing public awareness of COPD is a critical step in getting people with the disease diagnosed and into proper treatment. It is especially important that women who are at risk, and their healthcare providers, get the message that COPD is not just a man’s disease. The situation is similar to that in 2002, when the NHLBI responded to concerns of experts in heart disease and women’s health to launch the Heart Truth campaign. At that time, only 34 percent of women knew that heart disease was their leading cause of death. NHLBI and its network of partner organizations determined to develop the campaign with the goal of creating a strong brand that would have a powerful emotional appeal to women of all ages and ethnicities: the now-famous Red Dress. The campaign took off, becoming a catalyst for a wide range of activities at the national and local level, and driving awareness levels up to 69 percent by 2009. More importantly, women who had been exposed to the campaign were more likely to take action to protect themselves from risk and to talk to their doctors about heart disease.

In 2007, NHLBI took on the similar need to raise awareness about COPD by launching the Learn More, Breathe Better® campaign. When the campaign started, baseline surveys showed that only 49 percent of adults had heard of COPD. Although Learn More, Breathe Better does not yet have the strong brand recognition of the Red Dress, it has built a strong national network of partners that supports the campaign through a range of promotional activities. Since then, annual surveys showed incremental success in increasing awareness, up to 71 percent of adults in 2011. Long-term success will require long-term investment in the campaign, as well as tailoring of key messages for high-risk audiences.
Engaging Women in Leadership

The Women in Government (WIG) Foundation is a national nonprofit, nonpartisan organization of women state legislators that provides leadership opportunities, networking expert forums and education resources to address the complex public policy issues confronting their members. Since its founding in 1988, the organization has had women’s health as one of its priority areas of focus. For the last several years, WIG has been working in partnership with the COPD Foundation to educate their members about the burden of COPD in their communities and the role that state legislators can play in making a difference. They have hosted joint educational sessions at WIG’s regional conferences and annual Healthcare Summit, conducted COPD screening events for members and developed a COPD Toolkit for action, among other activities.

Through conference programming, this partnership has reached more than 210 women state legislators representing 30 states. At the Third Annual Healthcare Summit, 45 veteran legislators from 25 different states recorded PSAs, and in January 2013, 23 newly elected women state legislators recorded PSAs, all of which will air throughout 2013. Together, the two organizations plan on expanding collaboration to co-host a series of briefings, screenings and awareness events at state capitals, raising COPD’s priority level in state legislatures across the country.
Finding a Better Way to Provide Care

In recent years, researchers and healthcare systems have been experimenting with a patient-centered approach to care that is promising to yield better health outcomes than the standard physician-centered approach. Patient access is improved, disease self-management is emphasized and hospitals and physicians operate in integrated systems that improve collaboration. The results are demonstrating better knowledge of patients and their needs, improved quality and greater efficiencies in the delivery of care.

At the Mayo Clinic, clinicians are having some success combining conventional medicine with complementary and alternative medicine, using self-empowerment and mindfulness training. This approach was designed by Roberto Benzo, M.D., a pulmonologist and epidemiologist with an interest in behavioral medicine. The result is that the patients in his care report that they feel better physically and emotionally. Data analysis suggests that hospital admissions could be reduced by 20 percent, a huge impact for individual patients and on overall healthcare costs.

An innovative program at Temple University Health Systems Lung Center is the COPD-PILOT (Personalized Daily Exacerbation Management Tool). This clinically validated monitoring system using smartphone technology allows patients to log in daily to report their symptoms. Each patient is assigned a score and a member of the clinical management team follows up with the patient with appropriate recommendations and encouragement. A recent review demonstrates a 30 percent reduction in acute exacerbations versus standard of care, with a 90 percent compliance rate for patients monitored daily.

Better Breathers Club

For more than 40 years, the American Lung Association has offered Better Breathers Clubs to patients and their caregivers who are living with chronic lung disease. Better Breathers Clubs meet regularly and are led by trained facilitators. Patients and their loved ones learn ways to live better with COPD while getting support from others who share many of the same struggles. These support groups give patients tools they need to live with the best quality of life possible.

For people living with COPD who feel alone and isolated, these support groups do help. Through educational programs, skills building and talking with others who understand, patients report that not only do they benefit emotionally, but it also has a positive impact on their health.

Questions About COPD?
The Lung HelpLine is a toll-free resource for patients and their caregivers to speak with a registered nurse, respiratory therapist or quit smoking specialist about COPD. Call 1-800-LUNGUSA (1-800-586-4872) from 8 am–12 midnight, Eastern time.
My mother would often say to me, “You don’t know what it is like to not be able to breathe. You don’t know how hard it is,” and I was sad because I just wanted to know what I could do for her.

- Lynn S., daughter of Marilyn K.

Taking Action

There are a number of positive steps that can and should be taken to make a difference in the health and well-being of the millions of women at risk from COPD in the United States. The American Lung Association calls upon government agencies, the research and funding communities, insurers, health systems, employers, clinicians, women and their families to take action now. Most importantly, the leadership in public health and health care at the national, state and local level must embrace a sense of urgency and a can-do attitude about COPD. This will benefit both women and men living with COPD, as well as their loved ones and their communities, all of which are suffering from this terrible disease.

- The Centers for Disease Control and Prevention must recognize the fact that COPD is a leading cause of death and disability in the U.S., and create and support a comprehensive COPD program commensurate with the magnitude of the burden this disease has on public health.

- All 50 states, the District of Columbia and Puerto Rico should adopt and retain the optional COPD question module as part of the annual Behavioral Risk Factor Surveillance System.

- State and local governments should enact and enforce laws that protect the public from exposure to secondhand smoke.

- The COPD research community, including public and private funders, should ensure adequate participation of women in clinical trials, as well as analysis and reporting of sex-stratified data.

- All healthcare systems, including public and private payers, purchasers and providers, should implement and be accountable for patient-centered practices that address access, operational excellence and quality of care for COPD.

- Employers should include COPD prevention and management in their workplace wellness initiatives, including smoking cessation, accurate diagnosis, reduction of occupational exposures and guideline-based management as key interventions.

- Agencies and organizations that provide community-based smoking cessation programs should ensure that the counseling, medications and follow-up they provide are effective at meeting the particular needs of women.

- Healthcare providers should adopt policies and practices that improve diagnosis and treatment of COPD in women, including spirometry, screening and referral for depression, and linkage with community programs for social support.

- Women’s health advocates should recognize and address the importance of COPD as a priority issue for their constituency.

- Women living with COPD should take steps to learn all they can about their disease and how it affects them; to advocate for their own best care, including the disease management services and social support that they deserve; and to become a voice for themselves and other women with COPD in their community.
References

20. Figure is based on NHIS or related data since 1965 and NVSS since 1981. Earlier years are estimated based on summation of multiple sources, including cigarette consumption data, age-specific cohort trends, estimates of lag times and vital statistics summaries of the United States.


Acknowledgments

“Taking Her Breath Away: The Rise of COPD in Women” is the sixth report in the American Lung Association’s Disparities in Lung Health Series that takes an in-depth look at the needs of populations that bear an unequal burden of risk and disease.

These reports build on the American Lung Association’s long-standing commitment to saving lives and improving lung health and preventing lung disease for all Americans. For a compendium of information about lung disease in various racial and ethnic populations, see the “State of Lung Disease in Diverse Communities: 2010,” available at www.Lung.org.

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Chris Garvey, FNP, MSNMPA, FAACVPR - Manager, Seton Medical Center Pulmonary and Cardiac Rehabilitation

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About the American Lung Association

Now in its second century, the American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease. With your generous support, the American Lung Association is "Fighting for Air" through research, education and advocacy. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call 1-800-LUNGUSA (1-800-586-4872) or visit www.Lung.org.