

# How do patients conceptualize chronic obstructive pulmonary disease?

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## Abstract

Chronic obstructive pulmonary disease (COPD) is a leading cause of death in the United States, yet even at risk or diagnosed patients misunderstand COPD and its consequences for their quality of life and mortality. This study explored how patients conceptualize the causes, symptoms, consequences, treatment, and risk for developing COPD. The study consisted of six focus groups: 39 participants who were adults  $\geq 40$  and current smoker or have COPD symptoms, family history, or exposures. Although many participants had some familiarity with the breathing, lung function, physical, emotional, and social consequences of COPD, confusion and misunderstanding prevailed. Few knew that COPD, chronic bronchitis, and emphysema are synonymous. Some participants claimed that they “only” had bronchitis and/or emphysema and not COPD. Some participants described behavioral adaptations to decrease symptom impact and others expressed strong interest in learning how to increase daily functioning. Insufficient knowledge and persisting misconceptions about COPD can prevent patients from accessing life-enhancing strategies. Patients can benefit from (1) providers clarifying COPD’s connection to chronic bronchitis and emphysema to aid them in recognizing the need for mitigating action; (2) encouraging smoking cessation, specifically to stem worsening of disease; and (3) explaining lifestyle adaptations for easing daily life despite decreased lung function.

## Keywords

COPD, qualitative, patient perspective, patient education needs, primary care

## Introduction

Chronic obstructive pulmonary disease (COPD) is progressive, debilitating and constitutes the third leading cause of death in the United States.<sup>1</sup> Most cases of COPD are caused by cigarette smoking and are associated with chronic, often worsening airflow limitation.<sup>2,3</sup> In response to this health crisis, in 1998, the National Institutes of Health, along with the World Health Organization, initiated the Global Initiative for Chronic Obstructive Lung Disease,<sup>4</sup> which in 2001 issued its first report about the causes, pathology, and treatment of COPD.<sup>4</sup> Nevertheless, there remains significant lack of knowledge among the public about prevention, diagnosis, and treatment of COPD, notably by individuals who are themselves at risk for or already diagnosed with COPD.<sup>5–17</sup>

As more is understood about the relationship between patients’ perceptions of COPD and disease prognosis/outcomes, there has been growing interest

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in delving more deeply into patient experiences.<sup>5,6,9,10,12,18</sup> Research highlights that for many, receiving a diagnosis of COPD is confusing. Lack of information or adequate explanation can leave patients misinformed about the causes, symptoms, consequences, and treatment of COPD.<sup>8–10,12,13,17</sup> Further, studies found that COPD often goes undiagnosed among at-risk patients until symptoms are pronounced because many patients attribute their worsening symptoms to the natural process of aging.<sup>6,12</sup> In some studies of patient comprehension, individuals reported being unaware that the disease is chronic and did not understand that a diagnosis of emphysema and chronic bronchitis is in fact a diagnosis of COPD, at times due to providers' deliberate omission.<sup>10,12,14,16,17</sup> In addition, this lack of awareness of the chronic and irreversible nature of COPD can lead patients to remain ignorant of both appropriate treatment options and ways to slow the progress of the disease.<sup>9,15,17</sup> As such, patients may view their condition as minor and may be prevented from seeking help.<sup>12,13,15</sup> Furthermore, as yet undiagnosed individuals may delay seeking medical attention due to the fear of receiving a diagnosis of COPD.

This article reports findings from focus groups conducted with individuals who were either at risk for COPD or have been diagnosed with emphysema, chronic bronchitis, or COPD. Our overall research question was: How do patients conceptualize the causes, symptoms, consequences, treatment, and risk for developing COPD?

## Methods

### Research design

We designed a phenomenological qualitative study<sup>19</sup> to elicit in patients' own words what their experience and understanding is of COPD and to explore their perceptions of risk for and living with the disease and its symptoms. We collected study data through use of focus groups to benefit from the interactive discussions among participants that focus groups foster.<sup>20,21</sup> The focus group data served as the formative phase of a randomized clinical trial addressing patient activation for reducing risk or worsening of COPD.

### Instrument design

Given our interest in hearing participants discuss their own experience with and thoughts about COPD, its risk and symptoms, we used a phenomenological approach to the way we chose focus group question

topics and worded our questions to understand the meaning of the study topics to participants.<sup>19</sup> We developed a core list of multipart, predominantly open-ended questions informed by published literature on patients' perceptions of COPD risk, prevention, and treatment; and the chronic care model that served as the guiding theoretical framework for the study. The chronic care model is aimed at improving management of chronic diseases. The model holds that an informed, empowered patient, and/or caregiver will interact with a patient care team led by the physician to develop productive communications and actions leading to improved health care outcomes. Elements of the model include self-management support, delivery system design, decision support, and clinical information systems.<sup>22–25</sup> To prepare for implementation in a subsequent phase of this study of an intervention based on the chronic care model, it was important to identify attitudes, beliefs, understandings, perceptions, experiences, resources, and knowledge according to patients' supports (facilitators) or inhibitors (barriers) within the primary health care setting.

Core questions were supplemented with spontaneous probes and follow-up questions during the focus groups. We discussed participants' own beliefs, behaviors, and concerns about COPD, and their perceptions of those they observed among others. Questions relating to the findings reported in this article addressed: What participants knew or had heard about COPD, emphysema, and chronic bronchitis; perceptions of risk for developing or worsening of COPD; physical, emotional, and social consequences of COPD; and strategies for living with COPD. We drew from our local patient population to test our questions for meaning and clarity and adjusted wording as necessary. The resulting question guide is included in Appendix 1.

### Setting, sample, eligibility criteria, and recruitment

The sample was drawn from the greater Providence, Rhode Island area (encompassing the city of Providence and a number of small former manufacturing towns) and Boston, Massachusetts, USA. We used a criterion-based purposive sampling technique<sup>26</sup> such that we strategically recruited individuals for participation with the prescribed inclusion criteria of being  $\geq 40$  and having at least one of the following conditions: COPD, a positive history of COPD symptoms (chronic cough, sputum production), family history of COPD, occupational and/or environmental tobacco

smoke exposure, being a current smoker. Because we were interested in both perceptions of COPD risk and experience of living with COPD, we recruited individuals who either had COPD or were at risk for developing the disease. Participants were recruited by calling a toll free telephone number listed in advertisements posted in Providence and Boston newspapers and at Memorial Hospital of Rhode Island. A brief telephone screening survey ensured eligibility, and participants were assigned to attend a group that was convenient to them. We designed our focus group composition to ensure a diversity of participant characteristics to facilitate production of discussions that would generate a range of insights on our study topics.

### Data collection

Focus groups were facilitated by one of the authors (REG), an experienced qualitative researcher; project staff attended as note-takers. Two groups were held in Boston and four in the Providence area. We terminated focus group implementation at six groups, having reached data saturation where no new information was obtained.<sup>27</sup> Discussions were audio recorded and professionally transcribed. Healthy refreshments were provided and participants received US\$20. The study was approved by the Institutional Review Board of Memorial Hospital of Rhode Island and participants provided written informed consent.

### Data analysis

We used an iterative immersion/crystallization qualitative analysis process,<sup>28</sup> which entailed each coauthor individually reading the focus group transcripts in their entirety to reflect on the contextual nuances of the discussion, taking notes on our individual analyses, and then meeting regularly as a group to discuss our evolving interpretation of the data. Based on these preliminary analyses, we created a code book comprised of topical codes that covered concrete subject areas that were included in the question guide or arose during discussion; thematic codes that covered the abstract concepts that emerged during initial reading of the transcripts; and theory-based codes consistent with precepts of the chronic care model.<sup>29</sup> Each code was thoroughly discussed until the entire team agreed upon what the code definition would encompass. We tested the usefulness of the codes by applying them to the first available transcript and modified as needed, testing them again on the next transcript. A research assistant under the supervision of the project

**Table 1.** Characteristics of participants (N = 39).

| Characteristic                                     | N     | %    |
|--|-------|------|
| Gender   |       |      |
| Male   | 16    | 41.0 |
| Female   | 23    | 59.0 |
| Race/ethnicity                                     |       |      |
| Hispanic/Latino (% yes)                            | 1     | 2.6  |
| Caucasian  | 26    | 66.7 |
| African American                                   | 8     | 20.5 |
| Native American                                    | 1     | 2.6  |
| Other  | 4     | 10.2 |
| Education  |       |      |
| ≤HS graduate <sup>a</sup>                          | 18    | 46.2 |
| College  | 15    | 38.4 |
| Post graduate                                      | 6     | 15.4 |
| Income   |       |      |
| ≤US\$30,000  | 23    | 58.9 |
| US\$31,000–US\$60,000                              | 13    | 33.3 |
| >US\$60,000  | 3     | 7.8  |
| Employment status                                  |       |      |
| Working  | 15    | 38.6 |
| Retired  | 12    | 30.7 |
| Other <sup>b</sup>                                 | 12    | 30.7 |
| Diagnosed with COPD                                | 10    | 25.6 |
| Current smoker                                     | 14    | 35.9 |
| Chronic cough/sputum                               | 22    | 56.4 |
| Family history of COPD                             | 23    | 58.9 |
| Family history of COPD among individuals with COPD | 5     | 21.7 |
| ETS exposure                                       | 26    | 66.7 |
| Occupational exposure                              | 15    | 38.5 |
| Age (years) <sup>c</sup>                           | 42–79 |      |

COPD:chronic obstructive pulmonary disease.

<sup>a</sup>Includes technical school.

<sup>b</sup>Includes three disabled, three stay at home, and six missing data.

<sup>c</sup>Range.

investigators then coded all transcripts using the qualitative data management software, Weft QDA.<sup>30</sup> The resulting code reports were then further analyzed by two authors (REG and LM). They read each code report while writing notes and interpretive memos to track the data for each code as manifested in each of the focus groups.<sup>31</sup> These notes were then used for discussion with the coauthor team and to guide our final interpretation and presentation of the data.<sup>32</sup>

## Results

We conducted six focus groups with 39 participants (Table 1). Forty-six percent were men; two-thirds were White; over 50% had at least some college education; 58.9% had income of ≤US\$30,000/year; and

age range was 42–79 years. Twenty-eight percent reported having been diagnosed with COPD; almost 59% reported family history of COPD; and over one-third were current smokers.

### Knowledge about COPD

Most participants who had neither been diagnosed with COPD, nor had a family member with COPD, were unfamiliar with COPD. Some, who felt personally unaffected by COPD but had heard the term in the media, knew little about what the disease entailed. A participant commented, “It’s like the new word that comes out . . . It’s got something to do with the lungs and I really don’t know that much about it” (Focus group [FG]4).

For most participants who were diagnosed or knew someone with COPD, understanding was limited to recognizing that COPD somehow affects lungs and daily functioning. “It’s obstruction of the airways . . . where you feel like you’re suffocating. You’re on oxygen all the time” (FG5). While many used some medical vocabulary to describe COPD, they were unclear about the meanings. One participant ventured, “Chronic obstruction of the pulmonary gland, or something like that. It’s respiratory. It’s in your lungs” (FG6). Another offered:

I know basics of it. Damage to the lungs and . . . it greatly distracts from your quality of life. I also know about the oxygen and the nasal cannula. (FG3)

Another participant, referring to emphysema, gave more details:

The air sacs in your lungs . . . tend to be distended over a period of time and become flaccid. So they don’t have the ability to shrink and grow . . . It makes it difficult to move air through your lungs. (FG1)

While many participants believed that emphysema and chronic bronchitis are somehow related to COPD, few understood that they are the same disease. Some asserted that they were diagnosed with emphysema and/or bronchitis but not COPD:

Q: Has anyone been told that you have COPD?

A: No. I have emphysema and bronchitis . . . My husband—he’s got bronchitis and emphysema and asthma. And now he’s got COPD. (FG6)

Others thought that COPD is a catch-all phrase for various diseases:

COPD is a kind of alphabet soup of various breathing problems which consists of asthma, emphysema, bronchitis and other miscellaneous things. And it could be one or two or all. (FG1)

After eliciting participants’ perspectives, the moderator explained that COPD is a term used to describe progressive lung disease and *includes* emphysema and chronic bronchitis. Nevertheless, participants continued to express confusion: “So bronchitis then eventually leads to emphysema?” (FG4); “Chronic bronchitis is emphysema along with COPD? I don’t have COPD” (FG6). Most who had heard of COPD knew that it is considered to be a “chronic” condition; however, some misunderstood what chronic entails and believed that COPD is not a permanent condition. Participants were far more familiar with asthma than with COPD, and some merged the two: “I’m just assuming [COPD is] kind of an acute version of the chronic asthma stuff” (FG1).

### Causes of COPD

Some participants who had heard of COPD attributed the development of COPD to other conditions that affect breathing, such as asthma, allergies, and pneumonia. Most who knew of COPD, did, however, have an understanding of associated risk factors, stating that smoking and/or environmental conditions were paramount. Many claimed that their own or family members’ COPD was caused by smoking or exposure to secondhand smoke. However, several participants expressed doubt that smoking would cause them to develop COPD, citing older smokers who never developed the disease, and attributing their own symptoms to aging. A few believed that doctors use the specter of illness to scare them into quitting. Some participants did not know that smoking-related lung damage may not be evident until later in life, or that health problems can develop after quitting.

In contrast, participants who had regularly inhaled particulates at work even years earlier asserted that these conditions put them at greater risk for breathing problems such as COPD. The most commonly mentioned inhalation exposure was asbestos. Other job-related exposures included cotton mill fibers; lace machine graphite; paints; galvanized iron smoke; asbestos at shipyards and elsewhere; chemicals used in production of medications, jewelry, and other products; formaldehyde; and dust from slaughterhouse bone grinding.

The most frequently mentioned causes of COPD emanating from the broader environment were air

pollution and exhaust fumes associated with modern urban society. Some stated that home environmental conditions contributed to COPD risk, including mold, carpet fibers, cat hair, and wood smoke. Many participants believed that COPD, asthma, and the propensity to develop bronchitis could be inherited, which triggered some to take health precautions such as seeking information and being tested if there was a family history of the diseases. However, others expressed fatalism: "What I think right away is, 'Jeez, I'd really like to have a cigarette. It's in my family anyway, so let's smoke.' Right?" (FG4). Some participants were unaware of or unconcerned about a hereditary factor in COPD.

### **Consequences of COPD**

**Physical consequences.** The physical sensation of not being able to breathe well, especially when walking, climbing stairs, or lying down, was described in detail by participants who were familiar with COPD. As one participant avowed, "Nothing else matters when you cannot breathe" (FG1). A man described his mother: "She labored to breathe. And it wasn't good to see" (FG4). Another participant said her mother was overusing the medication at the end of her life because, as she would say, "It feels like I'm drowning or smothering" (FG3). Another described her worries:

You know what my fear is? Of one day not being able to breathe on my own. Struggling, having to be on a machine . . . Just the idea of maybe one day I suffocate to death because I can't get enough air. (FG5)

Others mentioned lightheadedness, flu-like symptoms, and irregular heartbeat.

**Functioning.** Participants throughout the groups noted that COPD greatly limits physical capabilities, particularly stair climbing, and makes walking, exercise, house cleaning, yard work, and grocery shopping difficult. Participants described even the simplest daily tasks like negotiating a short flight of stairs to let the dog out, as no longer possible for them. "Everything is an effort—to get up, to move, to breathe" (FG5). "A lot of the functions that you would normally do are limited, such as you can't reach for things. It's hard to bend over" (FG1). Inability to complete basic tasks was associated with loss of independence and control. As one participant admitted, "Sometimes I can't even get up and go to the bathroom because I have to get on my face oxygen to help me breathe" (FG2).

**Emotional consequences.** Some participants noticed that they or others suffered from depression because they were impeded in their activities and disappointed or concerned family members. "You get depressed over it because you can't go out. You can't move . . . stuck in the house" (FG5). Themes throughout the focus group discussions related to people's inability to maintain control over their environment and their body's response to the environment, such as changing weather conditions making breathing more difficult. This included climates that are too cold, hot, humid, or dry. Inability to predict how they will feel from one moment to the next caused anxiety, as a participant explained:

[COPD] puts me in a state of always wondering how things are going to turn out, and just because I'm feeling good right now there's no insurance that that's [not] going to change quickly . . . It also affects your personality—it's hard to be happy when you're facing constant imminent changes. (FG1)

While some participants openly discussed COPD with friends, family, and coworkers, others, particularly if they were not ready to quit smoking, were discouraged from talking about the illness because they received repeated admonishments about quitting that they did not perceive to be helpful or supportive. One participant described his girlfriend's reaction whenever he mentioned his difficulty breathing:

"Cut down on cigarettes," and "That's your problem," and "You know how you're going to feel when you come up that hill every day." . . . So I keep it to myself. (FG5)

Some participants were fatalistic about how smoking puts them at risk for COPD. One described his mother's dependence on a portable "breathing machine" and oxygen, stating, "It's not a pretty sight." Yet he also asserted, "As far as it affecting me, I don't worry. I'm 67 years old now. I'm not going to worry about making big changes in my life, what's left of it" (FG4). And another claimed:

I know that eventually I'm going to get [COPD]. But I'm not scared to get it. I already have a nebulizer. I'm beyond breathing medication. So I already know what to expect. But I haven't quit yet. I'm not scared into quitting. (FG6)

Fear of experiencing a painful death was expressed by many of the participants who knew about COPD.

Some current smokers conveyed angst about not having quit. A nurse who had witnessed patients suffering with advanced COPD, stated, “That’s what I’m trying to avoid even though I still smoke. I want to really stop, because I know the risks that you take” (FG5). For some, this fear inspired preventative action:

I think one of the most painful deaths I ever had to witness was people with COPD or emphysema . . . And that scared me enough to make me quit smoking. (FG5)

### ***Making the most of the day, even with COPD***

Despite the barriers and challenges that these participants endure, many were thoughtful about strategies that they use to reduce incapacitation from their disease. A patient remarked, “The doctor can do only so much; you have to do something” (FG2). A few spoke positively about joining a supervised pulmonary rehabilitation program that combined breathing techniques to maximize air intake with less effort, supervised aerobic exercise, and dietary recommendations. They felt that the exercise strengthened their lungs, and losing weight lessened the severity of breathing and walking difficulties. However, more participants described techniques that they implemented themselves, including quitting smoking. As one participant enthused, “I’ve only been a nonsmoker for a year. And I can tell you that you feel better!” (FG5). Another, whose sleep apnea had also subsided, claimed, “I was coughing a lot especially at night and also wheezing, and since I quit smoking I don’t do that anymore” (FG4). Many participants highlighted the need to keep active despite the physical limitations COPD imposes, both to raise one’s spirits and for the health benefits of losing weight. A participant who enjoys spending time with her multigenerational family observed that there are many with COPD who give in to depression and become isolated.

Participants offered strategies to mitigate the discomfort of COPD while persisting with desired activities, including finding ways to control the ambient environment. They recommended use of air conditioning, dehumidifiers, humidifiers, and on a cold day, wrapping a scarf around one’s face to warm the air one breathes. Participants explained in various ways how they learned to “pace” (FG2) themselves and not hurry even if others are waiting for them, walk slowly, clean part of the house at a time, and rest every few steps when climbing stairs. A participant asserted that people with COPD are “ordinary people.

That’s what we’re doing—trying to live, you know?” (FG2). Participants who admitted that they had given in to the constraints imposed by their decreased lung function and those whose breathing problems had recently begun appeared to listen closely to these suggested adaptive strategies.

## **Discussion**

Similar to findings from other publications, in our focus group study, there was considerable confusion among participants about what COPD is.<sup>9,14–17</sup> A theme running through all the groups was the misperception that COPD is a separate and more severe disease than chronic bronchitis or emphysema. This was true both for individuals who were diagnosed with COPD and those who were at risk for COPD. In fact, many who had been diagnosed expressed relief that they had bronchitis or emphysema rather than COPD. Similarly, Hansen et al. found that no participants voluntarily labeled their illness as COPD, instead calling it emphysema, asthma, or bronchitis.<sup>16</sup> A study of Canadians at risk for COPD found that 60% knew very little or nothing about COPD.<sup>33</sup> Among Brazilian primary care patients, only 9.2% recognized the term COPD.<sup>34</sup> Jones et al. and Walters et al. found that primary care medical providers often obfuscated the diagnosis, either intentionally, or because they had difficulty explaining the concepts used by respiratory specialists to patients.<sup>14,17</sup> Despite patients’ common misunderstanding of COPD, those in our study who had heard of COPD knew that it affects breathing and lung function and were well aware of the difficult physical and emotional consequences of the disease.

Participants in our study were more familiar with asthma than COPD, and many who had heard of COPD merged the two conditions. An important implication for patients’ confusion about asthma and COPD is highlighted by recent research describing an overlapping condition. That patients tend to conceptually combine these conditions may be due in part to the way their providers explain their disease when patients present with clinical features of both. Until recently, asthma and COPD were typically regarded as two distinct disease entities, but they are increasingly recognized as constituting an overlapping condition for about 20% of patients with obstructive airway diseases.<sup>35</sup> A new term has been created for patients with clinical features of both asthma and COPD: the asthma–COPD overlap syndrome (ACOS).<sup>35,36</sup> Patients have heterogeneous presentations of ACOS

that may more resemble one disease over the other and that require complex assessment to identify effective treatments for this combined condition that has been associated with increased negative outcomes over either condition alone.<sup>35</sup> Definitive clinical guidance for ACOS requires further research,<sup>37</sup> and while an approach to initial treatment has been proposed,<sup>38</sup> primary care providers are challenged in discussing the disease overlap with their patients. Provider uncertainty may contribute to persisting confusion among patients regarding asthma, COPD, what obstructive airway disease they are being treated for, and implications for future outcomes.

While not all of the smokers in our discussions were ready to quit, almost all acknowledged that smoking is the predominant cause of COPD. Similar to our findings, de Castro et al. noted that most of their participants (87.5%) knew that smoking was a risk factor for COPD,<sup>34</sup> whereas in a large international survey, just 38% of patients strongly agreed, and 28% somewhat agreed that smoking “is the cause of most cases of COPD.”<sup>11</sup>

Hansen et al. found that individuals diagnosed with COPD preferred external explanations of their illness such as exposure to toxins and prior conditions like asthma, over perceived self-perpetuated ones like smoking.<sup>16</sup> Interestingly, as our focus groups drew participants from regions that have historically been centers of manufacturing (lace, other textiles, costume jewelry, etc.) and shipbuilding, occupational health risks were on participants’ minds.<sup>39,40</sup> While people in each group believed that they had personally experienced occupational exposures or knew others who had and they maintained that these exposures resulted in the development of COPD symptoms, these participants did not rule out the role of smoking as well.

Studies have shown that even for those who are well-informed about COPD and treatment, there are varying levels of acceptance and motivation to change because individuals report feeling overwhelmed by a disease so complex and far-reaching in its effects.<sup>15,41–43</sup> Some of our participants seemed acutely aware of what their symptoms indicate and steps that are necessary to improve their health. However, many were in denial about their symptoms worsening or being attributable to COPD. A few held fast to their belief that quitting smoking would not stop development of COPD and may even make their condition worse. Compounding these beliefs, low self-esteem and the shame of having contracted what patients may perceive to be a “self-inflicted” disease

has been shown to prevent many from seeking help in response to symptoms.<sup>5,6,12,15,16</sup>

Psychologically, COPD has been correlated with anxiety and depression, as individuals feel helpless to prevent what often seem like life-threatening episodes of breathlessness, and is increasingly forced to limit activities.<sup>9,15,41,42</sup> Our participants noted how they have observed others succumbing to frustration, depression, and inactivity, and participants who have COPD described adapting to the disease through curtailment of activity. Physical and psychological problems can seep into the social sphere of patients’ lives, as the benefits of daily activities and social engagements are weighed against the concerns of managing symptoms and eliminating distressing or potentially embarrassing episodes.<sup>5,6,9,18,44</sup> Some of our participants avoided family and friends to escape their unsolicited advice to quit smoking. This increasing isolation is especially concerning because support from others is reported to be critical for taking care of daily tasks and is motivation to fight for life.<sup>9,44,45</sup>

Innumerable websites, self-help books, and magazine articles assert that breathing is a powerful metaphor for living. The sources advise readers that the manner in which they take each breath signifies how they feel about themselves, and further, about their interactions with the world. Important to their arguments is the premise that individuals can improve their life by controlling how they breathe.<sup>46–48</sup> Our participants described that for COPD sufferers, lack of control over breathing is frightening and limiting, resulting in a sense of helplessness and increasing isolation. Those participants who felt this way expressed high interest in hearing how others have devised logistical strategies to regain some control over their breathing in adverse environmental conditions.

To reduce the sense of hopelessness that can envelope COPD patients who are at risk for increasing isolation and inactivity, providers might place higher emphasis on the steps patients can take to prevent or mitigate exacerbations of breathing difficulties. As one participant with reduced lung function described, learning how to breathe more effectively greatly enhanced her daily life. While the suggestions for daily adjustments offered by participants may seem commonplace, other participants who had given in to their limitations clearly expressed high interest in adopting these ideas.

A limitation of this study is the small sample typical for focus groups. A strength is that we purposively recruited participants from health sites as well as the

general community. We elicited data through use of open-ended questions in a group format, which provided us with a broad range of how individuals talk with each other about COPD and its consequences. Current smokers and nonsmokers participated in all groups, as did individuals with a mixture of inclusion criteria characteristics. This may have influenced the discussion in ways that would not otherwise have occurred, both in negative and positive ways. At times, the smokers dominated the dialogue, frequently returning to the difficulties of smoking cessation. Including participants who were already diagnosed with emphysema, chronic bronchitis, or COPD, along with participants who had no diagnosis but were at risk for COPD, enabled dynamic discussions between them about perceptions of risk factors, symptoms, and disease management.

Our findings reveal that among the public there continues to persist significant misunderstanding and lack of knowledge about COPD, its course, and its consequences. This limited awareness causes some to suffer in isolation and prevents many from accessing life enhancing and disease-mitigating strategies, including social support, lifestyle accommodation, and medications that can impede worsening of COPD. Patients who are at risk for or have symptoms of COPD may lack motivation to address these conditions directly with their health care providers.

Caring for patients who experience the symptom burden and psychosocial impact of living with COPD requires providers to: help their patients by offering educational materials that address care gaps and refer to COPD directly; help break through denial by educating about the association of emphysema, chronic bronchitis, and COPD; become more familiar with the ACOS in order to better explain it to patients with this syndrome; continue to encourage smoking cessation; and explain simple lifestyle adaptations to ease daily living even as lung function decreases.

### Author note

This work was conducted at the Warren Alpert School of Medicine, Department of Family Medicine, located at Memorial Hospital of Rhode Island, 111 Brewster Street, Pawtucket, RI 02860.

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## Appendix I

### Focus group questions

1. Please tell me what emphysema is, or what you've heard about it.

- a. What about chronic bronchitis?
- b. Another name is chronic obstructive pulmonary disease or COPD. Who here has heard this term before? What have you heard about COPD?
2. What are some consequences of having COPD—in other words, what happens to people who have COPD?
  - a. What are some of your concerns and worries regarding COPD?
  - b. If someone has COPD, how does it affect their day-to-day activities?
  - c. What causes people to get COPD?
  - d. Is there anything you can do to feel better when you have COPD? What can you do?
3. How do doctors diagnose COPD in their patients?
4. Do you think if someone was short of breath (difficulty climbing one flight of stairs), or had chronic cough, and smoked, had exposure to occupational dust, or was exposed to secondhand smoke, that they would think that these were reasons to discuss these symptoms with their doctor? Why or why not?
  - a. How bad would it have to be to want to ask the doctor or nurse for a breathing test to diagnose COPD?
  - b. Has a doctor ever talked with you about getting a breathing test (spirometry or a lung function test)? Has anyone gotten this test?
  - c. What does the breathing test tell you and the doctor?
5. How comfortable do you feel asking your doctor about your chances of having COPD or whether it has gotten worse if you already have it? Why?
  - a. If your doctor does not mention it first, how comfortable would you be in insisting to your doctor that you have a breathing test (lung function test or spirometry) which measures how well your lungs work? Why?
  - b. How much information do you want from your doctor about your lung health?
  - c. What kinds of information regarding COPD do you want from your doctor?
  - d. What don't you want to hear about COPD from your doctor? Why?
  - e. Would you or do you ever ask your doctor about something you heard about that he/she didn't bring up on his/her own—for example, something you read on the internet or saw on TV?

- f. When you have to make decisions about medicines or treatments that your doctor recommends, how do you decide whether you get the tests or treatment recommended?
6. Do you talk to anyone when deciding such as family, friends, coworkers?
  - a. In fact, do you ever talk to your friends or relatives or coworkers at all about COPD?
  - b. Why or why not talk about this? What kinds of things do you talk about?
7. What kind of COPD health information are you interested in getting in general?
8. In general, where do you and your family get information about your health?

- a. If the Internet is not mentioned, ask: Does anyone use the Internet in general and specifically to obtain health information?
- b. What sources on the internet do you trust the most? Why? How do you decide whether a source of information is trustworthy?
- c. If we put together an information package for patients about COPD, what information should be included?

9. We mentioned the internet earlier as a source of health information. Do any of you use certain kinds of websites such as Facebook, Twitter, or MySpace?
  - a. If yes, ask: What websites of this kind do you use and why do you use them?