Published in final edited form as:

West J Nurs Res. 2011 November ; 33(7): 916–932. doi:10.1177/0193945910384602.

The Experience of Stigma in Chronic Obstructive Pulmonary Disease

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Abstract

People with chronic obstructive pulmonary disease (COPD) can experience severe dyspnea, tenacious secretions, and a disruptive cough. They often struggle with daily activities and over time tend to decrease the amount of time they spend outside the home. The functional decline accompanying these changes is not adequately explained by physical changes alone. This descriptive, qualitative study describes social changes and experiences of stigma from the perspective of people with moderate to severe COPD. A total of 16 participants (11 men, 5 women) participated in individual interviews regarding effects of COPD on social relationships and experiences with COPD-related stigma. Participants were aware of the potential for stigma related to COPD. Emerging themes included the prevalence of blame related to smoking, both from others, including health care providers, and from themselves. Although many decreases in social activities appear to be pragmatic adaptations to functional limitations, these decisions may also be attempts to avoid potentially stigmatizing situations.

Keywords

social discrimination; social behavior; stigma; chronic illness; lung disease

Individuals with COPD risk social embarrassment and stigmatization in several ways. In social settings, the severe dyspnea and disruptive cough of chronic obstructive pulmonary disease (COPD) can be embarrassing for the sufferer. At the same time, witnessing these symptoms may make bystanders uncomfortable, leading to more social awkwardness. Using inhalers or supplemental oxygen in public can also make the person with COPD stand out as “different” and increase the likelihood of being stigmatized (Johnson, Campbell, Bowers, & Nichol, 2007). In addition, the anti-tobacco movement’s effort to stigmatize smoking has also stigmatized smokers. This in turn can lead to the potential stigmatization of people with COPD, many of whom have a significant smoking history (Bayer & Stuber, 2006; Chapple, Ziebland, & McPherson, 2004). Feeling stigmatized may affect individuals with COPD

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Declaring of Conflicting Interests

The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.

deeply, shaming them and contributing to their social isolation and depression. Such feelings have been reported by people using supplemental oxygen (Earnest, 2002) and by women with COPD (O'Neill, 2002). However, little is known about the broader experience of COPD-related stigma.

Stigma and COPD

Stigma arises from the awareness that a person has an undesirable trait or characteristic (Goffman, 1963). This association of a devalued characteristic with a particular individual triggers the process of stigmatization. The stigmatized person is subject to various forms of social rejection. The intensity of this rejection is influenced by how overt and anxiety-producing the stigma trait itself is. Jones and colleagues (1984) identified six dimensions of a stigma trait that can affect the intensity of the stigma response: concealability, course over time, disruptiveness, aesthetic qualities, origin, and peril. All six of these dimensions may come into play with COPD.

Concealability refers to the obtrusiveness of the stigmatizing condition. People with COPD are primarily marked by their cough, dyspnea, and need for supplemental oxygen. In public places the persistent, productive cough of COPD draws the attention of others and is a constant reminder that the person is sick. People with COPD also experience episodes of dyspnea that are readily apparent to onlookers, and severe episodes can be frightening to witness. The oxygen equipment that people often require in later stages of COPD serves as another sign of their disability.

COPD is a progressively debilitating disease. As symptoms worsen over time, they become increasingly disruptive to the individual and more upsetting to others. Realizing that eventually the person is likely to die from this condition enhances the gravity of the situation.

The cough and dyspnea of COPD can be very disruptive to smooth social interaction. The persistent cough can be irritating and distracting. Dyspnea can interfere with speaking ability, making fluent communication difficult.

A productive cough may set people with COPD apart on aesthetic grounds as well. Onlookers find it unpleasant to observe a person trying to manage the tenacious sputum that can occur with COPD.

With few exceptions, COPD is a result of many years of smoking. This can affect people's response to a person with COPD. Depending on their knowledge of COPD, strangers may or may not make the connection with smoking. But family and friends are likely to be aware that the disease was caused by the self-imposed behavior of smoking, and this can contribute to blame from self and others. Health professionals will readily make the connection between COPD and smoking, possibly affecting their responses to the person with COPD.

For onlookers, the dyspnea and cough of COPD are likely to raise the specter of contagion, perhaps a cold or the flu, or something worse. Once they understand that the person has COPD rather than a contagious condition, onlookers' concerns about immediate peril to

themselves may diminish. But merely being in the presence of someone who is visibly disabled by illness can be anxiety-producing.

Based on this typology of stigmatizing traits, COPD can be a potent stigma (see Figure 1). As it gradually becomes more difficult to conceal visible evidence of the disease, others become more likely to avoid the affected individual. In response, the affected individual may withdraw to escape uncomfortable situations. Strangers may shun the person with COPD because they are repulsed by the sputum or distressed by the severe dyspnea. Friends may become reluctant to socialize for similar reasons. And because COPD is often seen as a self-imposed disease (Stuber, Galea, & Link, 2008), there may be little sympathy for the affected individual. As people with COPD withdraw from social activities to avoid unpleasant or embarrassing situations, they become isolated. In turn, this isolation may lead to further adverse emotional consequences as the result of COPD, such as loss of self-esteem and feelings of uselessness. The mood disturbances (depression, anxiety) often associated with COPD (Maurer et al., 2008) may be in part the result of giving up social roles in the community and the family.

We examined the experiences and meaning of stigma resulting from COPD in order to characterize the domains of COPD-related stigma and work toward conceptual clarity regarding the stigma associated with COPD. The specific aim of this study was to describe the experiences and perceptions of stigma and social isolation from the perspective of the person with COPD.

Methods

A descriptive qualitative approach was used, and data were collected using in-depth interviews of men and women with moderate to severe COPD. A purposive sample of 18 informants was recruited from a registry of people interested in participating in pulmonary research. Participants were selected based on their experience with COPD and their willingness to discuss the social and relationship changes it has brought to their lives. Sampling continued until thematic categories were saturated.

Sample

Criteria for inclusion were COPD previously diagnosed by a physician, 45 years of age or older, and a smoking history of at least 10 pack years. People were excluded if they had asthma diagnosed by a physician (since the potentially stigmatizing aspects of asthma may differ from those of COPD) or other major health problems that might influence symptoms and functional status. This study was approved by the Institutional Review Board. All participants provided written consent to participate in the research.

Of the 18 people responding to the recruitment letter, 11 men and 5 women completed the study. One person was excluded because he had developed cancer, and another dropped out due to an appointment miscommunication. The mean age of the participants was 70 years (range: 49–81). Participants had moderate to severe COPD with a mean forced expiratory volume in 1 second (FEV₁) percent predicted of 48% (range: 31%–75%). Using the Global Initiative for Chronic Obstructive Lung Disease (GOLD) classification of COPD severity

(Rabe et al., 2007), 6 were in GOLD stage II and 10 were in GOLD stage III. Participants reported a mean smoking history of 57 pack years (range 15 to 177) and an average of 3.5 comorbid conditions. Six participants used oxygen at home, two using it continuously.

Measures

Data on demographic characteristics, comorbidities, breathlessness, and functional performance were collected to describe the sample. Comorbidities were measured with the Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987), breathlessness was measured with the ATS-DLD 78-A Breathlessness Scale (Ferris, 1978), and functional performance was measured using the Functional Performance Inventory (Leidy, 1994, 1995). Spirometry was performed (Sensormedics VMAX or Medgraphics Breeze-SC) to document the severity of airflow obstruction (Miller et al., 2005), using prediction equations developed by Morris (1976).

The Charlson Comorbidity Index (CCI) predicts the 1-year mortality for people with comorbid conditions (Charlson et al., 1987). It is widely used, and there is strong evidence for its validity (Charlson, Szatrowski, Peterson, & Gold, 1994). Each condition is given a severity weight of 1 to 6 based on the mortality risk associated with the condition. The CCI score is the sum of the condition scores. The most commonly reported comorbid conditions in this sample included vision problems (75%) hearing problems (50%), high blood pressure (43.8%), spine or back problems (43.8%), and arthritis (31.3%). None of the participants reported that these significantly limited their functional status.

The ATS-DLD 78-A Breathlessness Scale is a widely used 1-item scale that grades the degree to which dyspnea interferes with function. Potential scores range from 0 to 5, with 5 indicating greater dyspnea. There is evidence to support validity of the ATS-DLD 78-A for people with COPD (Schlecht, Schwartzman, & Bourbeau, 2005). Overall, participants in this study reported a mean of 3.1 on the ATS-DLD 78A Breathlessness Scale (reported range of 1–4 for this sample), indicating moderate dyspnea.

The Functional Performance Inventory (FPI) was used to measure self-reported functional performance, defined as the extent to which people actually perform day-to-day activities (Leidy, 1994, 1995). The FPI measures functional performance with respect to body care, maintaining the household, physical exercise, recreation, spiritual activities, and social interaction (family and friends). Potential scores range from 0 to 3 (3 = higher functioning), and there is evidence to support its reliability and validity (Larson, Kapella, Wirtz, Covey, & Berry, 1998; Leidy, 1999). The Cronbach's alpha for the total FPI in this study was .88, and the mean FPI total score was 1.9 (range: 1.1–2.9).

Procedures

Potential participants who responded to a recruitment letter were screened by phone, and an interview appointment was scheduled. A semistructured open-ended interview (Patton, 1990) lasting approximately 1 hour was used to explore the individual's experience of stigma and social experiences related to COPD. Each participant was interviewed one time and then completed the FPI. Audio recordings of the interviews were transcribed verbatim. Participants received US\$25 at the end of the interview. The interview guide was developed

based on the researchers' more than 20 years of experience with stigma in chronic illness (e.g., Berger, Ferrans, & Lashley, 2001) and with functional aspects of COPD (Larson et al., 1998), and a review of the literature. Once data collection began, further modification of the interview questions was made based on participants' responses to the questions and the ongoing data analysis. The interview guide included questions about informants' physical changes and social experiences since developing lung disease. Participants were asked about their relationships and interactions with family members, friends, and strangers and were encouraged to talk about how other people react to their symptoms and their own feelings about having COPD.

Analysis

Demographic, spirometry, symptom, and functional performance data were analyzed with descriptive statistics. Qualitative data from transcribed interviews were analyzed using content analysis (Strauss & Corbin, 1998) supported by ATLAS.ti 5.2 (ATLAS.ti Scientific Software Development GmbH, 2007). Coding categories were generated from the data. The basic components of the model depicted in Figure 1 were used as a starting point for category identification, but primary attention was given to participants' accounts of their experiences. Coding was performed separately by three researchers and then refined through multiple iterations to achieve consensus. Categories and themes were organized to develop theoretical coherence regarding the participants' social experiences related to COPD (Huberman & Miles, 1998).

Results

Findings fell into two main categories: perceptions of COPD-related stigma, and people's responses to stigma. Perception of stigma related to COPD included the person's awareness of stigma; the interplay of different relationships on the experience of stigma; manifestations, including uncertainty in interactions; and triggers giving rise to concerns about stigma. Participants' responses to actual or anticipated COPD-related stigma addressed questions of blame, effects on the sense of self-worth, and efforts to avoid stigma. Themes identified in the analysis are italicized.

Most participants seemed *aware of the potential for stigma* in social interactions, especially with strangers. Stigma was not a major concern for many, but several participants were eloquent in describing the possible impact of COPD on social interaction.

[Someone with COPD is viewed with] disdain. Like a leper, almost, as opposed to any other illness that I can think of. I hear people talking behind people's back about this. It seems to have its own aura of discussion, it seems to be different.

You'll notice that people will kind of shy away from you when you have the cannula in your nose. You will notice that. Strangers aren't going to come up to you and ask, "What's wrong?" You sense it, I suppose.

Reactions from family or close friends tended to deemphasize differences related to COPD symptoms. Family members might help with tasks requiring even a little physical effort

without being asked, to prevent the respondent's having to exert or explain himself or herself. Most participants perceived family and friends as being unfazed by their COPD.

I had a coughing and sputum problem. But ... anybody I'm with isn't embarrassed by it, or at least they haven't said anything to me.

However, one participant gave examples of reactions from her family members in which they seemed embarrassed by her COPD-related behavior in public:

When I first got the inhalers, it was my time to use them, you know, every 4 hours. I was sitting there [at the bar] having a beer, doing the inhalers. [My husband] had a fit. He was so embarrassed. He said, "I thought you'd go in the washroom and do that." But after he died, then my kids would say, "Don't do that in public!"

Relationship distance appeared to play a role in the likelihood of having a stigmatizing experience. In most cases, less stigma was expected in closer relationships, whereas stigma was seen as more probable in encounters with strangers.

If they've got a tank [oxygen] with them or something, I think anytime you see something like that, you're a little more timid in involving yourself with them. ... So, there's the caution where people don't get involved. But if they knew the person before and they were friends, I'd say it'd continue that way.

Some participants expressed *uncertainty* about how other people, particularly strangers, might react to their symptoms or other evidence of COPD. Others were quite definite in stating that no one, whether friend or stranger, viewed them any differently because of their COPD. And for most, the possibility of stigma did not appear to color every social encounter. However, several participants' responses suggested they felt some ambivalence when anticipating such situations. The following exchange was interpreted as expressing uncertainty or ambivalence about the reactions of strangers in a circumstance that might lead to rejection. This participant seemed to have a plan for avoiding unwanted attention or reactions, but at the same time she downplayed her concern as being unrealistic.

Question: Have you ever been embarrassed by ... symptoms related to your lung disease?

Answer: No, I've been able to control it so far. Although if I have to use my inhaler, I'll go to the washroom or something like that. ... well, a lot of people don't like to see you take medicine in public.

Question: What kind of reactions have you seen?

Answer: I haven't noticed any, really. I'll just sit down—if I'm at a mall or the washroom is too far away. Nobody pays any attention, really.

Triggers for COPD-related stigma experiences fell into two main categories: (1) physical manifestations of COPD symptoms, and (2) equipment-related cues. Obvious symptoms such as coughing spells and copious sputum production were mentioned by many participants. Physical limitations, including being unable to keep up with others when walking and needing to go slowly and rest often, were also frequently reported. Participants often seemed most aware of the potential for stigma when using treatments in public

(inhalers or oxygen) or needing a wheelchair at a shopping mall or airport. All of these were reported as potentially embarrassing or stigmatizing, especially in public places:

When you're trying to walk somewhere with a group and say [to them], "Go ahead, I'll catch up." And then you're not sure you're going to catch up.

[Using oxygen is] embarrassing. ... A lot of it is ego. I don't want to appear to be that ill. So I'm not going to wear it, no matter how short of breath I get.

That's embarrassing, using the inhaler in front of people. It's okay if I'm ... by myself, but when I'm with people and trying to get some of that phlegm up

I think probably the time I might feel a certain amount of embarrassment is when I'm in a completely unfamiliar setting where nobody there knows who I am or what my disease is. Like, for instance, the movie theater where I have to climb stairs—the stadium seating. And I'm trying to catch my breath, and somebody says, "Oh my gosh, he's having a heart attack." ... I think there's a certain amount of embarrassment there when I'm around total strangers and have to explain myself.

In one form or another, *blame* was a common theme for these participants. Imputations of blame from others focused entirely on smoking, and an overt search for blame was virtually instantaneous when the person with COPD revealed his or her condition:

The first thing they say is, "Did you smoke?" Oh yeah, everybody says that. As soon as I mention breathing or use the inhaler.

Well, I'm sure there are a lot of people out there who think we're all idiots because we smoked. If they want to call me an idiot, that's the truth. ... They've never told it to my face, but you can see that they're thinking it.

I think it's like a disease that's a dirty disease as opposed to an appendix or cancer. It's ... self-inflicted—why are you so stupid for getting emphysema?

Several participants also explicitly blamed themselves for having acquired lung disease as a result of their own behavior.

Well, there's no question who to blame. I mean, nobody's ever said anything to me verbally. But, uh, I don't see where there'd be any question about who is to blame. I mean, at least in my case, being a smoker and all.

Unexpectedly, interactions with health care providers sometimes reinforced this sense of blame.

I went to the emergency room. And they told me after an x-ray to see my own physician when I got home. ... He's the one that said, "Don't come back and see me unless you stop smoking."

He wanted me to go get a chest x-ray. ... I got a call from his very abrasive nurse who said, "Do you smoke?" ... She said, "Quit, you've got emphysema." Click, like that. And I was traumatized by that.

But one participant brought up the addictive properties of cigarettes, which in his view mitigated the blame related to smoking.

He was on oxygen and was still smoking. And I thought, well that's brilliant. But I also know the addictive qualities of nicotine, and I shouldn't be judgmental to be sure. Because I was lucky enough to quit. ... I know a lot of people like that that just can't seem to quit. It's a horrible, horrible addiction.

Despite the prevalence of smoking-related blame from self and others, several participants instead offered alternative explanations for their COPD, including genetics, allergies, exposure to toxins, and air pollution.

For some participants, their *sense of self worth* was diminished by their awareness of their functional limitations related to COPD and feelings of being a burden.

I view myself as being flawed. I can't contribute as much as I'd like to. ... I'm envious of people when I see them get up and do things without a thought about what it takes me to do that.

I think it's changed ... the views of things that I realistically think I can do. And what I'm going to be able to do in the next couple of years. How I'll be then.

Well, I don't really socialize. I don't go out with girlfriends or anything like that. For what? They would have to cater to me, and it's just not worth it.

Well, [traveling] sort of puts the burden on my wife, too. If you have any carry-on luggage, 99% of time she's going to schlep that. And she's gonna push me in the wheelchair. ... I think it's sort of a burden on her.

A range of *efforts to avoid stigma* experiences were described, often beginning with attempts to minimize the obtrusiveness of symptoms or treatments around other people.

I usually don't use it [oxygen] in front of other people. If I need it, I'll dose it up in the car and get what I need, then go about my business.

Before, I never paid attention to [walking up stairs and long distances]. ... Now I pay attention. ... I have to think about that and plan that move, so that I don't look like I've got my tongue hanging out at the end of that walk.

Often these attempts to avoid stigma included techniques intended to remove ambiguity from the situation by helping observers understand what was going on. Some participants reported being aware that their symptoms might raise questions, and they chose to address those questions directly by offering anticipatory explanations of their symptoms and physical limitations:

If I'm out of breath, I'll explain why. Not that they care, I don't know. I'll bring it up most of the time. Or if it's time to do the inhaler. Then I say, "Excuse me, I have emphysema."

When physically able, others chose to *cover or conceal* their symptoms or treatments:

If I get into a situation where I start to breathe a little more than what would be considered normal for that activity, ... I just back off a notch and I play that game, obviously, with myself to protect my interests, so that I'm not looked upon as a

disabled person, a crippled old person. And I'm able to do that and get away with it.

Other people were generally viewed as willing to accommodate the person's COPD-related activity restrictions and smoke intolerance. Sometimes, however, that protectiveness was perceived as excluding the person with COPD. While acknowledging others' good intentions, some participants were annoyed by what they saw as *overprotectiveness*.

People react to my issue more than I do sometimes. I'll walk into a room full of dust and think nothing of it, and they'll say, "Get outta here." God bless them. ... Sometimes I get a little upset. I think that's the ego issue. Leave me alone, I'm just fine, I'll make it. So there's a certain amount of resentment on my part.

Anytime I've had an exacerbation ... in public, people are so very helpful. ... I just try to explain to them that I need to calm down. Thank you, but I'm okay. ... Even when I didn't have the oxygen, people were very compassionate.

Finally, several participants described the potential impact of COPD on *employment opportunities*, both via its effects on employers' health insurance costs and because the employee is more likely to be absent from work due to illness.

I think ... one of the reasons that I lost my last job was partly because of my lung disease. Being a small company ..., I think the insurance company had an influence in getting rid of me. ... All the tests and other things that went along with it were becoming very expensive. And I think that's part of the reason I was let go.

I think in some cases [emphysema would make it harder to get a job]. ... It would be a negative. It would be a health issue for their insurance policy if they're a small company. It would be a liability on the plan ... [and] just the fact you're ill. ... I certainly would think twice about hiring a person with emphysema. ... Because you get sick, you get colds. You're off three weeks for a cold.

I had to quit work. ... I missed more work than I attended. You get around the people, you get more infections. You know, you can't finish a project. I've always been really dependable, and I just didn't want to put my employer through that.

Several participants in this study did not seem aware of the possibility of stigma related to their COPD. But for others it was clear that aspects of their disease beyond the physical limitations they experienced had an influence on their interactions with others and the degree to which they stayed engaged in social activities and relationships. Still others had experienced COPD-related stigma and made adjustments in their lives to avoid repeating those experiences.

Discussion

The purpose of this research was to validate and refine our understanding of the concept of stigma in the context of the experiences of people with COPD. The basic elements of our initial stigma framework (Figure 1) were supported. Participants did report being aware of changes in their experiences (Figure 1, Box 3) as a result of their COPD, often related to uncertainty in social situations with strangers. Their responses to this awareness included the

use of classic techniques to minimize or avoid stigma (Figure 1, Box 4), such as covering or concealing their condition or trying to reduce tension by offering explanations about their symptoms or actions. The triggers for stigma (Figure 1, Box 2) were also much as expected, including coughing episodes, managing copious sputum, and using visible treatments (inhalers, oxygen) and other aids (wheelchairs).

Four of the six dimensions affecting stigma intensity (concealability, disruptiveness, aesthetics, and origin /responsibility) played significant roles in these participants' perceptions of COPD-related stigma (Figure 1, Box 1). In particular, the many comments regarding blame reflected the "origin/responsibility" dimension of COPD-related stigma. Consistent with the observations of Bayer and Stuber (2006) and Chapple et al. (2004), it appears that the blame attached to smoking has become attached to smokers themselves. Only one participant mentioned the addictive properties of tobacco when talking about people with COPD, and he was referring to the difficulties experienced by a third person, not himself.

The issues of uncertainty and ambiguity in interactions (Figure 1, Box 3) are so intrinsically a part of the phenomenon of stigma that it is not surprising that they echo through many of these findings. These are among the hallmarks of stigma—onlookers being uncertain about what is going on with a "different" person, and that "different" person being unsure of how he or she will be received in the interaction. This mutual social discomfort then leads to awkward interactions and a tendency by both parties to avoid those interactions. When among strangers, several participants dealt with possible uncertainty by explicitly clarifying their circumstances for bystanders, a tension-reduction technique typically used to head off other people's concern or confusion.

These findings also suggest a dimension not previously explicated in the model, relationship distance or closeness of the relationship as an influence on whether the person anticipates being stigmatized. A number of participants reported feeling more vulnerable to stigmatizing interactions when they were among acquaintances or strangers than when with family or close friends. Uncertainty may account for much of this discomfort with strangers, since family and friends would already be aware of the person's COPD and related symptoms.

Strong emotional reactions to feeling stigmatized (Figure 1, Box 4) were relatively infrequent, although one participant did report being "traumatized" by a nurse's abrupt comment. There were also several accounts of discomfort or embarrassment. Three underlying themes appear to be associated with their embarrassment: blaming themselves, not wanting to inconvenience or burden others, and not wanting to appear sick or disabled. Similar concerns were noted by Earnest (2002) in his study of people with COPD who were using supplemental oxygen therapy. It is possible that these are underlying themes for people with other chronic illnesses as well.

Whereas Earnest (2002) found that COPD patients on supplemental oxygen reported shame, our participants focused more on issues of blame and feeling limited by their functional changes. Because our questions pertained more to the dynamics of social interaction, we

may have been less likely to elicit comments about shame, but it is interesting that there were no allusions to shame even when talking about altered self-concept, self-blame, or feelings of being a burden. Further exploration of shame as a component of COPD-related stigma could be useful in fully understanding the impact of this disease on patients.

As clinicians, we were surprised at the extent to which people reported embarrassment about their physical limitations and their inability to keep up with others. In the clinical world, we see so many people with physical limitations that it no longer falls outside the norm for us. We may become desensitized to its potential for embarrassment and its effects on self-image. The findings in this study serve to remind us that conditions that are routine for clinicians may have deeper or more nuanced implications for patients.

People were embarrassed by the use of oxygen in public, which is consistent with previous findings (Earnest, 2002). But people were also embarrassed even about briefly using an inhaler in public. Similar concerns have been reported by people with asthma (Snadden & Brown, 1991), suggesting that it may not take much to trigger perceptions of stigma. This embarrassment may be heightened by the visible symptoms requiring the use of a rescue inhaler, though even routine use was embarrassing to one family. For people with COPD the perception of stigma may be more related to the total configuration of symptoms, physical limitations, and use of inhaler than simply to the use of the inhaler alone.

Interactions with health care providers can affect patients' perceptions of being acceptable to others, particularly when it comes to blame. A few informants reported being ridiculed or chastised by a health care provider, specifically on the topic of smoking. This phenomenon has been reported by others (Chapple et al., 2004; Gysels & Higginson, 2008; O'Neill, 2002). This is consistent with contemporary attitudes toward smokers (Stuber et al., 2008) and public health messages that stigmatize smokers in an attempt to stigmatize smoking (Bayer & Stuber, 2006). These interactions are concerning for their potential impact on the mental health of people with COPD. Such reactions by providers could drive people away from the health care system, thereby limiting their access to care.

In contrast, other informants felt fully accepted and supported in the clinical setting, finding it to be a comfortable environment in which there was no need to explain their symptoms or physical limitations. For these participants, health care providers (and researchers) performed Goffman's (1963) role of "the wise," people who, due to their specialized knowledge and experience, were able to see past the disease and stigma of COPD to the person.

These findings suggest several directions for further research. Continued research on the stigma triggers and experiences of people with other chronic diseases is warranted, to understand the commonalities underlying these phenomena. Developing interventions to help patients with COPD manage possible stigma may help them to maintain their social connections and stay engaged with the world around them. Finally, further exploration of the impact of public health campaigns on the well-being of individuals with lifestyle diseases such as COPD is indicated.

In summary, stigma is associated with COPD, and people with COPD are aware of this stigma. The personal experience of stigma for the individual with COPD includes elements of self-blame, not wanting to burden others, and not wanting to appear sick. In the most dramatic cases, individuals see their COPD as a dirty disease. The most potent triggers for stigma include COPD symptoms and the use of inhalers and supplemental oxygen. Others' responses to the person with COPD typically reflect uncertainty and subtle negative reactions in social situations, but COPD-related stigma may also extend to job-related discrimination. In addition, some health care workers express strong negative reactions to people with COPD, which can be potentially devastating to the affected individual.

Acknowledgment

We wish to acknowledge the contribution of Mary Knox and Jennifer Klecan in the preparation of the data.

Funding

The author(s) disclosed receipt of the following financial support for the research and/or publication of this article: The study reported in this manuscript was funded by the Internal Research Support Program of the University of Illinois at Chicago College of Nursing.

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Figure 1.
Preliminary model of stigma in COPD.

Source: Adapted from Berger, Ferrans, & Lashley, 2001.