



## Are people with chronic obstructive pulmonary disease prone to stigma in any culture? From a qualitative study in Japan

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### Abstract

**Background:** In recent years, a growing body of research has focused on the stigma faced by individuals with chronic obstructive pulmonary disease (COPD). These studies have revealed that people with COPD are prone to stigma. However, most studies have examined European and North American populations. The relationship between chronic disease and stigma can vary from culture to culture. Therefore, in order to explore whether there are cultural differences in the relationship between COPD and stigma, the present study investigates the relationship between stigma and COPD in Japan, which is one of the countries left unstudied.

**Methods:** Interviews were conducted with people diagnosed with COPD. Interviews were recorded and transcribed verbatim for thematic analysis. Six men aged 65 years and older were interviewed.

**Results:** Four themes were found in the analysis: unobtrusiveness of COPD for people with COPD, strong self-recognition as an older adult, unobtrusiveness of COPD for family members and friends, and neither hiding nor emphasizing COPD. In Japan, people with COPD were found to suffer less from stigma, compared with their European and North American counterparts.

**Conclusions:** There may be greater cultural differences in the relationship between COPD and stigma than previously thought.

**Keywords:** chronic obstructive pulmonary disease, COPD, stigma, Japan

### Introduction

The prevalence of chronic obstructive pulmonary disease (COPD) has been increasing worldwide in recent years. According to Adeyoye et al. [1], 391.9 million prevalent cases of COPD were reported globally in 2019. In the Global North, COPD is often caused by long-standing smoking habits, while in the Global South, it is often caused by air pollution in addition to smoking. Recent studies have also emphasized that genetics and childhood respiratory infections are possible causes [1]. The main symptoms of COPD are respiratory, including coughing and dyspnea; however, its physical symptoms can lead individuals to experience stigma (i.e., social exclusion), which can negatively affect their mental state.

Several studies have examined how people with COPD experience stigma [2–16]. According to these studies, people with COPD are prone to stigma because the public tends to associate COPD with smoking habits, for which the latter blames the former. Additionally, people with COPD tend to internalize this stigma and develop feelings of shame, guilt, and self-blame [17, 18]. These studies have revealed that people with COPD are prone to stigma.

However, most studies have focused on the European and North American contexts, while only one examined the Korean context [12]. This is an important gap in the literature, as the relationship between chronic disease and stigma can vary across cultures [19]. Therefore, in societies outside of Europe and North America, the experiences of people with COPD may vary considerably. This article will examine a previously unstudied context of Japan, which is considered to be geographically and culturally far removed from North America and Europe, where most of the previous studies have been conducted, to determine what people with COPD experience in their social lives due to its symptoms, and

what they think about themselves and their COPD. The purpose of this study is to determine whether there is cultural variation in the relationship between COPD and stigma by examining the Japanese case.

### COPD and Stigma

The following description largely relies on explanations provided by previous studies [3, 18]. Stigma arises from the perception that a person possesses socially undesirable traits [20]. Stigmatized individuals are subjected to various types of social exclusion. The strength of this rejection is influenced by how apparent and anxiety-provoking the stigma trait itself is. Previous studies have shown that the dimensions of the stigmatized condition—which affect the strength of the stigma response—include its concealability (i.e., whether the stigmatized mark is visible), course (i.e., whether the stigmatized mark disappears over time), disruptiveness (i.e., whether the characteristics of the stigmatized mark impede interpersonal relationships), aesthetic qualities (i.e., whether the stigmatized mark is aesthetically off-putting), origin (i.e., whether the stigmatized person is responsible for the stigmatized mark), and peril (i.e., whether the features of the stigmatized mark are unsafe—e.g., if the condition is contagious) [21, 22].

In the case of COPD, all six of these dimensions may be at play. In public, a persistent cough due to COPD may attract peoples' attention and remind them that the person is ill. People with COPD also experience dyspnea episodes that are easily recognizable and, in severe cases, can even be frightening to people around them. The coughing and dyspnea associated with COPD can also cause difficulty in speaking and be a significant obstacle to a functioning social life, while the persistent cough can also irritate other people; it can also be off-putting for onlookers to see someone

trying to manage the sticky sputum produced by COPD. The dyspnea and coughing of COPD can lead other people to believe that they have contracted a cold, flu, or worse. Understanding that COPD is not a contagious disease may mitigate bystanders' fear. However, the mere sight of someone with a visible disease tends to cause anxiety among those unfamiliar with it. COPD is often caused by years of smoking<sup>[23]</sup>, which can influence people's reactions to it. Depending on how much they know about COPD, strangers may not consider it to be a consequence of smoking. However, family and friends may perceive the illness as being caused by the voluntarily imposed behavior of smoking, which can lead them to blame the person with COPD.

Stigma involves various personal, social, and structural processes that provoke painful responses from socially inflicted marks. The stigma process comprises the following four types of stigma, all of which are interrelated: enacted stigma, felt stigma, self-stigma, and anticipated stigma. Enacted stigma comprises unfair treatment or discrimination against a stigmatized group and is based on negative social and cultural beliefs and feelings. Felt stigma refers to the stigmatized group/individual's perception of unfair treatment or discrimination related to their stigmatized status. Self-stigma is the individual's internalisation of their stigmatized condition. Anticipated stigma refers to the fear of being treated unfairly or discriminated because of one's stigmatized status.

Consequently, COPD can be a powerful stigma. Strangers may become dismissive of people with COPD upon seeing their phlegm and dyspnea, while friends may also refrain from socializing with them. Additionally, because COPD is a preventable disease and its onset is often viewed as self-imposed<sup>[24]</sup>, people show little sympathy for those affected. People with COPD may voluntarily withdraw from social activities and isolate themselves to avoid uncomfortable or embarrassing situations. This isolation can lead to harmful emotional consequences, such as loss of self-esteem and feelings of uselessness. Mood disorders often associated with COPD<sup>[25]</sup> may also stem from individuals abandoning their social roles within their communities and families.

Historically, smoking-related stigma in North America and Europe emerged from strategies to raise public awareness about the harms of smoking<sup>[26]</sup>. The 1964 Surgeon General's report played a trailblazing role in enlightening the public about the negative effects of smoking and contributed to a decrease in overall smoking rates<sup>[27]</sup>. Subsequent measures based on this report have reduced smoking-related illness and death, but these measures have also played a significant role in stigmatizing both smoking and smokers<sup>[28, 29]</sup>. Consequently, smokers increasingly encounter discrimination related to smoking in their daily lives. People who do not quit smoking are perceived to be disinterested in their health and that of others who inhale the secondhand smoke.

In Japan, the prevalence of COPD is estimated to be around 10% in people over 40 years of age<sup>[30]</sup>, which is somewhat lower than the global prevalence of 10.3% in people over 30 years of age<sup>[1]</sup>, given that COPD is more common in older populations. An example of a disease that has been stigmatized in Japan is HIV. People with HIV in Japan are subjected to stigma because this disease is contagious to others (i.e., peril), and they are often considered infected because of their sexual indulgence, a behavior based on their own free will (i.e., origin)<sup>[31]</sup>

## Methods

### Study Design

Semi-structured interviews were conducted with the participants, who were asked about their feelings about having COPD, their feelings about themselves, and their relationships and interactions with people around them (family members, friends, acquaintances, and strangers).

### Participants

The participants comprised individuals who had been diagnosed with COPD and were outpatients at the author's affiliated hospital. No prior restrictions were placed on the age of the participants. The hospital is located in a suburban area about one hour by train from Tokyo. All potential participants gave consent to participate in the study and met the following two criteria: they were able to communicate verbally and were not in need of treatment for other serious illnesses.

First, the hospital selected potential participants. Next, the primary care physician explained the purpose and methods of the study to the potential participants, and once the potential participants gave their written consent, they were officially enrolled as participants in the study, and were referred to the author.

### Data Collection

Interviews were conducted with the participants in a private hospital room. The interviews lasted 25–35 minutes and each participant was only interviewed once, in consideration of their physical burden. Interviews were recorded with the participants' consent. Just before the interview began, the participants were asked about their age, family, occupation, Modified Medical Research Council (mMRC) Dyspnea Scale score<sup>[32]</sup>, length of time since COPD diagnosis, and physical symptoms. The interviews were conducted from November to December 2016.

### Data Analysis

The data were analyzed via Braun and Clark's<sup>[33]</sup> phases for thematic analysis, namely familiarising researchers with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. First, a verbatim transcript was prepared based on the recordings of the interviews. Next, the verbatim transcripts were perused and coded one by one, separated by the minimum number of sentences whose semantic content was known to be relevant to each participant's daily life experiences and perceptions of COPD, as well as their perceptions of themselves. Subsequently, multiple codes with similar content were repeatedly grouped into categories, and once it was determined that they could not be grouped any further, a theme and subthemes were established. The analysis was supervised by an expert in qualitative analysis. The data collection and analysis were continued until the author and the supervisor agreed that data saturation was achieved.

### Ethical Considerations

Prior to this study, the content of the study was subjected to ethical review by the Ethics Committee of the institution the author affiliated at the time. Participants were informed orally and in writing of the purpose of the study. They were also informed that their participation in the study was voluntary; they were assured they would remain anonymous

and not face negative consequences if they withdrew from the study, while their written consent was obtained. The interviewer always paid attention to participants’ breathing and mental status during the interviews.

**Results**

Six participants were interviewed in total. All participants were men aged 65 years and older. All participants had

family members living with them. No participant was undergoing oxygen therapy; however, all participants were prescribed inhalant and/or oral medications. No participant had any respiratory disease other than COPD. Although people with COPD often suffer from depression, none of the participants discussed depression during the interview. Participants’ characteristics are presented in Table 1

**Table 1:** Characteristics of the participants.

	Age (Years)	Work	M MRC Dyspnea Scale	Length of time since COPD diagnosis	Symptoms appear to be caused by COPD
P1	76–85	Unemployed	1	One to 10 years	Dyspnea, Sputum, Coughing
P2	66–75	Unemployed	1	More than 10 years	Dyspnea, Sputum
P3	76–85	Unemployed	1	More than 10 years	Dyspnea, Palpitation
P4	76–85	Full-time	0	Less than one year	Sputum
P5	76–85	Unemployed	0	More than 10 years	Coughing
P6	76–85	Part-time	1	One to 10 years	Dyspnea

Note. mMRC = Modified Medical Research Council; COPD = chronic obstructive pulmonary disease.

Four themes and eight subthemes were identified in the analysis: unobtrusiveness of COPD for people with COPD (barely inconvenienced by COPD, more concerned with physical pain unrelated to breathing), strong self-identification as an older adult (attributing the cause of symptoms to advanced age, making decisions with their advanced age in mind), unobtrusiveness of COPD for family members and friends (unobtrusiveness of COPD for family members, unobtrusiveness of COPD for friends), neither hiding nor emphasizing COPD (no need to hide or emphasize having COPD, symptoms need not be hidden).

**Theme 1: Unobtrusiveness of COPD for people with COPD**

**Subtheme:** Barely inconvenienced by COPD, more conscious of physical pain unrelated to breathing  
Participants were not usually strongly aware of COPD. They were more concerned with physical symptoms that were not directly related to breathing, rather than breathing difficulties. One participant described his daily life as follows:

**P1:** “I am not particularly careful or restricted because of COPD. I just go about my day as I feel like it.”

Another participant described the feeling of going up the stairs as follows:

**P5:** “I use the escalator and elevator instead of taking the stairs at the station because my legs get tired when I climb the stairs. There are 39 steps at the nearest station. So, I go down the stairs, but I don’t go up them these days. My legs get tired.”

(Int: “Do you not use the stairs because your legs hurt or because you have trouble breathing?”)

**P5:** “Yes. I feel pain in my legs.”

**Theme 2: Strong self-recognition as an older adult**

**Subtheme:** Attributing the cause of symptoms to advanced age, making decisions with their advanced age in mind.

Participants were aware that they had COPD, but identified themselves more strongly with their advanced age. They also made decisions in their daily lives while keeping their advanced age in mind. One participant described experiencing heart palpitations as follows:

(Int: “When you are taking a walk, does your dog pull you around?”)

**P3:** “I guess so, yes. When that happens, my heart pounds very hard.”

(Int: “When that happens, don’t you think about restraining the dog because it disturbs your breathing?”)

**P3:** “I can’t control it. I think I am pathetic. But I am 77 years old. I may see myself as young, but I am physically old.”

Another participant described his recent lifestyle changes as follows:

**P6:** “I used to play baseball, but I gave that up.”

(Int: “Did you have trouble breathing while playing baseball?”)

**P6:** “I thought maybe I should stop playing strenuous sports. I stopped for no particular reason. I am old and I don’t want to bother my family.”

Yet another participant gave the following reasons for not quitting smoking:

(Int: “Your doctor told you that if you don’t quit smoking, your COPD will get worse. Don’t you ever think about quitting smoking?”)

**P4:** “I’m almost 80 years old. I don’t think I have many more years to live. I will smoke until I die.”

**Theme 3: Unobtrusiveness of COPD for family members and friends**

**Subtheme:** Unobtrusiveness of COPD for family members, unobtrusiveness of COPD for friends.

The participants’ family members and friends were not worried about the participants’ COPD. One participant described his family’s response as follows:

(Int: “Are your family members usually attentive to your illness?”)

**P3:** “When I was hospitalized for cancer before, they were considerate, but now they no longer worry about me. I think it is because I don’t tell them that I’m having trouble breathing or that my stomach hurts these days.”

(Int: “Are you consciously trying to avoid showing such behavior in front of your family members?”)

**P3:** “No, that is not the case. I really don’t have such symptoms these days.”

Another participant described that he regularly drinks with friends as follows:

(Int: “Do your friends smoke?”)

**P1:** “I always tell them, ‘I have emphysema!,’ but they smoke without a care in the world. Sometimes they even offer me cigarettes.”

(Int: “Did you ever feel annoyed when they offered you cigarettes?”)

**P1:** “I’ve never had a problem with it... but I end up smoking at least one myself.”

#### **Theme 4: Neither hiding nor emphasizing COPD**

Subtheme: no need to hide or emphasize having COPD, symptoms need not be hidden.

The participants had no intention of hiding or actively communicating that they had COPD to people who did not know their circumstances. One participant described his relationship with acquaintances in a community association as follows:

**P2:** “Sometimes I have difficulty breathing when carrying desks or pitching tents at community association activities. At those times, I rest alone because the symptoms subside after about 10 minutes of sitting still... some people may know that I have COPD, but I don’t actively say so myself.”

(Int: “Is that to hide your COPD?”)

**P2:** “I’m not trying to hide it, but I don’t think it’s necessary to say I have it, and I’m usually not even aware of it.”

(Int: “Have you ever confessed your COPD to the community association?”)

**P2:** “No, I haven’t.”

(Int: “Have you ever felt that people in the community association gave any consideration to your COPD?”)

**P2:** “I never felt they gave me any special consideration.”

(Int: “Have you ever thought about confessing your COPD to the community association to receive special consideration?”)

**P2:** “I do not think the community association is the place for that, so I’ve never thought about telling people about my illness and asking for help.”

Another participant described the symptoms that appear in front of strangers as follows:

(Int: “Have you ever experienced shortness of breath and worried about what strangers might think?”)

**P3:** “I don’t take a break even if I have symptoms. However, if a chair is available, I sit. But I’ve never been bothered by strangers’ opinions.”

#### **Discussion**

To the best of our knowledge, this is the first study to reveal the experiences of Japanese people with COPD, how it affects their daily lives, and what they think about themselves and their COPD. This study presents two key findings.

First, the participants did not try to hide their COPD from others. Simultaneously, people around them were largely unconcerned about the participants’ COPD. This attitude starkly contrasts the way individuals in North America and Europe perceive and behave toward individuals with COPD, as reported in previous studies [2-16]. One reason for this could be that COPD is still not well known to the general public in Japan. According to a survey conducted by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) Japan committee in 2022, few Japanese people indicated that they knew what COPD was, accounting for only 13.8% of all respondents [35]. Therefore, it is likely that the fact that COPD and its symptoms are closely related to smoking habits is not well known in Japan. Another possible reason is that, in Japan, social criticism of smoking may not be as strong as in North America and Europe. Hence, COPD and its symptoms are not as stigmatized, which may have influenced the perceptions of this study’s participants. According to previous studies, years of tobacco stigmatisation campaigns in North America and Europe have resulted in strong social criticism and stigma toward smokers [28, 29, 36]. Contrarily, a study conducted in Korea, Japan’s neighbor and a culturally similar country, revealed that people with COPD are stigmatized because, in Korea, COPD symptoms are often misunderstood as caused by tuberculosis, rather than smoking [12].

COPD is not currently stigmatized in Japan. However, in the future, when awareness-raising activities for COPD are conducted and social recognition of COPD increases in Japan, people with COPD may be stigmatized due to its association with smoking, as in North America and Europe. Subsequently, this may have a negative impact on the mental health and social life of people with COPD. In promoting widespread awareness of COPD in Japanese society, it is necessary to remain wary of the effects of the stigmatisation of COPD on the mental health and social lives of people with COPD. If people with COPD are stigmatized, the insights gained from the North American and European contexts suggest that individualized support is needed for this population [28, 29]. It can be said that similar caution may be required in countries other than Japan where COPD is not stigmatised at present.

Second, the participants usually live their lives mostly without worrying about the fact that they have COPD. This differs significantly from the European and North American contexts. In the present study, although the participants were aware that they had COPD, they were more keenly aware of their advanced age. In fact, according to Japanese government statistics [37], more than 80% of those diagnosed with COPD as of 2020 are over 65 years old. They were also concerned about symptoms such as dyspnea, palpitations, and sputum in their daily lives, but they attributed them to their advanced age rather than COPD. They perceived COPD’s symptoms to functional decline, which can be attributed to aging. As a result, they did not develop significant negative feelings, partly because they did not face societal stigma. The results of the present study suggest that there may be greater cultural differences in the relationship between COPD and stigma than previously thought [17, 18]. Even in countries in the Global South, where COPD is often caused by reasons other than tobacco smoking, people with COPD may not face stigma for the same reasons as in Japan.

### Limitations

This study is a single-center study. Therefore, there is a possibility of sampling bias in the findings.

All participants in this study were men over 65 years of age. Therefore, it is unclear whether the findings of this study can be directly applied to other cases, such as women or people under 65 years of age. However, according to the most recent epidemiological study we can find <sup>[38]</sup>, about 80% of people with COPD in Japan are men, and more than 90% of the cases are found to be mild or moderate based on GOLD severity criteria. In addition, as mentioned previously, more than 80% of those diagnosed with COPD in Japan are over the age of 65 <sup>[37]</sup>. Thus, the findings of this study may be applicable to a large population of people with COPD in Japan.

The interviews were conducted before the COVID-19 pandemic. Therefore, the stigma received by the interviewees may have changed to some degree during the pandemic. It is a future task to reexamine how the stigma will be changed after the end of the pandemic.

### Conclusions

People with COPD in Japan before the COVID-19 pandemic were found to experience no stigma, unlike their European and North American counterparts. The participants of this study went about their daily lives without facing stigma from people around them. Additionally, the participants usually lived their lives without worrying about their COPD. This study argues that their experiences could be explained by the lack of stigmatisation of COPD and smoking in Japanese society, and by participants' stronger identification as older individuals, rather than as people with COPD. This study revealed that there may be greater cultural differences in the relationship between COPD and stigma than previously thought.

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### Institutional Review Board Statement

The study was conducted in accordance with the Declaration of Helsinki and approved by the Chiba University Ethics Committee.

### Conflicts of interest

The author has no competing interests to disclose.

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